

Life-saving or life-limiting? Young women's experiences of the HPV vaccination programme

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Abstract

Taking inspiration from my professional youth and community work background, I merge this professional scholarship (Batsleer and Davies, 2010; Batsleer, 2013; Bradford and Cullen, 2012; Packham, 2000) with that on contemporary feminism (McRobbie, 2009; Ryan-Flood and Gill, 2010; Penny, 2014; Gill and Scharff, 2013; Dubriwny, 2013) and young sexualities (Holland, Ramazanoğlu, Sharpe and Thomson, 2004; Renold, 2005; Jackson, Paetcher and Renold, 2010; Robinson, 2012). In so doing, this research project is a political feminist case study exploring the construction of young women's sexuality in the UK through the development and delivery of a new vaccination, the Human Papillomavirus Vaccination. I interrogate the HPV vaccination programme as a feminist issue and ask; what are the diverse ways in which feminists can support, engage with, and critique the HPV vaccination programme? Methodologically I use a feminist activist lens which values and foregrounds women's knowledge and expertise about their own bodies. A participatory orientation (Eubanks, 2009) to research was employed and based upon research conversations, ethnographic observations, young women's diaries and analysis of documents I explore how young women's sexualities are constructed and practiced through the HPV vaccination programme. The thesis argues that the HPV vaccine and programme contributes to the articulation of the ways in which healthcare, education and the pharmaceuticalisation of young women's health anticipate and conjure a version of successful and appropriate (normative) femininity; women who are compliant and consensual sexual guardians who are invested in their future health and that of their (assumed male) sexual partner/s. This research has two main contributions. First, it is a feminist intervention based upon the core principles of professional youth and community work, providing opportunities and legitimacy to the exploration and learning around the HPV vaccination programme and its effects. Second, it draws attention to minority experiences through eliciting young women's experiences and accounts and opens the possibility of listening to and learning from the

accounts of young women's vaccine-injury. The thesis details the ways in which the HPV vaccine impacts upon and affects the lives of young women and their parents. The result of this research is the production of tangible recommendations for changes to the practices of sex and relationship/s education and of administrating the HPV vaccination and programme.

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Acronyms

A+E	Accident and Emergency
CDC	Center for Disease Control and Prevention
CRB	Criminal Records Bureau
CSE	Child Sexual Exploitation
DBS	Data and Barring Service
DfEE	Department for Education and Employment
DH	Department of Health
DWP	Department for Work and Pensions
DTC	Direct To Consumer (advertising)
EMA	European Medicines Agency
FDA	Food and Drug Administration
FII	Fabricated and Induced Illness
HPV	Human Papillomavirus
JCVI	Joint Committee on Vaccination and Immunisation
LARC	Long Acting Reversible Contraception
LGBT	Lesbian, Gay, Bisexual, Trans
MHRA	Medicines and Healthcare Regulatory Authority
MMR	Measles, Mumps, Rubella
MP	Member of Parliament
NICE	National Institute for Health and Clinical Excellence
NHS	National Health Service
NWRYWU	North West Regional Youth Work Unit
PIL	Patient Information Leaflet
PGD	Patient Group Directive
Sane Vax	Safe, Affordable, Necessary, Effective Vaccinations
SRE	Sex and Relationship/s Education
STI	Sexually Transmitted Infection
UNCRC	United Nations Convention on the Rights of the Child

VLP Virus Like Particles
WHO World Health Organisation

Declaration

I declare that this thesis is my own work and that it has not been submitted in any form for the award of a higher degree elsewhere.

Alison Hanbury

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Prologue

In 2007, the Joint Committee on Vaccination and Immunisation (JCVI) advised the Department of Health (DH) that HPV vaccination should be offered to females aged 12-13 with a catch-up campaign for those up to 18 years. (Parliamentary Office of Science and Technology, 2008)

The decision was made by the Department of Health for the UK to introduce a HPV vaccination programme in the UK. This was introduced in September 2008. GlaxoSmithKline's Cervarix vaccine was chosen rather than Sanofi Pasteur MSD's quadrivalent (protecting against four strands of HPV) Gardasil vaccine. Cervarix is a bivalent vaccine which suggests that it protects against two strands of HPV, whereas Gardasil is a quadrivalent vaccine which suggests it protects against four strands of HPV). For the first four years of the HPV vaccination programme, young women from age 12 years old were immunised with Cervarix in a three dose regimen administered over one academic year. Most young women were immunised by their school health advisors and school nurses.

As of September 2012:

[...] following a competitive tendering exercise the Department of Health (DH) will be providing the human papillomavirus (HPV) vaccine Gardasil® for the national HPV immunisation programme for girls in school year 8 (aged 12 to 13 years) from September 2012. (Department of Health, 2011)

In September 2014 the three dose regimen was reduced to two doses following research that suggested “that antibody response to two doses in adolescent girls is as good as a three dose course” (NHS England, PHE & DH, 2014:1). Furthermore, in July 2016 the DH announced changes to the cervical screening programme whereby:

The process of cervical screening is to be changed to allow women to benefit from more accurate tests. After a successful pilot programme and a recommendation by the UK National Screening Committee, screening samples will be tested for human papilloma virus (HPV) first. This will be rolled out across England as the primary screening test for cervical disease. (www.gov.uk/government/news/changes-to-cervical-cancer-screening accessed 19th July 2016)

These 'more accurate tests' will provide a stronger case for the HPV vaccination programme; collecting data that evidences high HPV infection rates. And as stated by the NHS website

More than 99% of cervical cancer cases occur in women who have been previously infected with HPV. HPV is a group of viruses, rather than a single virus. [However] some types of HPV don't cause any noticeable symptoms and the infection will pass without treatment. (www.nhs.uk/Conditions/Cancer-of-the-cervix/Pages/Causes.aspx accessed 22nd August 2016)

The information and materials that present facts and knowledge about the HPV vaccines support and celebrate the introduction of the HPV vaccination programme. The UK government has invested in this £1000m vaccination programme which is presented as "for their own good" (Ehrenreich and English, 2005). This research aims to question this assumption through exploring young women's experiences of the HPV vaccination programme.

Introduction: For their own good: assumptions of the HPV vaccination programme

Coordinating the HPV vaccination programme:

“You’ll work in either a sports hall or the assembly hall. So, the child will come in, you’ll have the clerk who will be sitting down. You’ve got your schedules with all the children’s names on, you’ve got your pile of consent forms that’ve been returned, you’ll have a runner for the school and a teacher, you know for crowd control etc. [laughs] And so you’ll perhaps have a class come in one at a time, 30 children for example. They’ll come through, they’ll sit down, they will give their name to the clerk. The nurses will set themselves up - so let’s say we’ve got a session with 300 girls - so you might have as many as 10 or 12 nurses possibly more, depending on how many you can get, all sitting on their own little station with their vaccines, the cotton wool and everything else, and the paraphernalia, waiting for the girls. I’ll be coordinating the whole thing and saying “right girls, come on through, talk to the clerk”. They’ll go and sit, once they’ve actually got the consent form in their hand. She’ll hold that and go and sit on a line of benches or whatever’s set up to wait and then the next nurse that’s free will put her hand up and whoever’s running or coordinating will say “right, go and sit with that nurse” and at that point then, she’s that nurse’s responsibility. And it’s that nurse who then needs to take responsibility for the consent form and to make sure that whatever type of consent form she’s filling in is sorted. So the nurse goes through the consent form, makes sure that the girl’s not poorly, and she’s got no allergies, and asks whether she’s had any other injections recently? You know all those kind of questions. The nurse then gives her the injection and then makes sure she’s [nurse] signed for it. Finally she’ll give the child a letter and then says “now go and sit in that little area for five minutes”, ten minutes whatever, “until you’re told to go back to class.”

Mary, School Health Advisor & Sexual Health Nurse, April, 2012

Accepting and receiving the HPV vaccination at school

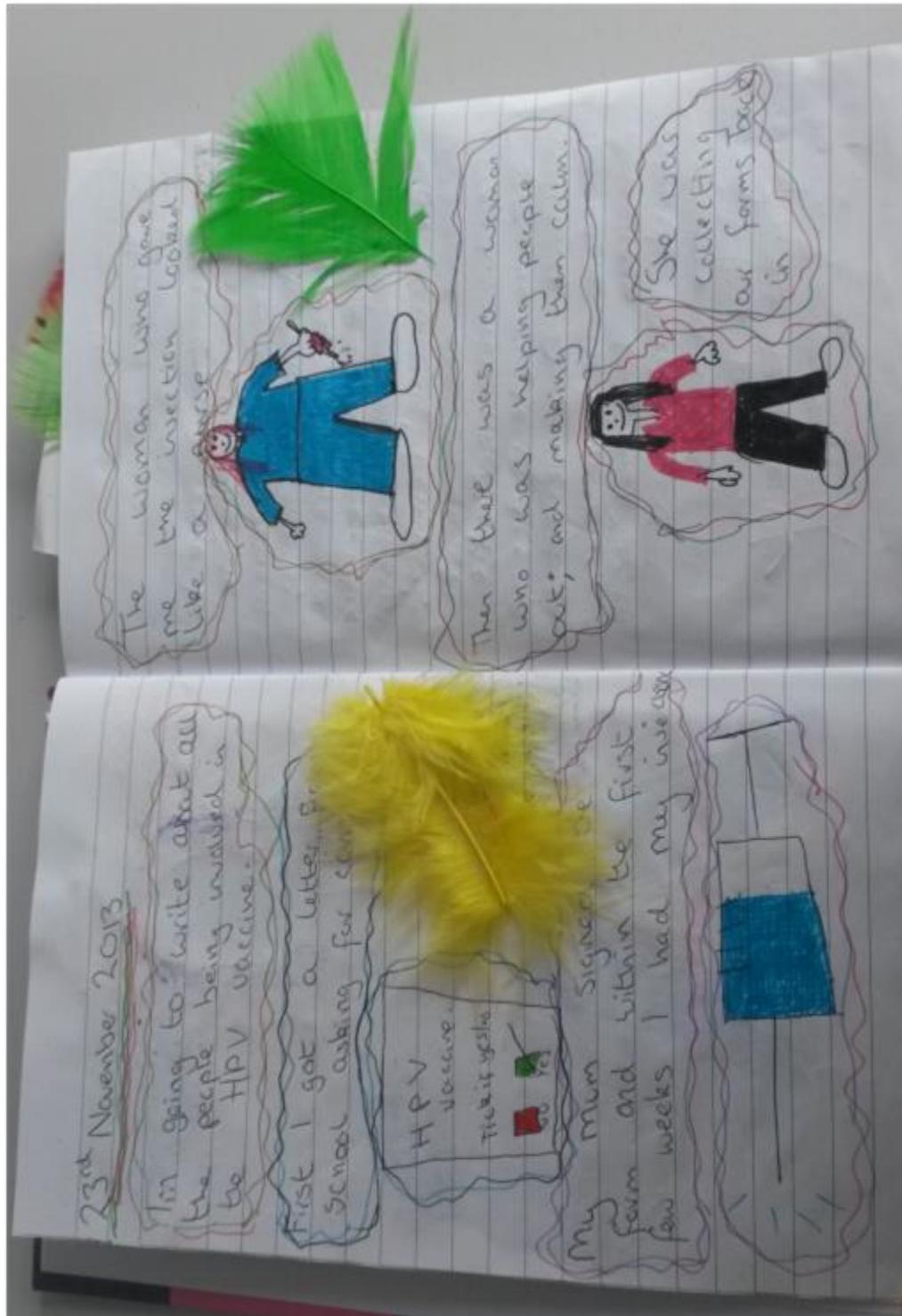


Figure 1 Ainsley, Wendy Chicken Shop School, HPV diary 2014-2015

Accepting and receiving the HPV vaccination at school

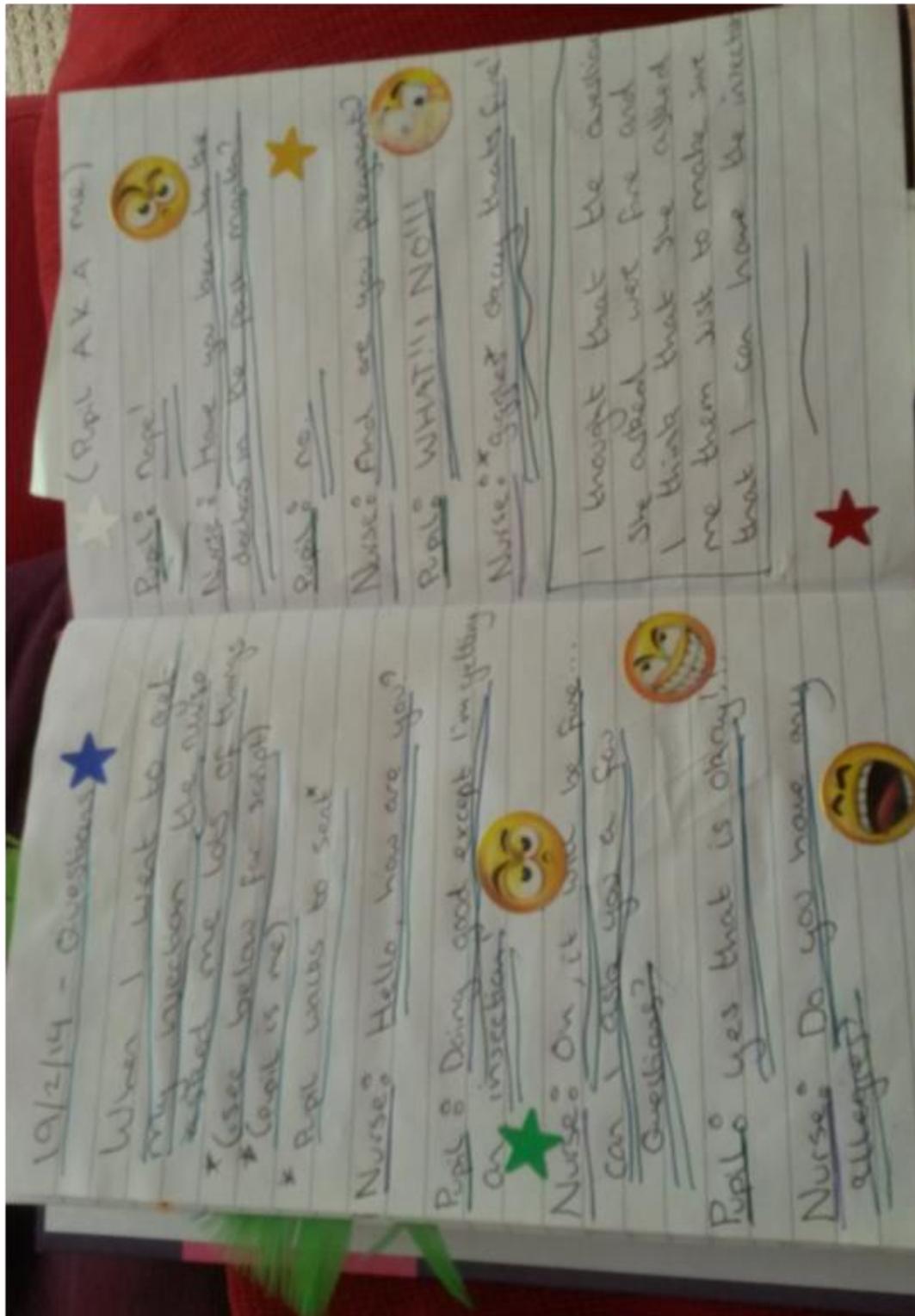


Figure 2 Ainsley, Wendy Chicken Shop School, HPV diary 2014-2015

Accepting and receiving the HPV vaccination at school

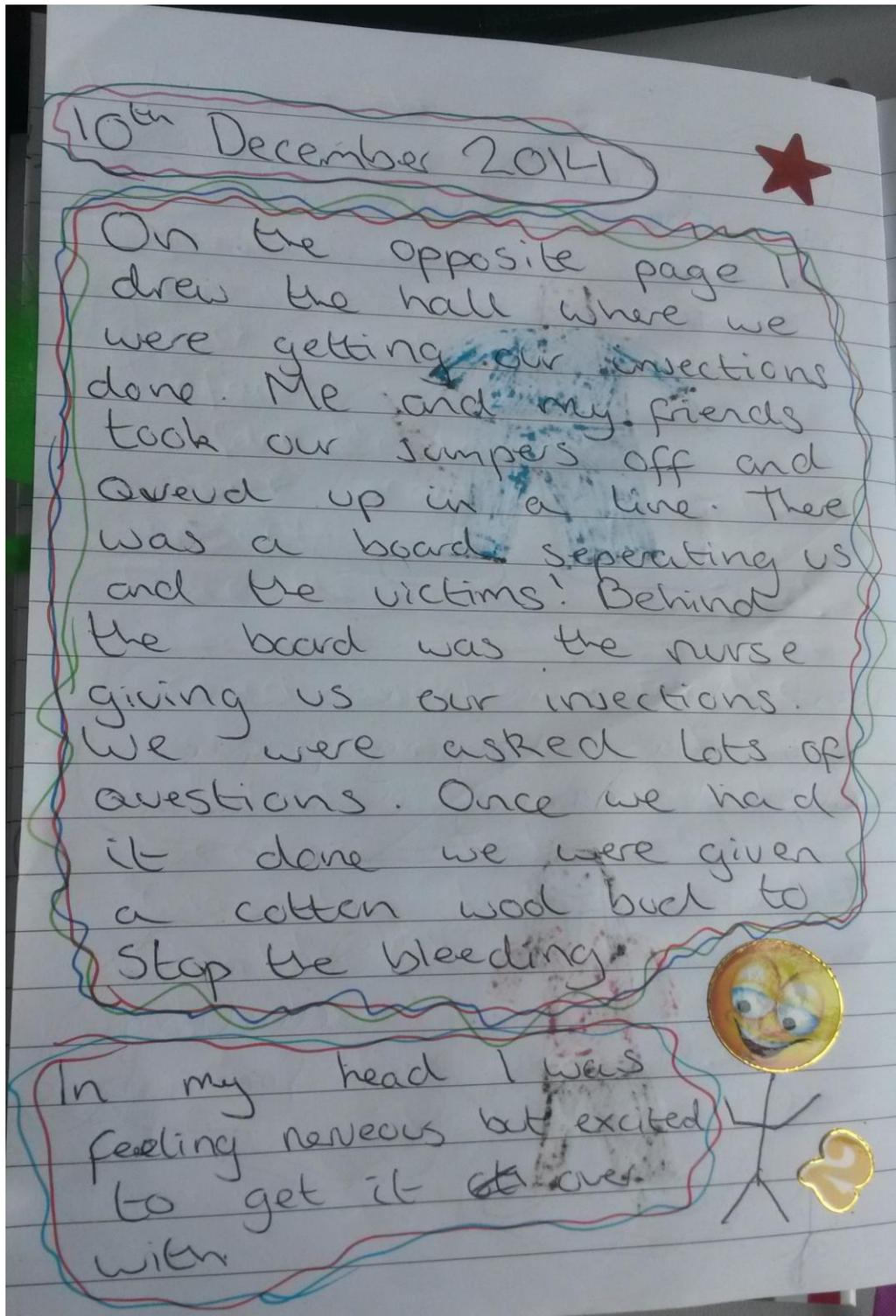


Figure 3 Ainsley, Wendy Chicken Shop School, HPV diary 2014-2015

What exactly is it like for the clinicians administering the HPV vaccination and the young women who are receiving it? The two stories above, from Mary and Ainsley, are taken from my research materials. They provide compelling accounts about the HPV vaccination and programme in the UK. I began this part-time PhD studentship in October 2011 whilst I was working for Brook, the UK's largest sexual health charity for young people. From April 2012 onwards I began my empirical research. This has involved individual research conversations, telephone research conversations, a focus group, small group discussions, home visits and young women's diaries. I have also been sent information via email regarding the HPV vaccination from several people including health practitioners and health campaigners. The research locations I visited were varied and included areas in the North West of England, North Wales, London and South East England, West Yorkshire and the Borders of Scotland. Further locations were covered via the telephone research conversations. I finished eliciting empirical research materials in July 2014. Chapter One will outline explicitly the methods and research materials gathered, but for now I continue with a brief insight into Mary and Ainsley's experiences.

Mary's account is from the transcript of a research conversation undertaken in April 2012 and Ainsley's shows three photographs of the 'HPV diary' she created between November 2013 and July 2014. Mary is *not* the School Health Advisor for 'Wendy Chicken Shop' school (but coordinates the vaccinations across many schools in the North West of England) but despite this their accounts both describe similar processes of the vaccine's administration e.g. the people involved and present during the vaccinations, the letters, the consent forms and the cotton wool.¹ Both Mary and Ainsley also make reference to the questions that the nurses ask the young women prior to the vaccination. Whilst for Mary this is an ordinary part of the process and thereby given a cursory mention (excluding the question regarding pregnancy), Ainsley has provided a

¹ As detailed in Chapter One, 'Wendy Chicken Shop' is the name given to the school by the young women

script of the interaction and describes her shock at being asked if she could be pregnant.² These accounts raise specific questions around the similarities and divergence (between young women and practitioners) of opinions and experiences of the HPV vaccination and programme. I am interested in these accounts as someone who has spent many years working with young women and girls in informal education settings, through my role as a professional youth and community worker.

This introduction is split into four sections. First I will introduce my research as an extension of my professional youth work experience in sexual health settings. Secondly I introduce the HPV vaccination and programme. I provide a brief historical account of how Human Papillomavirus (HPV) is understood, the development of the vaccines and the introduction of the HPV vaccination programme in the UK. Third is a section on the category of young women. I outline the ways in which I understand and will be approaching this category as part of my research. Finally, I provide an introduction to scholarship surrounding young women's sexualities.

Academic research as an extension of my youth and community work practice

As both a feminist activist and a professional youth and community worker I was confident when I began the PhD research that the professional principles and values of social justice and anti-discriminatory practice would assist me in my academic researcher role (Bradford and Cullen, 2012; Sapin, 2009; Davies, 2010). I have several years of experience working creatively with for example, street-based youth work projects, women's groups, in sexual health settings and with lesbian, gay, bisexual and trans (LGBT) communities. My experiences have led to critiques of various gendered and heterosexist interventions offered to women, including pharmaceutical and biomedical interventions such as hormonal

² I return to this in Chapter Two

contraception, sexual health screening and now the HPV vaccinations. This critique and curiosity has thus been extended into my PhD research, a feminist engagement with the HPV vaccination programme, leading me to ask what a feminist response to this programme could be. My research project offered a moment of interruption in the HPV vaccination programme's process and carved out a space for the young women (and others) to articulate their thoughts, feelings and/or their support or concerns about the intervention. This is based upon my previous experiences of having delivered several years of informal education in community settings with a commitment to liberatory education through various activity based work (Richardson and Wolfe, 2001; Batsleer, 2008; Bastleer & Davies, 2010; Sapin, 2009; Bradford and Cullen, 2010). Kate Sapin, the programme director of Community and Youth Work courses at the University of Manchester, defines the role of youth workers as follows:

A youth worker's role in addressing the purpose of youth work [...] is to promote social, educational and political change at various levels. Youth workers provide information and other support to effect changes in attitudes and practice within young people, services, communities and society as a whole in order to enable young people to have a say in the issues that affect them. (2009: 11)

Merging my previous experience with my role as a postgraduate researcher I aimed to create a new and emerging contribution to the existing body of work relating to professional youth and community work as well as feminist health concerns and studies of young women's sexualities.

I am interested in four main concerns that were born out of the unease I felt before, during and since I started this research project. They are:

1. Is it possible to critique and disagree with an organisation's (Brook) stance on the HPV vaccination and still deliver sex and relationships education

(sre) that promotes positive sexual health? As a sexual health worker at the time the HPV vaccination was introduced I was engaging in difficult debates around whether to support and promote it.

2. What effects is the HPV vaccination programme having on young women's sexualities and femininities? Are young women expected to behave in ways that are compliant, unproblematic, health seeking, future-orientated and as responsible for others?
3. What knowledge do various practitioners rely upon when administering and promoting the HPV vaccination? Do they have to uncritically administer it with unknown effects? How does medicine deal with its uncertainty and failings?
4. Can the administration of the HPV vaccination happen differently so to protect more young people from various risks?

These four broad concerns underpin the thesis. Each chapter will address these concerns by using relevant scholarship and, primarily, empirical research materials. The term I use to gather these issues is that of 'practices' (in relation to identities, femininities, health activism, 'difficult'/citizenship and everyday activism). The term resonates through my professional youth and community work; there are many books, articles and university modules that explore and teach 'youth work practice'. I opt for the term 'practices' and utilise this throughout the thesis when analysing the research materials.³ Other key terms I explore and use are in the thesis are: successful femininity (Holland, Ramazanoğlu, Sharpe and Thomson, 2004), neoliberal post-feminism (Gill and Scharff, 2013; Penny, 2014; McRobbie, 2009), young sexualities (Robinson, 2012; Allen, 2007; Cacchioni, 2015; Holland et al., 2004), and 'difficult'/citizenship (Dubriwny, 2013; Robinson, 2012; Bell and Binnie, 2000).

³ I use the term practices as opposed to 'enactments' (Mol, 2003) or 'performances' (Butler, 1990) because it aligns with scholarship that relates more directly to my particular research interests.

Being critical in my academic research is prompted by the contemporary employment landscape in which I have often found myself e.g. working in a variety of settings where young people spend their time. This has particularly been the case since the large-scale outsourcing and commissioning of local authority youth services to third sector providers. This can often lead to situations where professional youth and community workers are employed by organisations with a specific focus such as careers guidance, alcohol and drug misuse, or in my case, sexual health. In my role as the Education Outreach Coordinator with Brook I managed and delivered sexual health programmes and activities in a variety of youth settings, including schools, Pupil Referral Units (PRUs), youth clubs, sports clubs, Girl Guiding groups, hair dressing academies, further education (FE) colleges and supported accommodation projects.

Professional challenges arose when the agendas of the commissioners, Brook's mission statements and the values and principles of professional youth and community work were at odds. I was often in a position where the delivery of my work was hindered or constrained by the narrow focus of the commissioner's requests and the organisation's eagerness to satisfy them. I had previously been involved in promoting the HPV vaccination as it had been promoted by Brook's national policy team, and indeed locally by managers, as an easy and effective intervention that would increase sexual wellbeing for young women. It is only through applying a feminist critique to the vaccine, as I had done with other such offerings (e.g. hormonal contraception and sexual health screening) that I was able to reflect on the specific challenges that the HPV vaccination programme had introduced. My experiences in sexual health services and related critiques provide a starting point for developing an analysis of the HPV vaccination. I interrogate if and how the vaccine, like hormonal contraception and sexual health screening, is celebrated as an intervention in young people's services by the popular media, the NHS and through various information leaflets.

The thesis is framed by three further overarching research questions that are born out of the four concerns that I detailed above. They are:

1. How do young women engage with the HPV vaccination programme? I am interested in the ways that young women may or may not question, critique or comply with the programme. Examples of ways in which they might practice in participatory and youth-led ways are of particular interest and it is my belief that given a positive space and opportunities young women are able to engage with the information and offer of the HPV vaccination in a more interesting and enjoyable way.
2. How are young women's sexualities constructed and practiced through the HPV vaccination programme? Sex and sexualities are often left unexplored in the discussions and promotion of the vaccine even though HPV is transmitted via sexual contact. And related to this, how do knowledge practices of HPV vaccinations shape sexual citizenship?
3. What are the diverse ways in which feminists can support, engage with, and critique the HPV vaccination programme?

My project is part of a wider research project into four pharmaceutical drugs funded by the European Research Council, grant agreement no 263657. The project, titled *Prescriptive Prescriptions: Pharmaceuticals and 'Healthy' Subjectivities* explores how healthy 'subjects' are understood, framed and constructed through the many practices that surround use of pharmaceuticals. As well as research into the HPV vaccination in both Sweden (Lindén, 2016) and the UK (Hanbury, in Johnson, forthcoming 2016), colleagues in the *Prescriptive Prescriptions* project also explore the effects of hormone therapies to delay early onset puberty (Roberts, 2015), treatments for benign prostate hyperplasia (Johnson, forthcoming 2016; Johnson and Åsberg, 2012), and the development of drugs for Alzheimer's disease (Åsberg, in Johnson, forthcoming 2016 and Mehrabi, in Johnson, forthcoming 2016). The research foci and methods used

vary with researchers spread across two universities; Linköping University, Sweden and Lancaster University, UK.

From 'A Woman's Disease' to Human Papillomavirus (and its vaccine)

Vaccinations have been likened to the introduction of clean and sanitary water in terms of their population-level impact on improving the health of individuals (Sarraci, 2010). This section will track the developing knowledge regarding HPV and the emergence of the HPV vaccinations.

Andrea, a representative from the pharmaceutical company Sanofi Pasteur MSD, responded to my question about the risks and benefits of vaccines with:

It's been very, very, very well published that the benefits of vaccination, no matter what vaccination, outweigh any risk [...] it's been the most important public health intervention, I think, since clean water. (July, 2012)

Many people in resource-rich countries have a low risk of contracting or developing the diseases against which vaccines are claimed to protect. However, vaccinating entire populations is deemed to be necessary in order to build herd immunity:

Whereby the chain of transmission of an infectious disease like measles is interrupted, bringing down to almost nil (or nil) the risk for the totality of the population. (Sarraci, 2010: 46)

As such, the schedule of childhood vaccinations in the UK means that the parents of children and young people are accustomed to the universal offer of vaccinations from the National Health Service (NHS). Between the ages of two months and four years a child's parents will be encouraged to accept 12

vaccinations for them, with other vaccinations being offered to children deemed to be at a higher risk of infection or exposure to, for example hepatitis B and tuberculosis. This prevalence of vaccinating the UK's population, coupled with the pervasive rhetoric of the 'war on cancer', saw the HPV vaccination introduced in 2008, but its history and development can be traced back to the 1970s.

In 1971 the President of the United States of America (USA) Richard Nixon declared the 'war on cancer' by signing the National Cancer Act which was designed to encourage researchers to locate and understand the role of viruses in human cancers (Löwy, 2011). During the following years "the 1980s and 1990s saw a boom in the development and trials of new vaccines" (Wailoo, Livingston, Epstein and Aronowitz, 2010: xxii) and during this time - in 1988 and 1992 - new regulations were introduced by the Food and Drug Administration (FDA) to fast track the approval of drugs to treat life-threatening conditions including cancer. These regulations meant that the FDA would approve new drugs based upon:

Less data than normally required to support clinical efficacy [whereas] normally the [...] FDA requires at least two 'pivotal' Phase III RCTs to demonstrate drug efficacy. (Davis and Abraham, 2011: 732)

Randomised Control Trials (RCTs) are constructed and viewed as the "gold standard" (McCartney, 2012: 31) of clinical trials and would usually be undertaken to test the efficacy of a potential new drug on a specific endpoint e.g. cervical cancer, against a placebo drug. This would be undertaken so to evidence that the drug on trial is better than a placebo drug. However, as quoted above, regulations for approving new drugs by the FDA have been loosened and the long-ranging impact of this deregulation included the decision by the European Medicines Agency (EMA), most notably in 2004, to approve new drugs without previous higher levels of data supporting clinical efficacy (Davis and Abraham, 2011).

In June 2006 the United States' FDA was the first national health regulator to approve Merck's quadrivalent HPV vaccine Gardasil, and in 2007 approval for GlaxoSmithKline's bivalent vaccine Cervarix was given. This was set against a backdrop of controversies and competing agendas from policy-makers, pharmaceutical companies, parents and abstinence groups to name but a few (Wailoo et al., 2010). It is widely recognised that the FDA's approval and decisions have significant influence on the approval and decisions made by other countries' health regulators (Davis and Abraham, 2011; Moynihan and Cassels, 2005; Wailoo et al., 2010), and the approval and introduction of national vaccination programmes in many developed countries swiftly followed.

The HPV vaccination programme was introduced in the UK in 2008 and (according to early information leaflets) is offered to young women and girls mainly through the school health advisor and school nurse roles, and through GPs' surgeries (NHS, 2009; Mishra and Graham, 2012; Steenbeek et al., 2011). The vaccination administered between 2009 and 2014 comprised three separate doses via intramuscular upper arm injections. From September 2014 the HPV vaccination was reduced to a two injection regimen and, when first introduced, was offered to young women from age 12 years with a catch up programme (from 2008 – 2010) designed to vaccinate young women up to the age of 18 years old. Between 2008 and 2012 the vaccine used in the UK was Cervarix and since 2012 the vaccine used in the UK is Gardasil. The UK Department of Health training slides for nurses states that being able to offer 'catch up' vaccinations to older young women was possible through choosing the bivalent vaccine Cervarix which was cheaper than the quadrivalent vaccine Gardasil (DH, 2008). This opinion is mirrored by the quote from Iris, a manager at one of the Health Protection Units in the UK:

I think most people thought that they [the Department of Health] would go for Gardasil because you've got the additional cover for the genital warts

and I think, from what I understand actually happened was, that because of the price of Cervarix was so much lower than Gardasil you would've been able to immunise many many more young women to protect them against cervical cancer than you would've been probably able to immunise if you used Gardasil, so it meant that you were actually protecting more women against cervical cancer. I think that was the, one of the reasons why we were able to do the catch up programme to the age of eighteen, so it was a mathematical thing. (September, 2012)

Tracking the history of cervical cancer and links to the HPV virus not only provides historical and contextual understanding as to the reasons given for the vaccine's introduction, it also highlights the ways in which women's health and susceptibility to disease have been constructed and responded to by medical professions at different times through the past two centuries (Ehrenreich and English, 2005). This, once again, provides fruitful grounds for feminist critiques of the vaccine and the programme. What information do women now receive in relation to the health interventions available to them? I will return to explore this question in Chapters Four and Five. It also provides insight into knowledge claims and economic considerations which guided decision making by the Department of Health (DH) when deciding which HPV vaccine to introduce.

In her 2011 book *A Woman's Disease: The history of cervical cancer* Ilana Löwy provides an account of the developing medical descriptions of cervical cancer starting from the nineteenth and into the twentieth and twenty-first centuries. These medical descriptions have seen great variance – in the 1970s cervical cancer had been linked with the Human Papillomavirus – and have often reflected changing social attitudes. Such changes have been made following the advancement of medical knowledge and the discovery that cervical cancer is associated with HPV which is a sexually transmitted infection (STI).

Analysing claims that the 'weak constitution' and intellectual pursuits of nineteenth century computing pioneer Ada Lovelace caused violent haemorrhage, Löwy describes how early attitudes towards femininity constitute women's poor health as a result of "overexcitement," with women's bodies "seen as too weak for a powerful mental effort" (2011: 3). Despite the term cervical cancer not being used at this time, descriptions of Lovelace's symptoms and disease are now thought to be cancer of the uterine cervix, or cervical cancer. The physicians of the mid-nineteenth century, who diagnosed and treated Lovelace, disagreed amongst themselves and withheld information regarding the severity of her condition from her, instead choosing to inform her husband of her disease. This example serves to highlight the dominant historical account of medical attitudes towards cervical disease. The secrecy practiced by medical professionals was cemented through their position as experts and intellectuals.

Almost 100 years after Ada Lovelace's death, a study from the USA concluded that cervical cancer shared similarities with 'venereal disease' and was therefore deemed to be an STI. In 1976 the German virologist Harald zur Hausen found that cervical cancer was linked to the virus which also causes genital warts and "in 2008 zur Hausen was awarded the Nobel Prize in Physiology or Medicine for his discovery of the links between HPVs and cervical cancer" (Löwy, 2011: 140). From the mid-2000s onwards significant developments in public awareness and media coverage regarding cervical cancer occurred due to the approval and introduction of HPV vaccines.

My research responds to the dominant knowledge surrounding the HPV vaccination and I carry out this research in order to introduce an alternative feminist engagement with the HPV vaccination and programme. Building on feminist criticisms of past medical and healthcare practices, I look at how the HPV vaccination programme treats women's bodies, and whether there have been changes. Furthermore, I explore more specifically how the programme has been promoted with minimal information, exclusion of full information about risks,

the use of fear, and through obscuring the implications of the programme for young women's sexualities.

From the 'common' HPV infection to the 'rare condition' of cervical cancer

The UK is a resource-rich country with a national cervical cancer screening programme that is well established. According to Jessie, a manager with a UK cervical cancer charity, in the UK cervical cancer is "a rare condition" (December, 2012). Despite this in 2008 the DH training slides for school health advisors and school nurses on the introduction of the HPV vaccine in the UK state that in England in 2005 there were 2,253 cases of invasive cervical cancer diagnosed (but does not provide the mortality rate) and that routine HPV vaccination will save the lives of around 400 women each year. The NHS leaflet *Arm against cervical cancer. Your guide to the HPV vaccination* claims:

Cervical cancer can be very serious. After breast cancer, it is the most common women's cancer in the world. In the UK, around 3000 cases of it are diagnosed every year and about 1000 women die from it. (2014, inside page)

Statistics regarding prevalence and risk in the USA claim that the probability of an unvaccinated woman developing cervical cancer, in light of current screening prevalence, is 1% (Saraiya, et al., 2007 in Chapman, in Wailoo et al., 2010). And the Center for Disease Control and Prevention (CDC) in the USA state that:

Every year, about 12,000 women are diagnosed with cervical cancer and 4,000 women die from this disease in the U.S. About 1% of sexually active adults in the U.S. have visible genital warts at any point in time. (www.cdc.gov/std/hpv/STDFact-HPV-vaccine-young-women.htm, accessed on 12th December 2012)

HPV infections are commonly reported to occur in the intraepithelial layer of the mucosal lining of the organ i.e. the vagina, anus, throat etc. and do not elicit a forceful response from the immune system. The World Health Organisation (WHO) suggest that prevention rates of cervical cancer and treatment of precancerous infections and lesions is high (80%) in countries with well-organised and well-established screening and treatment programmes. Therefore incidence rates are reported as being highest in lower-income and less developed countries such as “Latin America and the Caribbean, sub-Saharan Africa, Melanesia, and south-central and South-Eastern Asia” (2009: 199). The low-incidence and mortality rates in the UK raises a basic question regarding the necessity of the UK investing in an HPV vaccine. And others have looked at the motivations for various countries in introducing the HPV vaccination and how this governs its population of young women (Maldonado Castañeda, 2015).

HPV vaccines contain virus like particles (VLP) but not an active infection, unlike other vaccination drugs. Chapter Five outlines how this is often stated as a reason as to why school nurses and parents have deemed there to be little risk involved in having the HPV vaccine. It is thought that the vaccine is more effective if given prophylactically prior to HPV exposure (to the vaccine-related types of the virus) i.e. through sexual contact with an infected partner, which is why the vaccine is targeted at girls aged 12 years. As I later discuss in Chapters Four and Five, these arguments are now well-established and successfully employed in order to promote the HPV vaccine and programme.

The HPV vaccination programme and successful femininity: an intimate relationship

The key areas of study in this project are young women and sexualities, and through foregrounding narratives from women in the structure of the chapters, I make women’s experiences of the HPV vaccination programme visible and place them at the forefront of the project. My research is multi-disciplinary. My starting point is my interest and experience in sexual health and

young sexualities, along with the range of disciplinary fields including health studies, youth studies and sexualities studies that prove to be useful in my research. The intersection of these disciplines provides useful inclusions to my thesis as a whole, and my research can make for interesting and insightful contributions to these fields. Drawing on these multiple storied accounts, or narratives, I add to the current (limited) feminist debate about the HPV vaccination programme (Dubrwin, 2013; Löwy, 2011; Conis, 2015). Utilising such scholarship I question which particular versions of young women's sexualities and femininities are both relied upon and constructed by the HPV vaccination programme in order to make it a success. In Chapter Three I explore whether the success of the vaccination programme and practicing successful femininity rely upon each other; is this relationship intimately connected? If young women critique the vaccine as anything other than "for their own good" (Ehrenreich and English, 2005), or decline the vaccine, does this render both the HPV vaccination programme along with their own practice of femininity unsuccessful? Here, I follow Ramazanoğlu et al.'s (2004) argument that highlights the practices young women engage in that are deemed to be successfully feminine. And as such, I use the term 'successful femininity' and detail this scholarship in Chapter Two and Three.

According to the vaccine information provided by the NHS (2009; 2012; 2014) and the pharmaceutical companies (Sanofi Pasteur MSD, 2011) the HPV vaccination provides an opportunity to significantly reduce the incidence of cervical cancer amongst women, and to significantly reduce the incidence of genital warts amongst all genders. Take, for example, the cover of the HPV information leaflet (Figure 4). Initially it was Mary who gave me this leaflet but I came to receive it many times at different stages during the research as it is ubiquitous within the programme. It is given to young women through schools and is also made available through youth projects and sexual health services.

The image of the intertwined arms is resonant of the 'pink ribbon' motif of the well-known breast cancer campaign which adorns everyday objects such as lapel pins, keyrings, shopping trolley tokens and t-shirts. Utilising the flower symbols above the 'i' letters in the 'arm against cervical cancer' copies a style of handwriting common amongst young women whereby they replace the dot of the 'i' with lovehearts, flowers or stars. Pink and purple are used which are colours commonly perceived to be, and often are, favoured by girls and women and are seen to be warm, soft and caring colours. The HPV vaccine is promoted via text message from one young woman to a friend or family member. She is endorsing the vaccination through the assertion that the "jab" was "no probs". This is followed by the assertion of the vaccine as being "for their own good" (Ehrenreich and English, 2005) through the statement that, collectively, young women and the nurses who administer the vaccine will be "beating cervical cancer". This front cover alone, in other words, constructs, in very few words and images, the necessity, legitimacy and efficacy of the HPV vaccine. Indeed, it celebrates the vaccine as not only fighting 'cervical cancer' but as beating it. I juxtapose this information leaflet with other versions of knowledge surrounding the HPV vaccine in Chapter Five.

Following this 'good news' representation of HPV vaccines, proponents (including some feminist activists and patient groups) have supported and lobbied for the HPV vaccination programme. Indeed, during the first four years of the programme (2008 - 2012) Cambridge University's Women's Union produced a pamphlet on *Human Papilloma Virus, cervical cancer, genital warts, smear tests, the vaccine* that states:

The new HPV vaccine can significantly reduce the number of women affected by cervical cancer. The NHS currently covers the vaccination for girls of school age. This means that University students **are not eligible** under the NHS program [...] The government's reluctance to protect the health of all women is shameful. If you are shocked by this failure, voice

your outrage to the Department of Health.
(www.womens.cusu.cam.ac.uk/campaigns/hpv/HPVpamphlet.pdf,
accessed online September 10th 2014, original emphasis)



Figure 4 HPV vaccination leaflet, front cover, 2009

Similar disappointment at the government's decision to opt for Cervarix in the first four years of the programme was also made by Brook. In their position statement on the HPV vaccination from November 2010 the organisation, which runs clinical, education and advocacy services for young people across the UK

state: “Brook supports the Human Papillomavirus (HPV) vaccination programme and encourages all young women to take up the vaccination where it is available” (2010: 1). However they go on to challenge the decision by stating “Brook believes that the choice of vaccine for the programme should be reconsidered” (2010: 1). During my time working to deliver sexual health education for Brook (in the late 2000s and early 2010s) young people often discussed receiving information about personal and social relationships and sex education that is too biological in nature (see also Ingham, 2005) and focussed upon negative consequences in relation to broader themes of sexual health and relationships. Indeed Brook often used the mantra “too little, too late, too biological” (www.theguardian.com/lifeandstyle/2011/oct/10/how-good-is-sex-education accessed 30th March 2016) when critiquing young people’s access to sexual health information in the UK.

The overwhelming meta-narrative of accounts of the HPV vaccination programme is that it is a welcome, positive, life-saving intervention. As Andrea asserts:

So we launched Gardasil in 2006 [...] it was one of the fastest vaccines to ever go through the European medicines approval system [...] it was fast tracked through because of its superior efficacy and safety profile and it was deemed to be a vaccine that could make such a significant impact to public health they really couldn’t afford to waste any time in bringing it to market. (July, 2012)

This quote reassures us that the vaccine is safe and efficacious, it also creates a sense of urgency to making it available or 'bringing it to market'. This relates to the ways in which the various health and clinical institutions and communities view young women and envisage particular aspirations of healthy and disease-free futures for her and her partner/s. It celebrates the vaccine as a positive development in prophylactic healthcare for women.

Recognising that vaccinations are celebrated as significant advancements in public health provides me with a starting point from which to use past feminist critiques, asking how medical advancements position and control women, specifically in relation to the HPV vaccination programme (Bunkle, 1993).

A professional youth and community worker's look at the category of young women

Of particular concern to the HPV vaccination programme is the category 'young woman'. Since its inception in the UK in 2008, the HPV vaccine has been offered to young women only. In addition to this, the category of young woman appears to be fixed in place by a number of other structural practices. For example, the schools that these young women attend (and where they are offered and largely receive the HPV vaccine) separate them from the young men through such practices as the allocation of school uniforms; through being divided in sport lessons and sex and relationships education; by young women being siphoned off for the 'period talk' (a common discussion provided in many high schools around menstruation and sanitary products) and for the HPV assembly where the vaccine is introduced and promoted. The arguments against the HPV vaccination being routinely offered to boys and young men is based upon the notion of 'herd immunity' (Reich, in Wailoo et al., 2010) which suggests that as more people are vaccinated, the infection rates drop which then reduces incidences of transmission amongst the wider population. Herd immunity is thought to be most effective against highly infectious diseases when 90% of the population is immune through vaccination (www.nhs.uk/Conditions/vaccinations/Pages/How-vaccines-work.aspx, accessed online 11th March 2016).

During a research conversation conducted over the telephone with Andrea, who secured the DH tender for Gardasil in 2012, I was told:

For young boys, there is an argument that, if you vaccinate enough girls you don't have to do boys because of herd immunity, so they become protected because there's less HPV around. But the herd protection is fine as long as you stay in the herd and if you leave, you become at risk again. (July, 2012)

The HPV vaccination programme thus reinforces a pervasive heterosexual script, with added coital imperative (Barker, 2013), assuming that young women will engage in penis-in-vagina sex as a key element of heterosexual adult life. Leaving 'the herd' increases your risk - Andrea is suggesting here that those who leave the herd are those who jeopardise the success of herd immunity, e.g. women who are not vaccinated and men having sex with men.⁴ The assumed future hetero-sex is taken as the dominant form of sex and thus of transmission of HPV infections. Therefore, structurally, heterosexuality is the best-fit for the success of the vaccination as a biomedical intervention. The problem with this assertion is that it constructs a normative script for young women to follow, with the added pressure of altruism in the expectation that they will safeguard the health of others. How does setting up the vaccination programme in this way situate these young women? Does it construct them in responsible and compliant ways? In which ways are they expected to look to the future? What expectations are levelled at them based upon them being targeted by information leaflets, campaigns and information assemblies in schools? Indeed this early indication appears to place a heavy responsibility on these young women (Holland et al., 2004; McRobbie, 2009; Dubrwin, 2013; Gill and Scharff, 2013).

It is precisely such compliant young women (and their consenting parents) who are relied upon to make the HPV vaccination programme a success. These

⁴ In the UK guidance was issued in 2015 from the Joint Committee on Vaccinations and Immunisation (JCVI) recommending that men who have sex with men under the age of 45 years are to be offered the HPV vaccination as they fall outside of 'herd immunity' (www.pinknews.co.uk/2015/11/26/final-approval-given-to-hpv-vaccine-for-men-who-have-sex-with-men/)

young women are expected to accept the injections which are promoted as dramatically reducing the incidence of cervical cancer (and genital warts). And it is precisely this message and success narrative that has been popularly reported as being welcomed and celebrated amongst some feminists (<http://www.theguardian.com/commentisfree/2014/jun/23/slut-female-word-women-being-female> accessed on 27th June 2014; www.womens.cusu.cam.ac.uk/campaigns/hpv/HPVpamphlet.pdf, accessed online September 10th 2014; Dubriwny, 2013). Feminists are concerned with women's health, therefore to make a vaccine available which any girl can access through her school nursing team during the school day where she doesn't need to make appointments, take a day off school nor require her parents/carers to take time off work, is often seen as a good thing.⁵ It is this 'everydayness' of the vaccine, I suggest, that signifies the advancement of medical knowledge and efficacy that makes the programme difficult to critique.

It seems that the HPV vaccination programme relies upon particular health agendas, which incorporate powerful social norms. These include (hetero)sexuality and the desire to be a future healthy sexual citizen and partner, raising the question: do discourses of HPV pre-suppose a particular life trajectory for the vaccinated young woman? As I will explore in Chapter Three, the offer of the HPV vaccine creates and shapes the young woman as imminently becoming a sexual citizen, who will be engaging in penetrative sex with a male partner(s). This raises further questions, particularly: what image of young women's sexualities does the HPV vaccination programme construct? And furthermore, what kind of response is expected from these young women based upon such constructions? As Holland et al. state in relation to young women's awareness of sexual risks, "young women [...] may find themselves under pressure to adopt feminine identities [...] characterised by complicity" (2004: 51). This complicit response is one which encourages a particular set of health-seeking practices

⁵ See the feminist DIY 'zine on HPV from the 'Down There Health Collective' for a discussion on this.

that fall in line with a version of appropriate and successful femininity. Yet this creates a tension for young women, as described here in a US context:

The HPV controversy was not, therefore, a one-dimensional debate, for it threaded many questions – family values, the role of government, the reliability of scientific evidence, the oversight of sexuality, global inequity, and trust in drug companies – into a dense tangle of scientific claims and political assertions. At the center of the storm were young girls, with intense anxieties swirling around them about their futures, their sexuality, their health, and the world of risks confronting them. (Wailoo, et al., 2010: xiii)

The quote above highlights a very different view of the HPV vaccination programme from the positive and affirmative messages promoted through the materials provided to young women and parents through the schools, DH and pharmaceutical companies in the UK. This quote succinctly highlights several topics of interest and concern which are explored in the edited collection.

Working through these tensions about the storm that young women are in, and how they may play out in the practice of academic research, I return to my professional youth and community work background to look at a wider and more recent-historical view of youth policy and opportunities in the UK. Young women's programmes are often reported to be far less resourced than those for young men (De St. Crix, 2009 accessed via www.feministwebs.com accessed on 21st January 2012). One possible exception to this is the specific work targeted at young women during the period of 2000-2010 which was aimed at reducing teenage pregnancy through the Teenage Pregnancy Strategy (Social Exclusion Unit, 1999; Hanbury in Batsleer, 2013).

It is just such strategies that see young women occupying a precarious position, often thought of as a transitional period of adolescence or 'youth'. In some

everyday media portrayals they are deemed to be troublesome or vulnerable, thus in need of intervention or protection. Accessing knowledge, particularly sexual knowledge, poses a difficulty during these years, especially when such knowledge transgresses the heterosexual identities that are so readily promoted throughout childhood, adolescence and into adult life (Robinson, 2012; McRobbie 2009; Walker, 2014; Curran, Chiarolli and Pallotta-Chiarolli, 2009). The will and desire to protect the vulnerability and innocence of childhood and youth can often result in the re-articulation and recycling of unhelpful (mis)information regarding, for example, conception, pregnancy and childbirth (Cook, 2005; Chiarolli and Pallotta-Chiarolli, 2009; Ingham, 2005; Williams, 2001), along with the eradication of the recognition, value and worth placed upon women's labour in them. I am interested in the expectations that are subsequently placed upon young women as a result of their sexualities being constructed as at risk. As such I begin to consider, what tensions are there that young women must negotiate in order to practice femininity successfully?

My thesis builds on this scholarship and focuses upon the experiences of young women in the UK. In particular I focus upon the 'oversight of sexuality' and the 'tangle of scientific claims and political assertions' (Wailoo, et al., 2010: xiii). And beyond this I contribute new scholarship specific to the UK regarding young women's sexualities, of vaccine-injury and provide specific recommendations for increasing opportunities for political education and for improving vaccination administration practices.

Successful girls, slutty girls and restriction

In their edited collection *Girls and Education 3-16: Continuing Concerns, New Agendas* Carolyn Jackson, Carrie Paechter and Emma Renold (2010) bring together a wealth of empirical work highlighting tensions that girls and young women experience within the education system. Such tensions prove important for my project, as school is where young people will spend a significant period of

their 'youthful' lives in the company of peers and with the potential/opportunity to engage in myriad intimate and/or sexual relationships. It is not only in this setting that young women explore, play out and negotiate their sexual selves but they are also encouraged and supported to look to the future, anticipate events and act now for the benefit of their own lives and those of their imagined future partners, families and children. This occurs through careers fairs, subject options choice during high school and through the relatively new HPV vaccination which claims risks to health and promotes young women's responsibility for their own and their future partner/s health.

Jessica Ringrose's chapter in Jackson et al.'s collection describes young women's difficult and complex subject positions, highlighting a 'pornified' culture that spills over from the 'virtual' through to the 'real' world of the school. Her chapter title, 'Sluts, whores, fat slags and playboy bunnies: Teen girls' negotiations of 'sexy' on social networking sites and at school', captures the negative ways of marking young women's lives i.e. as sexually promiscuous, aesthetically displeasing or available for salacious consumption. Ringrose highlights the prevalence of sexual language and culture in which young women have a restricted set of options from which to 'choose' how they relate and perform in sexual ways.

More recently Jessica Valenti's (2014) article for the *Guardian*; 'What makes a slut? The only rule, it seems, is being female,' highlights the 'cancer vaccine' (HPV vaccine) as a current issue related to the pejorative word 'slut'. Indeed Valenti argues that the fear surrounding the term slut has delayed the introduction of the HPV vaccination. She attributes this to the fear of young women's sexuality - "because of fears they would make women "slutty"" (www.theguardian.com/commentisfree/2014/jun/23/slut-female-word-women-being-female accessed on 27th June 2014) - being brought to the fore of public and political debate. The argument follows that women would gain a false reassurance that casual, unprotected sex would become less risky after

vaccination. The article suggests that there is a public discourse that both constructs and laments young women as promiscuous, or at risk of being so. Consequently, there is a fear from some, with more conservative abstinence-only views, that policy and political debate could promote or encourage this risky behaviour with the creation of a specific 'culture' or 'crisis' that then justifies policy development and constructs specific sexual selves (Wailoo et al., 2010). Valenti provides a hyperlink to a *Time* magazine article from 2006 entitled 'Defusing the War Over the "Promiscuity" Vaccine' that quotes several campaigners who fought against the widespread introduction of the vaccine. Supporters of the vaccine believe this opposition was an inappropriate 'moral' interference with a medical breakthrough that would benefit young women.⁶ Arguing that the cancer vaccine's introduction was held up by anti-choice legislators, Valenti suggests that the term slut is therefore politically harmful to women, and by extension, could also be physically harmful by delaying the introduction of the HPV vaccination. These are just two examples of popular media articles that highlight controversies surrounding the HPV vaccine, but which ultimately - through Valenti's particular feminist perspective - promote its importance for women.

This acceptance of the HPV vaccination programme fails to interrogate the programme as a further social, political and medical intervention in women's lives and bodies. Feminists have long been critical of numerous ways in which women's bodies are sites of surveillance and control (Ehrenreich and English, 2005; Moore, 2010). Youth and Community Work academic Janet Batsleer (2013) suggests that dominant versions of successful femininity centre on bodily practices such as removing hair, fluids, fat and of restricting bodily smell and movement. This thesis questions the appropriation of the HPV vaccination within this framing of young women and such bodily practices. It is my suggestion that

⁶ A range of studies in relation to sexual behaviour change or 'promiscuity' have been conducted since the introduction of the HPV vaccinations that have found no significant increase. See Forster, Marlow, Stephenson, Wardle and Waller (2012) for a cross-sectional longitudinal survey conducted in England and Bednarczyk, Davis, Ault, Orenstein and Omer (2012) for a clinical outcomes based study.

the HPV vaccination programme contributes to problematic assumptions about young women's sexuality and reproduces an appropriate successful femininity which counters this. This is what I will be exploring further in Chapters Two and Three.

The fallacy of freedom and choice: neoliberal post-feminism

Could the complicity and compliance of the young women - that the HPV vaccination and programme relies upon in order to be a success - be undermined by an increasingly prevalent postfeminist discourse of opportunity, choice and independence? This neoliberal discourse of individual choice is not necessarily reflected with the option to decline the HPV vaccination i.e. the 'choice' is pushed in the direction of vaccine acceptance. In their edited collection *New Femininities: Postfeminism, neoliberalism and subjectivity* feminist scholars Rosalind Gill and Christina Scharff bring together chapters that interrogate the relationship between postfeminism and neoliberalism. Gill and Scharff state:

[I]t appears that there is a powerful resonance between postfeminism and neoliberalism which operates on at least three levels. First, and most broadly, both appear to be structured by a current of individualism that has almost entirely replaced notions of the social or political, or any idea of individuals as subject to pressures, constraints or influence from outside themselves. Secondly, it is clear that the autonomous, calculating, self-regulating subject of neoliberalism bears a strong resemblance to the active, freely choosing, self-reinventing subject of postfeminism. These two parallels suggest, then, that postfeminism is not simply a response to feminism but also a sensibility that is at least partly constituted through the pervasiveness of neoliberal ideas. However, there is a third connection which might imply that the synergy is even more significant: in the popular cultural discourses examined in this volume it is *women* who are called on to self-manage, to self-discipline. To a much greater extent to men,

women are required to work on and transform the self, to regulate every aspect of their conduct, and to present all their actions as freely chosen. (2013: 7 original emphasis)

The powerful social scripts that this synergy constructs will be explored in Chapters Two and Four in relation to young women's engagements with the HPV vaccination programme. Laurie Penny, journalist, political commentator and feminist writer, filters many academic positions and describes neoliberalism in feminist activist terms, thus:

Neoliberalism refers to the attempt to reorganise society and the state on the basis of an ideal of 'the market'. Neoliberalism proclaims that the logic of business and money is the best determinant of human happiness. Neoliberalism also says that human beings can't be trusted, so the market must necessarily dictate what the people want. Every category of human interaction, therefore – from the public sector to the intimate adventures of love and lust – must be made to work like a market, with in-built competitive mechanisms and cost controls. Every personal choice, including democratic choice, must be subsumed into the logic of the market: flesh itself can be remoulded for profit [...] The self is just an entrepreneurial project. The body is just human capital, a set of resources – whether the brain, the breasts or the biceps – which can be put to work generating an income stream. This affects everyone – but women most of all. Women are more likely than men to perform labour that is socially necessary but low waged or unwaged, and more likely to need public services and welfare. In this nominally freer and more equal world, most women end up doing more work, for less reward, and feeling pressured to conform more closely to gender norms. (2014: 2-3)

Describing the 'self' as an 'entrepreneurial project' Penny asserts how not only the body, but emotions such as love and lust are also co-opted into neoliberal

systems which dictate movements and decisions. She also claims that, through the market-like systems, women experience pressure to conform to regulated gender norms more strongly than men with myriad effects. Both Gill and Scharff and Penny's assessments of the pressures women undergo resonates with Angela McRobbie's critique of the aftermath of feminism. In her 2009 book *The Aftermath of Feminism: Gender, Culture and Social Change* McRobbie summarises the position of feminism within this discourse of freedom and choice, and the effects this has on young women's abilities to achieve sexual recognition:

By means of the tropes of freedom and choice which are now inextricably connected with the category of young women, feminism is decisively aged and made to seem redundant. Feminism is cast into the shadows, where at best it can expect to have some afterlife, where it might be regarded ambivalently by those young women who must, in more public venues, stake a distance from it, for the sake of social and sexual recognition. (2009: 11)

McRobbie reminds us that a neoliberal rhetoric of individual choice has replaced a more collective solidarity of feminist action and equality. By focussing on (the fallacy of) freedom and choice, young women are cast as autonomous subjects with access to the means and opportunities through which to make agential decisions. McRobbie also critiques the postfeminist view that feminism and feminist concerns should be banished to the realms of history because they lack contemporary relevance for women.⁷ This thesis questions whether feminism continues to be a necessary lens through which to critique the offers made to young women in contemporary UK health. As Valerie Hey suggests, we must respect:

⁷ There are significant young feminist activism including for example the Everyday Sexism project and UK Feminista and more specific single-issue or local campaigns such as No More Page 3 and 16 days of street art action.

The autonomy of girls' and young women's social relations while simultaneously providing resources to think with and against their limits [and] avoid[ing] the perhaps too easy temptation to give in to our own version of feminist melancholia. (cited in Jackson et al., 2010: 219)

The juxtaposition and tensions that are created by merging the deficit-model of young women's sexualities with the neoliberal approach of consumer (health) choices should be kept in mind. I have recognised the relationship between postfeminism and neoliberalism, as well as the contradictions of choice and decision-making. These construct particular pressures for young women, and in particular, upon their sexualities. I now turn more directly to introduce the concept of young women's sexualities as the second overarching consideration of the project

Young women's sexualities: traversing the difficult line between desirable 'hetero-sexy' and being prophylactically chaste

Drawing a distinction between the HPV vaccine and the HPV vaccination programme is vital in order to be able to introduce the impact and effects relating to young women's sexualities in this project. The HPV vaccine is a biomedical intervention; the liquid drug is suspended in an aluminium adjuvant and administered via intramuscular injections. The HPV vaccination programme involves large scale logistical management, procurement practices and economic calculations; it is political, moral and ethical and relies upon discourses of fear and common sense understandings of cancer as something to be avoided. This thesis considers both the HPV vaccination programme and the vaccine itself as interventions on and into the body which produce particular sexualities. I will explore how particular feminine sexualities are constructed as desirable and active identity positions. My engagement with the term 'choice' is based upon the term being a ubiquitously promoted norm of postfeminist neoliberalism. Despite many advances in women's health activism increasing the capacity and choices for women (Murphy, 2012; Ehrenreich and English, 2005), I argue that there is a

distinction between (active) choice and (limited) decision-making. As such I ask: are young women being steered into particular versions of becoming and practicing as sexual subjects (Gill and Scharff, 2013)? And must they traverse the difficult line between being desirable ‘hetero-sexy’ and being prophylactically chaste? Moreover, this frames my understanding of sexualities as embodied and therefore the embodied aspects of sexualities are further explained in Chapter Three.

Various health behaviours are carried out by women such as a focus on diet and exercise and various screening tests that have been viewed as “It’s just part of being a woman!” (Bush, 2000: 434). That is to say, to be a woman is to engage with these health behaviours and screen tests. Such health behaviours involve “constant bodily awareness, openness about symptoms, risk-reduction, and readiness to seek and attend to medical advice” (Moore, 2010). And nowhere is this more explicitly seen than in relation to sexuality and sex. For example, the Social Exclusion Unit’s ten year Teenage Pregnancy Strategy, highlighted earlier, has been celebrated as a success (Francis, 2010). This aimed to reduce teenage pregnancy by 50 per cent and promoted young women’s long-term use of hormonal contraception methods. Such prescribing was linked to financial reward through commissioning practices that saw cash-strapped sexual health services receive additional funding when targets were met (Hanbury and Eastham, 2015). The focus on encouraging young women to ‘opt’ for Long Acting Reversible Contraception (LARC) rather than other methods of hormonal contraception is one example of how sexual health providers collude with the discourse around young women’s sexualities as being risky and in need of interventions that are seen to be ‘for their own good’ (Ehrenreich and English, 2005). Such advice and prescribing practices, while being about preventing pregnancy, also suggest how to ‘do’ successful female sexualities and avoid negative risk-taking behaviours. This thesis explores how the HPV vaccination programme, as an example of a public health intervention, provides a forceful

script of expected behaviours for both women and medical professionals that construct young women's sexual health as inherently risky.

Such dependence and reliance on medical interventions to be a healthy and disease-free person becomes an ongoing project for young women. It requires young women to work hard to assume and absorb various interventions into their lives, involving everyday diarising, monitoring and scheduling. Mobile phone applications, menstruation diaries, letter reminders and school assemblies all 'assist' in young women being able to perform in particular sexually surveyed ways. Margaret McCartney, a Glasgow-based GP, in her 2012 book *The Patient Paradox: why sexed-up medicine is bad for your health* states that in her surgery's waiting room:

There are large pink posters, fronted by smiling attractive women, asking you to 'Make time for your smear test' [...] The NHS says 'Put it on your list' and even manages to put 'go for screening test' in between 'book haircut' and 'buy cinema tickets'. (2012: 68-69)

Healthcare practices have become a mundane part of being a sexually healthy woman. They are often represented as an aspect of femininity. However they also reflect an historical view of women as at the mercy of their bodily weakness and susceptibility to ill-health; consequently women must actively manage this through active health-seeking measures (Moore, 2010; Löwy, 2011; Ehrenreich and English, 2005). At the same time, through a neoliberal framing, such practices are bound up with celebratory discourses of success, health, achievement and desirability. To avoid ill-health and to engage in bodily measurements, restrictions and prophylactic screening, women are congratulated and rewarded with positive rhetoric and the promise of being successfully feminine.

In the early 1990s, as part of the 'Women, Risk and AIDS Project' and 'Men, Risk and AIDS Project', Holland et al. interviewed young people about their sexual lives and perceived risk of sexually transmitted infections, namely HIV/Aids. They utilise the term 'institutionalised heterosexuality' to trace the conceptions of 1) young women's individual sexual risk, 2) the social constructions of femininity, 3) the impact of male power and 4) the privileging, and reliance of heterosexuality on masculinity. As Holland et al. assert, they were aiming to make "the power of heterosexuality-as-masculinity visible" (2004: 12) and explain this idea through suggesting:

Individual women can be stropky, aggressive, violent or uncaring, but they cannot be successfully feminine in being so. Male assertiveness is consistent with masculinity: female assertiveness is perverse femininity. (2004: 23)

Despite significant changes since the 1990s, there are also several connections with the current climate. Parallels can be drawn between these projects' interest in sexual health initiatives to reduce risk taking behaviours and HIV transmission, and the HPV vaccination's promotion to reduce the risk of HPV infection and the development of cervical cancer and genital warts. Holland et al., highlight that choice, as debunked by McRobbie above, was not displayed by young women who were involved in sexual encounters with young men. Rather, they were making negotiations "within structurally unequal social relationships" and that:

The overwhelming conclusion that came from the interviews [with young women] was that femininity constituted an unsafe sexual identity, and that conventionally feminine behaviour was putting young women at risk. (2004: 5)

This unsafe sexual identity was evidenced particularly through the young women's negotiation of condom use i.e. to appear knowing about sex and safer

sexual practices jeopardises conventionally feminine behaviours. The feminine body, according to Holland et al., is something that requires effective management; femininity is unsafe. As such this provides the powerful subject position upon and to which masculine forces are able to be co-opted and played out. They suggest that the body is:

Always material, hairy, discharging, emitting noises, susceptible to pleasure and pain. This materiality is in danger of erupting into men's space and so has to be carefully regulated. (2004: 7)

Being more than susceptible to pain but also at risk of 'erupting into men's space', women's bodies constitute such a social and medical problem that they are not only 'protected' (read: restricted) by masculine-bias professions such as biomedicine, but also socially controlled through heterosexuality-as-masculinity. Therefore does the HPV vaccination programme mediate the risks associated with young women's bodies and the social control of heterosexuality-as-masculinity?

In this thesis, I propose that femininity (and its interrelatedness with sexuality) is in flux, complex, contested and contestable. Femininity is itself unsafe yet sought after, and it is through this assertion that women must perform their femininity and womanhood in regulated ways. Being a successful or conventionally feminine woman requires constant management and negotiation in order to limit the risks of being deemed unfeminine and potentially undesirable as a sexual subject. To a large extent this requires 'conventional' feminine aesthetics in order to be achieved. For young women in particular, transgressing the normative ideals of hetero-femininity is problematic as the intersection of age with a 'challenging' sexual identity is inappropriate, perverse and can be seen as abusive (Curran, Chiarolli, and Pallotta-Chiarolli, 2009). At Brook I was often confronted with the view (from other adult professionals working with young people, in right wing media and from some parents) that childhood and youthful

sexuality is something which is in danger of being corrupted by the influence of SRE, awareness of LGBT identities, advocacy for disabled people's sexual rights and access to contraception and sexual health services. This is despite the fact that, from early in childhood, children are coached into heterosexual norms through various school processes (Renold, 2005). As such, I ask: are these normative sexualities utilised to promote the HPV vaccination programme or are other versions of youthful sexualities possible?

As Chapter Three will show, practicing well as a successfully feminine woman requires young women to achieve a balance between being a knowing and invested (sexual) health-seeker and someone who relies upon the knowledge of others i.e. science and medicine, in order to avoid ill-health. This requires the completion of, and investment in, a stream of difficult tasks. For young women many of these tasks relate to the production of sexualities, including attending regular contraception consultations, undergoing STI diagnostic tests and treatments, and engaging in prophylactic measures such as vaccinations and screenings. None of which are more applicable to youthful sexualities than the HPV vaccination.

Conclusion: exposing the complicity required of successfully feminine young women

Theorising young women as a category of particular analytical interest has allowed me to stake a feminist claim to the project. Specifically, young women's sexualities are central to, and yet missing and often invisible from, the HPV vaccination programme. Consequently, this project aims to interrogate the particular construction of young women and their sexualities - asking: are they promoted in ways which assume their complicity and unproblematic engagement with the HPV vaccination programme? Through an examination of influential research about young women and young sexualities, I have drawn out how and why particular feminist positions have been mooted yet remained inefficient to analyse and explain the contemporary critical issues regarding the HPV

vaccination and its programme. I have also identified key questions raised from the current literature that I will respond to through the thesis. As such, my research contributes to current feminist debates through my engagement with the pharmaceuticalised approach to young women's sexual health.

Chapter one: The joys and frustrations of a feminist participatory orientation

Field note entry:

It was a Sunday afternoon in April 2012. I was at Brook, the young people's sexual health organisation where I work. After the clinic had closed a part-time member of the clinical team; Mary who was also the School Health Advisor for the area, agreed to talk with me. Mary's role was to coordinate the HPV vaccinations in all of the high schools in the area (an urban city in the North West of England). A few days before our research conversation Mary asked me how things were going with my project; I told her they were going well and that I was learning lots and being challenged by a particular book (Wailoo et al., 2012). She seemed keen to read this book too. Mary told me that she had conducted some early small-scale surveys of parents who had declined consent for the vaccine. During the research conversation Mary referred to a story that she said she'd tell me 'off tape'. This was in relation to some feedback parents had given for declining/refusing the vaccine for their child. I thought this was intriguing; that despite anonymity, it appeared that Mary still felt that it was a risk to disclose this information and/or to commit it to a recording. I now 'have' this story that Mary shared with me 'off tape'. And I am left with a research material which I am unsure how or when/whether I can present it. I think I will only share this story verbally and not commit it to writing. In this sense, I will respect Mary's wishes and share her hesitancy or sense of risk with this story.

This story is just one of many simultaneous methodological joys and frustrations that I will detail in this chapter. It reflects that fact that I have gathered lots of materials that I will not be able to use as part of my analysis, conclusions and recommendations. Carrying out the empirical fieldwork has been the most enjoyable and comfortable part of my PhD project. I have experienced a great sense of unease during my time as a PhD candidate born from working-class anxieties of not being smart enough to achieve academic success, my feminist awareness of the sexual inequalities within academia and a general sense of there being a perceived authority and/or superior intellectual ability that would distance me from the women involved in my project, that would now accompany my privileged position.

In this chapter I detail my methodological concerns about the research, highlighting specific issues and debates that relate to the work I have carried out. I interrogate and introduce issues such as the category of woman, their voice and silence as well as influential scholarship on engaged pedagogy and participatory orientation. As with all chapters in this thesis, my research materials will be included to highlight the constant and inseparable interplay and relevance of the empirical materials with academic thought. In the second half of this chapter, I introduce the details about, and practicalities of, carrying out the research.

Feminist research, when explicitly concerned with exploring sex and gender, unifies those categories based upon a specific understanding and construction of their sexed or gendered selves. This is not to say that all other aspects of the person's identity are muted, excluded or ignored, but instead it focusses on the feature which is of interest at that time and within that project. Kathy Davis (2009), feminist scholar working on women's bodies and health suggests that 'intersectionality' has had the unintended consequence of taking the focus away from particular identity categories i.e. 'women', to the extent that we no longer speak of women (much as the re-naming of many women's studies programmes to 'gender studies' has had a similar effect). According to Davis:

'Intersectionality' refers to the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power. (2009: 68)

Though both vague and all-encompassing, the term intersectionality is a successful theoretical term and discursive tool, but debates still exist about:

Whether intersectionality should be limited to understanding individual experiences, to theorizing identity, or whether it should be taken as a property of social structures and cultural discourses. (Davis, 2009: 68)

Similarly feminist researcher Lena Gunnarsson (2011) defends the category woman. Gunnarsson states “we can talk about ‘women’ without thereby assuming that ‘women’ is the only thing that these persons are, or that ‘woman’ is a fixed category” (2011: 32). By not taking other identity categories into account, for example race/ethnicity, sexual orientation, class, nationality, language etc., some feminist researchers may create false abstractions - such as, that white women’s experiences are the experiences of all women (Sayer, 1992 in Gunnarsson, 2011) - without appreciating the possible further complexities that are intrinsic in women’s lives. Gunnarsson has compellingly argued that historically there has been a false dichotomy of a 'universalising before' and an 'intersectional after' within feminist theory and research; a position which she troubles and questions. Gunnarsson argues that it is the very commonality of the category 'women' that then makes the diversity among us so interesting.

Feminist methodological issues regarding voice, representation and agency are considered later in this chapter through an exploration of the contemporary issues surrounding the notions of silence in the research process and how secrecy and withholding information can be signs of strength and survival (but also create difficulties for how to work with the research materials which have been captured ‘off tape’ as seen in the opening field note). In this chapter I present the creative work with young women, carried out to provide enjoyable and engaging activities and with a view to encouraging their voice and agency. I do this through providing images and descriptions of the participatory methods and outputs I have used with them, which reflect the organic and unanticipated trajectory of the project. It is through these descriptions and this empirical work that I have most frequently reflected upon the possible ways in which/whether activism and academia can be made compatible through what bell

hooks refers to in *Teaching to Transgress: Education as the Practice of Freedom* as “engaged pedagogy” (1994: 13).

Such reflections have developed my identity throughout this period, which has seen me merge my positions as professional youth and community worker and feminist activist with that of academic researcher and writer, whilst maintaining my commitment to creating new opportunities and experiences for young women through my participatory orientation (Eubanks, 2009). Virginia Eubanks, who lives in the New York community within which she works as a researcher (across the street from the YWCA) states:

Participatory orientations to research and action often combine grassroots research projects with education efforts and direct action organizing in order to provide more equitable control over the means of both material and intellectual production. In so doing, they create reliable and rich empirical knowledge of social conditions generated by the people who most directly experience them, provide space for the growth of critical collective self-consciousness (Friere's conscientiazation), and mobilize people to achieve transformation of social relations through the exercise of power in political struggle. (2009: 114-115)

Working on women and information technology projects Eubanks states women:

Don't need *more* interaction with computers - they already face being catalogued, tracked, and disciplined by social service information systems – they need *better, less disciplinary* interaction with computers. (2009: 111, original emphasis)

A similar argument applies to the ways in which women are permitted engagement with health campaigns and programmes. They are seldom involved in the development of interventions and instead they are expected to be passive

recipients of a system which catalogues and tracks their interactions (read: compliance) with various public health initiatives. Such realisations serve as fertile ground for embracing a participatory orientation to feminist research such as mine.

Feminist methodology

Early feminist research aimed to include the experiences of women and girls into academic practices and theorising as an attempt to make strides in equality between the sexes (Harding, 1987). Since then many feminist researchers have critiqued this aim and have prompted new and emerging trajectories for feminist research projects. As Davina Cooper highlights in response to a round-table panel at *Gender Unbound*, an AHRC International Conference in 2007:

What was striking about the responses was how they all, in different ways, focused on the problematic of how to research, identify, think, and talk about the intangible, the invisible, the virtual and the haunting. (2009: 275)

Such a response was in relation to the brief of exploring “new bridges, relationships and cleavages between humanities and social science methods” (2009: 275). Cooper suggests that as a result of this round-table and subsequent articles published, there needs to be new approaches to:

Accounting for the opaque, intangible presence of intimacy, sexuality and domestic relations as they saturate, circulate through, or simply emerge within public life. (2009: 275)

These articulations resonate with my research as the HPV vaccination programme appears to coach young women in complicity and consent. I argue that issues of sexuality and sexual responsibility are mere banal undercurrents or

have an intangible presence. I make the presence of sexuality, sex and associated 'risks' visible by questioning and challenging the practices within the HPV vaccination programme.

I define my methodology as feminist. This is as a result of the convergence of my own political positioning as a feminist activist, professional youth and community worker and researcher, along with my PhD project's focus on a medical/pharmaceutical intervention offered to girls and young women (despite HPV affecting boys and young men too). I focus my attention on young women as women occupy a distinct social group who experience under-representation in many social institutions and over-representation in others i.e. in the case of being responsible for reducing the incidence of HPV transmission. I also define my project as participatory (Eubanks, 2009; Banks et al., 2013) and foreground the fact that as a result it has thrown up a range of unanticipated elements and is organic in nature. I use the term 'organic' to refer to the research developing and growing according to the investment and interests of the young women who are supported by my encouragement as a professional youth and community worker and researcher.

Employing a feminist methodology involves a commitment to critiquing other methodologies and methods which, at best, include yet neutralise gender through gender-neutral (but arguably masculine/male) accounts of research and, at worst, exclude, violate and render invisible the experiences of women and girls; it involves an attention to people's experiences, world views and epistemic privilege (Holland et al., 2010), and thoughtful considerations seeking to trouble and disrupt dominant forms of knowledge and ways of knowing that focus on certainty and universal truths.

Feminist principles also guide research which is approached from an acknowledged standpoint (Hartsock, in Harding, 1987; Stanley and Wise, 1993) and one which aims to change the relations of power between those researching

and those being researched. This too is a professional principle within youth and community work which continues to guide my practice (Bastleer & Davies, 2010; Davies, 2010). The project of feminist standpoint has marked a significant movement in academic thinking and has helped to introduce a political and experiential element to research and knowledge. However feminist standpoint theory has been critiqued for attempting to deconstruct and focus upon relative and situated knowledge whilst also attempting to produce knowledge which reflects women's 'reality' i.e. that white women's experiences reflect those of all women (Ramazanoğlu and Holland, 2002). Feminists have contributed to identifying ethical dilemmas in relation to the power dynamics of the research process (Scharff, in Ryan-Flood and Gill, 2010). Research that is self-reflexive, that fosters principles of active participation from the respondents and takes the form of a collaborative venture but does not explicitly deal with issues of sex and gender, can also be viewed as broadly feminist by some because they have concerns with equality and reducing the power imbalance between those being researched and those doing the research. However, this can also be questioned by others as to whether they are distinctly feminist.

Feminism and the pursuit of feminist researchers and activists refers to a broad set of actions based upon a political interest in equality between and amongst the social and biological categories of sex, gender, sexualities etc. Having an awareness of the risk of the potential problems of essentialising social categories based upon 'natural' characteristics and therefore perpetuating the differences which it aims to address is a difficult task for feminist researchers. Feminists grapple with the reduction of women to a singular category that limits diversity and multiplicity and the necessity of reproducing such categories in an attempt to highlight issues and experiences, access resources, and to develop and progress in equitable terms. In response, feminist scholarship has used strategic means and explicit research boundaries by which to utilise the category woman in ways which will garner benefits to some but not all women.

Applying these feminist methodological concerns to the difficulties in implementing this approach in practice, Ramazanoğlu and Holland (2002) open their book *Feminist Methodology: Challenges and Choices* with three broad challenges. They are, 1) feminist researchers face the challenge of not producing valid or authoritative knowledge in their pursuits, 2) feminist researchers do not always attend to the multiplicity of power relations and how women's relationships also affect their experiences and subordination, and 3) the poststructuralist challenge which claims feminism has taken for granted categories of gender which, through researching these, seemingly uncover and describe the effects of pre-existing sex/gender categories. Ramazanoğlu and Holland provide a useful summary of what feminism and therefore a feminist methodology can be. They state "feminism provides theory, language and politics for making sense of gendered lives, but no orderly position on pinning down the contradictions of 'gender'" (2002: 4). Reflecting on this summary provides a useful account of the way in which the projects of feminist researchers can potentially be viewed whilst also attending to some of the disorderliness which is also inherent in feminist methodology. As Ramazanoğlu and Holland state:

Feminist research is politically *for* women; feminist knowledge has some grounding in women's *experiences*, and in how it *feels* to live in unjust gendered relationships. These appear to be the only grounds on which something distinctively feminist might be claimed in diverse approaches to methodology. (2002: 16, original emphasis)

The emphasis here is placed upon the pursuit of research being for women, benefiting a particular population that has previously and, despite advances, continues to be oppressed through patriarchy and affected by the privileging of maleness and particular masculinities. It emphasises experiences, versions of which can be explored, recorded, questioned and observed through various methods of research. And lastly it emphasises the feelings of women in relation

to their experiences. The sense of self and ways in which their embodied experiences and identities as women, are important to feminist researchers.

As Niamh Moore explains in her 2015 eco/feminist book on oral histories with women activists, feminists need to research and write stories documenting women's lives, for without them, these versions of the world will not exist. These versions include eco/feminist concerns, activism and practices of those from women who have rarely had their views and experiences, and expertise committed to, and celebrated in, print. Drawing upon the work of Joan Scott, Ann Cvetkovich and others, Moore states that "narratives foreground the emergence of the subject" (2015: 86) which allows insight into women's experiences and the storying of their subjectivities. She reflects upon her motivation and understanding that the stories she has collected are not hers; she does not 'give voice' to the women she researched with. Instead Moore sees the archiving of these narratives as a collective effort of "includ[ing] other worlds in their own words" (King, 2010, in Moore, 2015: 87). This assertion is useful for me when considering the 'other worlds' of the HPV vaccination experience, specifically the competing accounts of a vaccine that claims to be and is promoted as 'life-saving' yet, as I present in Chapter Five, has significant 'life-limiting' side-effects. Beyond this, the life that is being protected and safeguarded is one which is restricted and limited into the idealised feminine life with consummate health practices.

Whilst feminist methodologies have been critiqued on the basis that they are not distinctive, given that other methodological positionings share certain claims and commitments (such as critical race methodologies or anti-ableist methodologies), the characteristic that unites these methodologies is one of holding a political approach to exploring the historically excluded or peripheral positions of women and girls. For me it is important to raise the idea that each feminist researcher's experience is unique and specific. Coupled with a feminist political positioning this project is contributing to an emerging critical feminist response to the HPV vaccine and its programme.

In this project I demonstrate variance and divergence of the experiences of the HPV vaccination and its programme, but also I have been embraced by and witnessed a bond amongst a community of parents and young women concerned with vaccine safety. These narratives, which will be more explicitly introduced in following chapters, each trouble truth claims and the politics of knowledge.

Voice, silence and women's agency

Here I invite the reader to recall the story that opened this chapter; of Mary speaking to me 'off tape'. Consider this vignette as an example of the trickiness of accessing and analysing voice, silence and women's agency in research. The story Mary shared will not be presented in text, for which I apologise as it is a very revealing and funny one! But coming across insights in this way highlights the ways in which agency can be enacted in particular moments, and the issue of silence and voice is a nebulous one that is difficult to clearly and confidently understand and present in academic pursuits. In addition, Mary told me how the HPV vaccination programme is such a large-scale logistical and bureaucratic task that there is little opportunity for young women to ask questions and explore the nature and meaning of the vaccine. To me, this appeared to be an enforced silencing of the young women's potential questions or concerns; not necessarily a planned and conscious one, but one born out of a busy and resource-strapped staff team. These limitations, in a practical sense, mean little or no reflection or critique can come from the nurses and instead there is a trust and blind faith in the new intervention that has been introduced. I am troubled by this lack of opportunity for both the nurses and the young women to expand their knowledge.

Disagreements exist in relation to the connections claimed to exist between ideas, experiences and material and social realities (Ramazanoğlu and Holland, 2002; Scott, 1991). These knowledge claims are reached as an outcome of academic research and thus must be based upon the 'data' which has been

utilised by the researcher in order for the knowledge claims to be made. Difficulties arise when questioning what is claimed and what those things are reflective or constitutive of. Can what is voiced be reflective of experience itself? Are they only, upon speaking, creating what is claimed to be a certain experience or reality? Experience is often called into question through narrative work and oral histories, rather than taken for granted as a 'true' reflection of what has been lived (Moore, 2015). And further difficulties and disagreements arise when we consider the input and impact of the researcher in the creation of these knowledge claims. How do the researchers' methods interfere with and ultimately change the course of knowledges produced? Can knowledges be known, felt, and therefore made real, without them being expressed/voiced, least of all through academic means and the researcher's lens? Voice and narrative is thus integral to me in dealing with these issues. Voice is of concern to me as it is often considered an integral aspect of identifying inequalities, disclosing experiences and challenging norms. It has also been widely viewed as a distinguishing feature of agency, particularly in feminist consciousness-raising practices. I am keen to explore when and where young women's voices are silenced, discredited or simply not elicited, and instead others are positioned as knowing what they think and what is best for them (see Chapter Four). In contrast to considering what is captured through speech, articulation, the verbalising of experiences, many researchers are more recently concerned with the notions of silence and secrecy (Mazzei, 2007; Ryan-Flood and Gill, 2010; Jolly, Cornwall and Hawkins 2013) and the agency which is involved in keeping secrets and being silent.

Ryan-Flood and Gill's 2010 collection *Secrecy and Silence in the Research Process: feminist reflections* provides a helpful focus on 'voice' and 'representation'. It offers a troubling of the widely circulated false dichotomy; that voice is equal to representation and equality, while silence is equal to powerlessness and oppression. Jane L. Parpart's chapter for example, provides examples of women's resistance and survival in the context of national conflict, of civil unrest and war. Parpart quotes Everjoice Win who states that for women in

Zimbabwe “there are no prizes for speaking out” (2004: 76, in Parpart, 2010: 17) and therefore to voice a concern and to bring attention to inequality, suffering and violence would indeed be the ‘wrong choice’. In these examples it is easier for me to see how voice and choice do not relate with one another in as straightforward a way as one would expect living in a peace-time democratic nation such as the UK (i.e. the assumption and taken-for-granted dichotomy of voice equals empowerment, silence equals subordination). Parpart suggests that there are other, more subtle forms of agency that can be demonstrated through a range of tactics, particularly when there are significant challenges to women’s advancement. Accordingly, I consider and identify possible examples of how silence and secrecy can be deployed as tools used to maintain individual strength, create future possibilities and reduce the chance of further negative experiences.

Considering the young women offered the HPV vaccine, there are many ways in which being silent could be used tactically. For example the young women may hide their knowledge and use silence as a means of not appearing to be too knowledgeable, sexually ‘advanced’ and therefore deemed ‘at risk’ by teachers and nurses through being ‘interested’ or engaged in sex (Attwood, in Ryan-Flood and Gill, 2010). During my first observation of the HPV vaccination being administered, the following was observed and written in my field work notes:

As the final group were coming to the end, one young woman went to Eryl [nurse] who was sat on her own and asked why they didn’t give the vaccine to you if you’re pregnant; “Does it kill the baby?” she asked. Eryl said “We don’t really know. We don’t think it’ll affect the baby though”. She went on to explain that only the flu vaccine is given if a woman is pregnant, otherwise they avoid giving vaccines to pregnant women. I overheard this conversation and Helen [nurse and sexual health project co-ordinator] then came and asked me if the young women were asking

about being pregnant, I said yes. Helen was helping administer the vaccine today and also runs a sexual health clinic for young people. Helen then spoke to Eryl about the young woman's query, in an attempt to ascertain whether Eryl had a concern about a potential pregnancy. (November, 2012)

Here I highlight the ways in which voicing a concern or showing an interest in pregnancy and the effect on the foetus could be interpreted in a particular 'risky' way. The situation presented above resulted in Helen discussing this young woman with Eryl. Of added significance is the way in which risky sexuality, sex, conception and pregnancy are issues of concern bubbling underneath the 'primary' focus of cancer prevention within the HPV vaccination programme. I discuss this observation again further in relation to young women's 'risky' sexualities in Chapter Three.

I recognise that the issue of silence has implications for my research process and methods, as well as the claims to knowledge I make. Ramazanoğlu and Holland (2002) state that to situate oneself within an empirical epistemology is to link what is available to our senses through observations etc., with 'what is actually there'. The reality which is claimed and created is deeply contested but at the very least, empirical researchers hold that what is created or practiced are particular versions of reality. These versions are constitutive of time, place, people and interference from the researcher. They merge together the ideas, experiences and the material and social realities of those involved. As such my focus will be upon bringing together different narratives that abound surrounding the HPV vaccination and its programme, and analysing the narrated selves of the young women.

My role as researcher is aided by these considerations that serve as useful and fruitful prompts for reflexivity. It is with this in mind that I both recognise knowledge from young women who are often excluded or marginal in

the generation of knowledge on the topic of the HPV vaccination and its programme, and also employ methods selected by them. My aim of creating a permissive, positive space and opportunities for the young women is most clearly demonstrated through a feminist methodology. The methods were selected on the basis of the young women's interests as opposed to the prescriptive 'best fit' method for specific knowledge generation, hence the unanticipated and disorderly nature of the project.

The emotional practicalities of research

Before outlining the work I undertook in order to carry out the empirical research with young women, I will highlight the emotional practicalities of research. Early in my research Mary told me how one assembly is given to all of the year group a number of months prior to the first of three vaccines (which are administered over approximately a six month period), and the consent for all three vaccines is also signed prior to the first one's administration. Mary described the situation in the school hall on the day of administering the vaccine, where up to 200 young women are brought in to wait on a bench before being called to sit at one of approximately twelve nurse stations/desks. I imagined the young women being herded through the process and receiving a vaccine that will benefit the whole population/herd at the painful expense of only half of the population/herd. I experienced an emotional and politically-fuelled response to this account. I felt it was a brutal image of a mass of young bodies being taken through a painful, controversial and paternalistic process with unknown benefits and consequences. Thankfully this scene was not replicated in the school where I carried out my observation and recruitment. Partially this was due to the school population being much smaller. However these concerns remain. Thus I held this sense of unease and concern for the young women when I began the empirical research. I now detail the empirical research I undertook.

Accessing and recruiting participants

The methodological approach I employ in this project provided access to, or elicitation of, particular narratives of young women's lives. I have gained insight into the experiences of young women through:

- Research conversations with adult stake holders
- Field notes of observing vaccines being administered
- Research conversations with parents and daughters
- Young women's surveys of HPV
- Lunch time sessions/focus groups with young women
- Field notes from home visits
- HPV diaries.

The first thing I did as a PhD student was to think of the people I knew who may have something to say about the HPV vaccine and its programme. Luckily, due to my job at the time, I didn't have to look far. The sexual health organisation I worked for (Brook) had a position statement supporting the introduction of the HPV vaccine. The Chief Executive Officer (CEO) had links with a pharmaceutical representative, Andrea, who had brought the vaccine to market in the UK. I had easy access to a clinician, Mary, who delivered the vaccine programmes in schools. Making the most of these contacts and networks I sent emails and had conversations with several people about my PhD project. In common methods parlance, I employed a 'convenience sampling' approach to recruiting the first 'round' of 'stakeholders'. I used my work contacts and the powerful position of the organisation to access adult professional stakeholders. This was largely undertaken via email; I felt that having an email address with a known charity in the UK would help me gain access to the stakeholders I had identified. I conducted three face-to-face research conversations (or semi-structure interviews) and one over the telephone, all of which were audio recorded and transcribed verbatim. They were with:

- Mary, the School Health Advisor. She coordinates all immunisations in a local area; overseeing each school's delivery of the vaccination programmes (April, 2012)
- Andrea, the pharmaceutical representative. Worked on the tender document for the UK's HPV vaccination; securing the change from Cervarix to Gardasil in 2012 (July, 2012)
- Iris, a manager with the regional Health Protection Unit. This is the local work of the Health Protection Agency. They investigate outbreaks of communicable diseases, provide information and support to professionals who deliver immunisation programmes (September, 2012)
- Jessie, a manager for a UK cervical cancer charity. Managing the information produced by the charity, making it available to volunteers, cancer patients and their families (December, 2012)
- Olwen and Dilys, school nurse and school nurse support worker at Wendy Chicken Shop school (April, 2014)

I use excerpts from these research conversations along with my analyses in this chapter and elsewhere. However the main focus of this project is the work with young women who are directly affected i.e. who have been offered, and largely accepted, the HPV vaccine.

At a similarly early stage of my project, and upon having re-located my life to Lancaster, I decided to look up youth provisions in the city. I found a local youth association and applied to volunteer once a week at their junior youth club night. I was successful and started volunteering every Thursday for almost one year. Despite attempts to access and recruit young women to my project through this connection, it was unsuccessful and following a year of volunteering I decided to pursue other recruitment avenues. This was a difficult decision because I had begun to develop positive working relationships with some of the young people I was working with and had introduced some new learning opportunities at the club. However, I am motivated by working with young women

as the core focus of this project, and so despite various 'plan B' suggestions of working with parents, nurses or retrospectively with over 18s I continued to work towards recruiting young women currently being offered the HPV vaccine. This was not least because the HPV vaccination programme has prompted both global and topical wide-spread debate which, I argue, has resulted in a situation where young women are in a difficult and vulnerable position.

I also contacted other networks I am or have been involved with, including; a feminist network of academics, youth practitioners and young women based in the North West of England (Feminist Webs) and a Participation Workers Network which is convened through a regional body; then named the North West Regional Youth Work Unit (NWRWU). These did not garner any responses so I then switched my focus to schools. In short, following several months of emailing schools; numerous telephone conversations and voicemails; tens of emails; ethical approval process; permission forms; project outlines; one year of weekly volunteering at a youth club; meetings with school nurses and teachers; sending e-bulletin project invites across the UK; exhausting personal networks and 'calling in' favours, I was finally granted permission to access young women in one high school.

I was also keen to find opponents of the vaccination, or feminist critiques and campaigns. I found the Sane Vax website and made contact with the UK secretary, Morag, who was based in Scotland. All parents of vaccine-injured young women that were involved in my project were contacted via the Sane Vax network (www.sanevax.org), which campaigns for safe, affordable, necessary, effective vaccinations.⁸ Their core activities and campaigning has been with regards to the vaccine-injury cases following HPV vaccinations. I designed a semi-structured research conversation and carried this out with young women

⁸ Other groups also exist such as www.regret.ie in Éire and the UK Association of HPV Vaccine Injured Daughters covering Scotland, England, Wales and Northern Ireland www.efvv.eu/images/pdfs/AHVID.pdf

and/or their parents. The cases presented in Chapter Five are a selection of the stories I have collected via research conversations at home, on the telephone and during a focus group. These stories focus on vaccine-injury as an empirical fact of the research materials I have gathered. These research materials were generated during the period February 2013 to September 2013. I have chosen to use five case studies of vaccine-injury within my thesis. This mirrors the number of HPV diaries that were generated, and whilst I have more vaccine-injury cases I did not want to present them in a way which may have suggested there were a greater number of vaccine-injury cases than non-vaccine injury cases. However, the stories of vaccine injury are used here, which are those more keenly told, shared, and campaigned for by the young women, parents and campaigners.

Whilst this took a great deal of time and resource this process again highlights the unanticipated and disorderliness of the research project. The emotional engagement, the sweat investment and the number of emails, planning meetings and attempts at accessing different groups and people that did not then lead to a positive outcome, far outnumber those that I was able to carry out. The practicalities and disappointments of this are not new or unique to this research; within youth and community projects there are often many creative ideas that are planned for but few are able to be carried out for all manner of reasons (de St. Croix, 2013). Most tellingly for me, and disappointingly, was the situation at the youth club at which I volunteered. After a year of volunteering it was clear that the young women who I was working with and building relationships with were too young for the project and the youth club's 'girls group' had only one member, who was too old for the research project (and the vaccination programme). The management did not seem to be interested in investing to increase young women's attendance and engagement at the club.

Research materials

I eventually garnered many research materials as part of my project, which I depict here. I have divided the research materials into four main categories; health professionals, school, young women and vaccine injury.

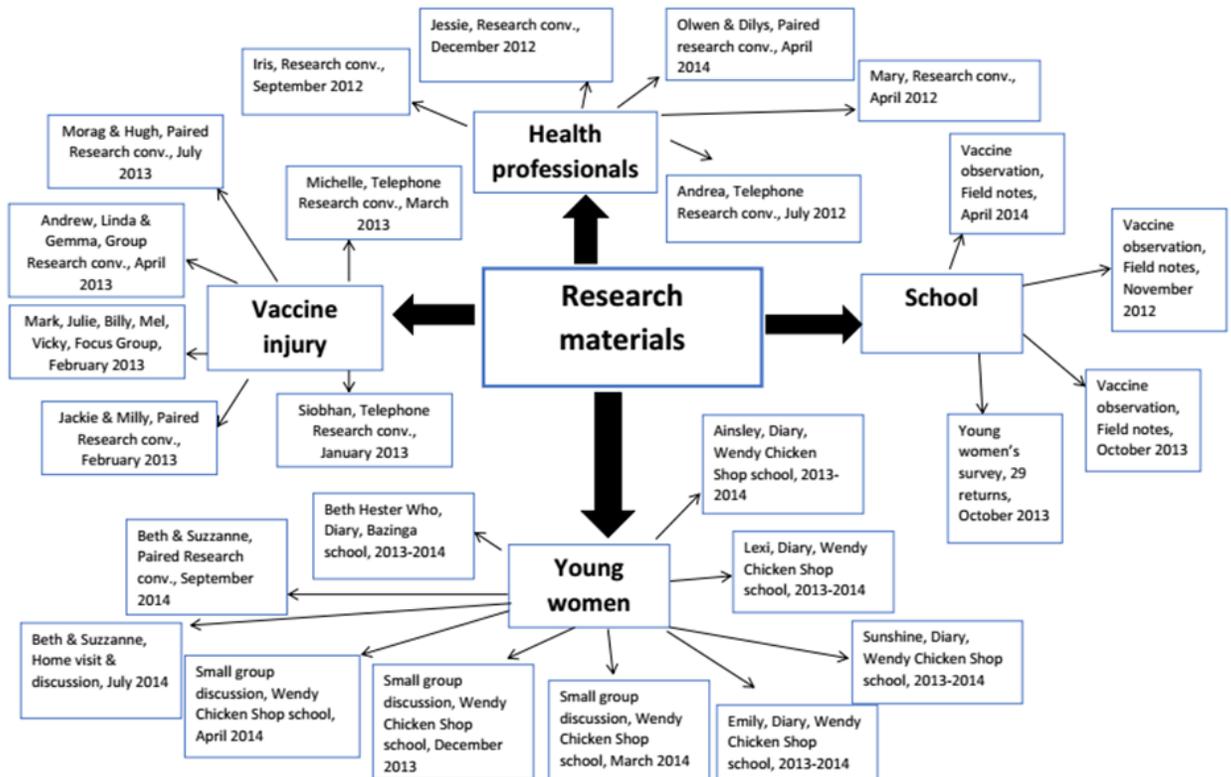


Figure 5 research materials map

I do not afford equal weight to each category, this is due to the specific research focus and political commitment I have to ensuring that the experiences of young women themselves are elicited, valued and given greater prominence in this project. There are excerpts from research materials scattered throughout this thesis and, indeed, presented at the start of each chapter. However, more explicitly, I dedicate specific chapters to exploring these materials in more detail (what could conventionally be referred to as data chapters). Chapter Two explicitly details and explores the young women's diaries and Chapter Five details and explores the vaccine injury case studies.

As figure 5 shows, the sequencing of me collecting and eliciting the research materials dated between April 2012 and September 2014. The materials I collected relating to vaccine-injury preceded the materials I collected from the diaries and group conversations through Wendy Chicken Shop and Bazinga Schools. Despite this the order in which I present and attend to these sets of materials is reversed within the thesis.

I made the decision to structure the materials in the thesis in this way for two reasons. Firstly, it reflects the order of access and awareness of HPV vaccines as experienced by all, or most, people being offered it. The health professionals, young women and their parents are first told about the vaccine with information that promotes it as safe and efficacious. It is not until post-vaccination that the possibility of negative side-effects is uncovered through the receipt of the Patient Information Leaflet and/or through embodied ill-health. Secondly, I am mindful not to present the cases of vaccine-injury first as I do not want to present these as the majority experience of receiving HPV vaccination. Whilst the side-effects are devastating and life-limiting for these young women, the families and young women themselves recognise that for most people the HPV vaccine does not have such effects.

In structuring the thesis in this way, I write the accounts and tell the story in a way that signals forward to something that will be uncovered. I encourage an investment in the sequencing of the accounts and the telling of these HPV vaccine stories in a particular fashion and order; I do this not to dupe the reader but rather to try to take the reader on the journey that these young women and their families experience.

Some reflections on ethics and consent

A major ethical concern for me is the issue of consent. Largely, most empirical studies involving young people require informed and voluntary consent

(BSA, 2004 in Rogers and Ludhra, 2012). In many cases this is requested from the person with legal authority for the person under 18 years, namely a parent. However this is not to say that those under 18 years are unable to consent for themselves. Utilising a participatory orientation to research requires me to show commitment to young people shaping and making sense of their social worlds and challenging stereotypes about them. I believe that a crucial aspect of garnering investment, ownership and therefore meaning in the research process, for any participant, is achieved through the opportunities and processes of discussing and providing (or otherwise) consent.

Through my experience in youth and community work settings for both local authorities and for charitable organisations, a central ethos of the work with young people is that they choose whether or not to get involved in a voluntary relationship with the workers and the activities available (Davies, 2010). This is considered a core professional principle with which I have worked for many years; young people choose whether to attend sessions and whether or not to get involved. A second professional principle is to work from a rights-based perspective, namely in accordance with for example, the Children Act (1989, 2004) the Children and Families Act (2014) and in accordance with the United Nations Convention on the Rights of the Child (1989). My approach and commitment to gaining consent from young people themselves regarding involvement in my project is informed by this (Larcher, 2005; Steenbeek, MacDonald, Downie, Appleton, and Baylis, 2011; Wood, Morris, Davies, and Elwyn, 2001).

In our initial research conversation Mary, the School Health Advisor, informed me that nurses can assess young women for 'Gillick Competency' in the event that parental consent to vaccinate is not received. Following the Gillick vs West Norfolk and Wisbech Area Health Authority in 1985, Lord Gillick ruled that:

As a matter of law, the parental right to determine whether or not a minor child below the age of 16 will have medical treatment terminates if and when the child achieves sufficient understanding and intelligence to understand fully what is proposed. (Larcher, 2005: 353)

This means that young women are, if deemed mature and competent by a relevant health professional to understand the intervention, able to consent to receiving the vaccine themselves. I viewed this as a positive aspect of the process, but one which I later came to question and critique, particularly as it seems to be utilised operationally as a way of guaranteeing increased complicity and acceptance of the vaccine rather than through a commitment to young women's active participation in decision-making.

Given the focus on young people's participation and the approach I was taking to my research, I saw my project as having few difficult ethical considerations in the early stage. I completed the ethical approval documentation with confidence, feeling that the ethical approval process would be relatively problem-free. As I began to complete the University's *Stage One Self-Assessment Form (Part A) – for Research Students* I soon realised that the questions asked prescribed my responses and told me that they (presumably the committee who created the form) viewed the participants as 'vulnerable' due to their age and the research topic itself being 'sensitive' due to the issue of sexual behaviour, rendering the proclaimed 'self-assessment' nature of the form a fallacy in that it pre-judged the ethical considerations of the project based solely on the limited factors, and creating an ethically problematic view of the project.

In order to stand up to the ethical scrutiny placed upon my project by the prescribed positioning of the potential respondents, I had to consider both the 'vulnerable age' and the 'sensitive' issue of sex separately. In relation to age I remained confident that if adequate information was provided and that young women were able to say no as well as say yes to (consent to) being involved with

my project, and would sign a document saying as much, this would suffice. I therefore created a young people's information sheet and a young people's consent form. I also have years of experience as a professional youth and community worker and many enhanced Criminal Records Bureau (CRB)/Disclosure and Barring Service(DBS) certificates. In relation to the issue of sex, the vaccine itself is administered to reduce the incidence of a sexual transmitted infection and so information regarding safer sex messages, cervical screening and cervical cancer would be provided by the school nursing team, and not by me. I explicitly stated this on the ethical approval documents so to ensure that the ethical responsibility for information provided by the schools was not placed with me.

I was surprised by two key responses from the ethics committee. First they appeared to be asking for written consent from the organisations I am involved with to agree to disseminate information about my PhD in order for me to recruit participants, *before* they would grant ethical approval. And second, they requested parental consent forms for the potential young women I hoped to recruit. I had included an adult participant information sheet and consent form which I have used with adult stakeholders and, looking back, perhaps this was not the best decision as ethical approval for working with adults had previously been secured.

With regards to the written approval from the organisations, I had sent supporting documents to the ethics committee showing draft proposed emails and letters to organisations describing my project. However, they stated that I would need a written approval form from them instead. I tried to argue that the role of the ethics committee is to review that the *nature* and *means* of accessing the organisations for their permission was the focus of ethical scrutiny not *whether* or *how* they had provided that permission. To avoid further delay to the process, I created a written permission form for the organisations I have mentioned previously, and

set about getting them signed. This added approximately three weeks to the ethical approval process.

In relation to the parental consent forms, I was unhappy to have to focus the decision to participate with parents and carers, instead preferring to encourage and allow young women to consent for themselves. Despite this, and with the guidance from my supervisors, we decided that I should create a parental consent form (Appendix 1) and if there were instances where young women wanted to participate but consent was not or could not be gained from her parents or carers, we would address this situation on an individual basis. I was, however, keen to include a section of the parental consent form which stated “I agree to my child/ren consenting on their own behalf” so that the issue of young people consenting for themselves could be raised with parents and carers. On reflection however, where I recruited young women, the parents signed the form on behalf of their daughter as well as the young woman signing her own form. This was because I had put this final statement at the end of the consent form, whereas on reflection I should have made it more explicit that the young women could consent for themselves, and put this question first on the form. However, I do feel that the process of consenting by the young women is perhaps a novel experience for them in the oft-adult led decision making that governs young lives, something which I have gone some way to countering through using a participatory orientation.

Asking the right questions?

Exploring the range of research questions and eliciting contrasting opinions from different people requires a variety of questions being asked. In order to gain an understanding of people’s perspectives and opinions I asked adult stakeholders; where do you receive your information about HPV and the vaccine from; what is the process of giving/declining consent for the vaccine; what do you see as the benefits and risks of the vaccine; how have young women responded to the vaccine (i.e. what questions do they ask); has the

vaccination programme increased the levels of knowledge relating to the risks of sexually transmitted infections and cervical cancer?

The methods I have used with adult participants is semi-structured research conversations or semi-structured interviews. This method is both convenient and common therefore familiar to professionals working within various practitioner fields. Using a semi-structured research conversation gave me a basic structure and allowed me to prepare initial questions which some of the participants requested sight of prior to getting involved, also allowing them to ask colleagues and prepare responses. The loose structure also allowed me the opportunity to ask additional questions during the research conversation based upon the responses. I employed this method as it is familiar and therefore was seen as 'nothing out of the ordinary' or anything too trying for the often busy and time-constrained professionals who I approached. Towards the end of the research conversation I also asked the adult participants to identify other relevant people within the HPV vaccination programme, which elicited various and extensive suggestions. Although some suggestions were people I had already contacted another was new and led to me contacting and conducting a research conversation with a representative from Jo's Trust, the UK's only cervical cancer charity.

Whilst I draw on the accounts of these professionals throughout the thesis I do not focus on these research materials in an explicit and dedicated way. Instead, as a commitment to being youth-focused and youth-led, I focus upon the accounts from young women who have been offered the vaccine and their experiences.

Conclusion: embracing an organic and unanticipated trajectory

Participatory methodological concerns, particularly within youth studies, have shifted from an approach of finding the 'best fit' methods for carrying out the

work of generating research materials, to having an approach to thinking, critiquing and attending to the lives of women that do not prescribe, thus allowing for the unimaginable and unplanned to be acknowledged and engaged with. My particular feminist methodological positioning, complemented by an awareness of engaged pedagogy and activist leanings has allowed me to embrace the organic, unanticipated trajectory whereby I hold a commitment to a participatory approach informed by my background as a professional youth and community worker. I take lessons from past histories and contemporary thought in relation to, for example, intersectionality and the supposed heresy of essentialising the category woman. And whilst acknowledging the risks and challenges posed when eliciting 'voice' and 'experience', I set out to work with young women so to carve out a space and opportunity to reflect upon and critique the pharmaceutical intervention being offered. I created an explicitly feminist project that recognises and values the alternative 'unimagined' experiences of the vaccine-injured young women.

My sense of excitement and creativity will be developed through the research materials that the young women have created, which will follow in Chapter Two. The involvement of the many people within this project has interfered with the experiences, the high school lives and immunisation trajectory of the young women. I view this research project as creating sites of potentiality and change. This approach values a dynamic and praxis-oriented focus to the empirical work that places emphasis upon a participatory orientation with the aim of including other experiences 'in their own words'.

In Chapter Two, I introduce the young women and their research materials more explicitly. The chapter mainly focuses upon the materials generated through their HPV diaries and small group discussion at lunch time and I thus analyse these materials in relation not only to the HPV vaccination programme, but to the broader issues of young women's interests and feminine identity practices.

Chapter two: 'A life worth recording': diaries, self-narration and young women's identity practices

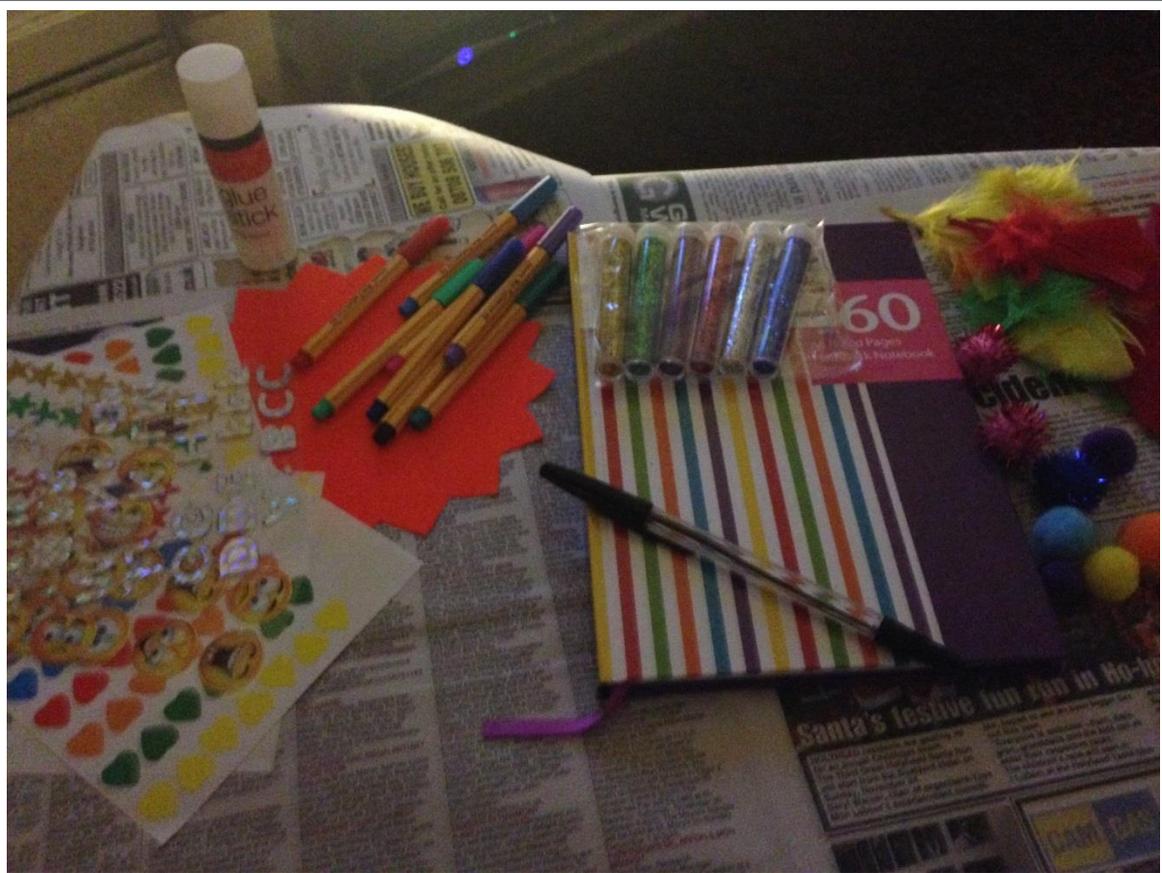


Figure 6 Ainsley, Wendy Chicken Shop School, HPV diary materials 2014-2015

This chapter builds on the methodological considerations I presented in Chapter One. It is the empirical starting point for me addressing a central question of my thesis; how are young women engaging with the HPV vaccination programme in the UK? This question is particularly pertinent given the concerns presented in the introductory chapter about my unease at having to promote the vaccine, and the complicity required and expected of the young women. Therefore there is a social justice concern within this research. The chapter has three main sections; the first details the methods employed as part of the research with these young women, the second presents scholarship about diaries, narratives and construction, and the third presents the young women's

diaries and my analysis of them. As such it could be viewed as a merging of the conventional methods and analysis chapters of a more traditionally styled thesis. The identity practices of young people are sometimes commonly portrayed as problematic; a period during which young women are at risk of sexual coercion and engaging in anti-social behaviour such as 'underage' sex which risks pregnancy and sexually transmitted infections (these themes will be taken up more specifically in Chapter Three). The period of adolescence is widely understood in many education, health and social settings to be one of transition, oscillating between the vulnerable and innocent age of childhood into an increasingly autonomous state of adult life. The journey between the two is conceptualised as a tricky time that creates unique issues. There are specifically gendered issues in relation to adolescence that I will also consider in this chapter. First I provide a more detailed introduction to the work carried out with the young women who selected and generated HPV diaries.

Organic and unanticipated research: researching with young women

My research approach was participatory, which included ongoing opportunities for the participants to shape the nature and the methods of the empirical research. I created a permissive and organic space where the young women were able to choose and lead the direction of the research and control their involvement. This is labour intensive for the researcher, as well as emotional and tiring. And, as seen in Chapter One, it was also very difficult to achieve ethical approval. Here I outline the research process working with year 8 young women, their involvement in the project and how they selected the method. Year 8 is the second year of high school where the students are aged 12 – 13 years old.

Upon being granted permission from a high school to recruit young women, I attended the school on the day of the first vaccination's administration

in October 2013 And I took several photographs of the school hall and nurses station (Figures 7, 8, 9).



Figure 7 The school hall



Figure 8 The nurses' stations

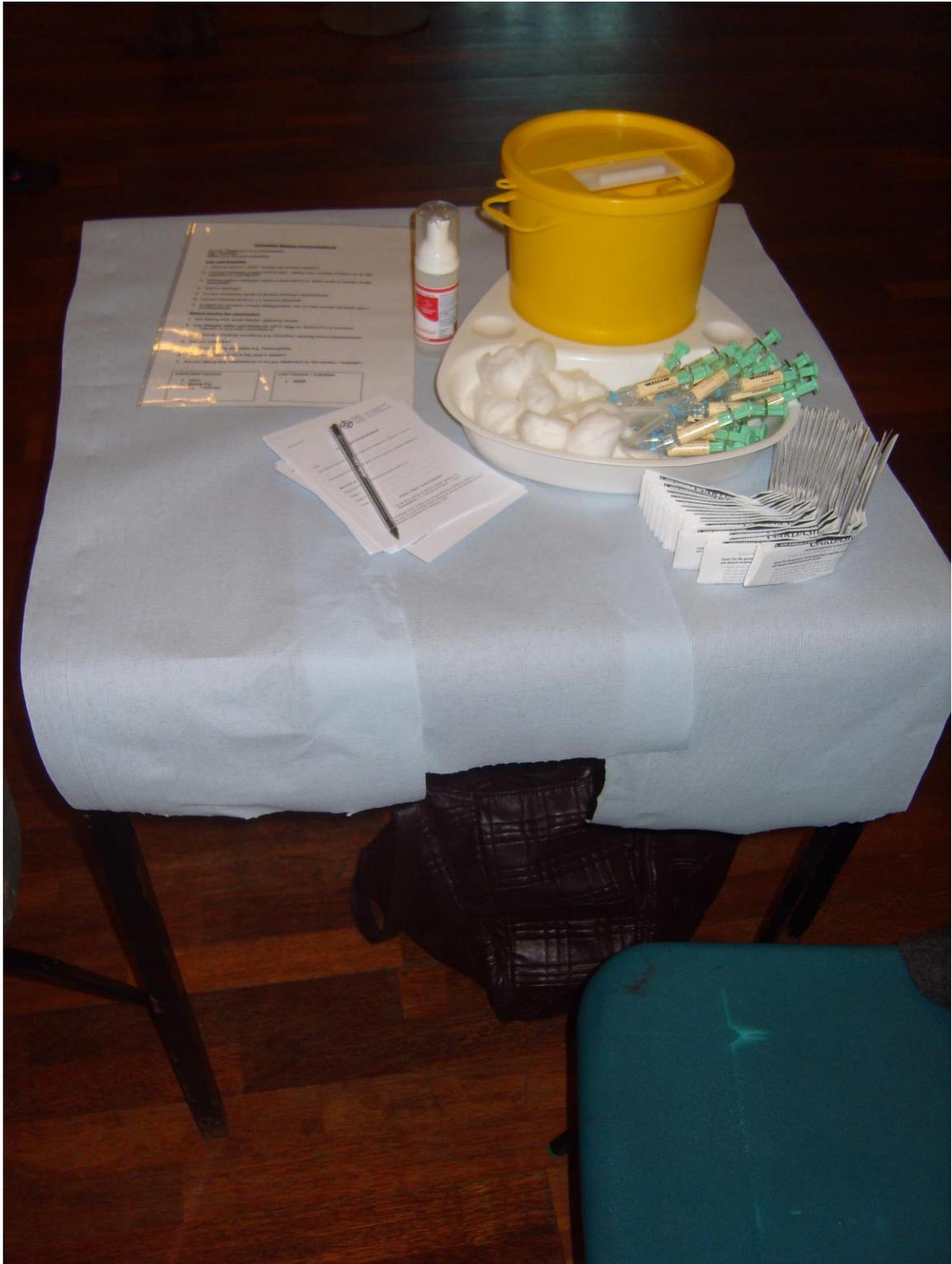


Figure 9 Nurse's station with medical history form, immunisation record, needles, cotton wool balls, sharps bin and PILs

This high school – later given the name ‘Wendy Chicken Shop’ school by the young women - is located in a small working-class town in North Wales with mostly white-Welsh students. I made contact with the nurses who would be there on the day and offered to help prepare the hall e.g. by carrying their equipment. I placed my surveys, pens, information sheets and consent forms on the stage at the front of the hall and waited whilst the health care assistant registered the students and their consent forms. The Deputy Head Teacher of the school suggested I use surveys as a way to “at least get some data”, whereas I had initially planned to simply inform the young women of the project and ask for any interest.

Once the first few young women were being vaccinated I sat with the others and told them I was from a university doing a project about their experiences of the vaccine and wanted to know what they thought of it. I told the young women that I had a few questions on a survey (Appendix 2). In blue boxes on this survey there were seven questions and there was a yellow box they could fill in if they’d like to talk to me after that day about it. Of almost 80 young women that day I received 29 survey responses and 12 put their name and contact details down for wanting to get involved further.

Later that day I emailed, sent a text message or telephoned the 12 young women. Two of these responded to me. On the next vaccine date I attended the school again and two of the young women agreed to meet me at lunch time. I booked a room at the school for this. During the vaccine administration I reminded some of the young women of my project and invited them to come to see me at lunch time too if they were interested. A further five young women said they would attend. At lunch time four young women came. The room that I booked was immediately opposite the school’s reception and the security door which leads to the Head Teacher’s office and other staff offices. It was a small meeting room often used for meetings with parents or visitors to the school. Next to the door was a line of three chairs. This is where I had sat previously as I

waited to meet the Deputy Head Teacher to discuss access to the school. It is also where the naughty kids have to wait to learn their fate, or the sick kids wait for their parents to collect them. It is not a cool or desirable place to be!

I had prepared a session plan for this first meeting with the young women. I used what are commonly referred to in academic research as creative methods (Allen, 2011). Such methods are integral and commonplace within youth and community work. They are inspired largely by the everyday creative work of youth practitioners, facilitators and trainers e.g. Vanessa Rogers and Feminist Webs network (www.vanessarogers.co.uk; www.feministwebs.com) and the experiential learning style of the profession. Indeed there are many examples of activities and tools developed by youth and community workers and they are often printed in-house on office photocopiers e.g. Wigan Youth Service's 'Owt for Nowt' resource pack of activities that can be carried out with no budget.

Here I outline the small group discussions that took place. This is where I provide details of the methods I used to facilitate the young women's interest and involvement in the research. Following this I then move on to presenting and analysing the research materials from each young woman's diary.

The first small group discussion

During this first session I discussed confidentiality and reminded the young women of the aims of the project. I then delivered an activity using four A5 sized images (Figures 10, 11, 12, 13) that showed some examples of different research methods. They were; a diary, scrap booking method, a one-to-one research conversation and a focus group discussion. I placed these images on the table and discussed each one. I told the young women that if they had any other ideas of how to record their views and experiences they could let me know.

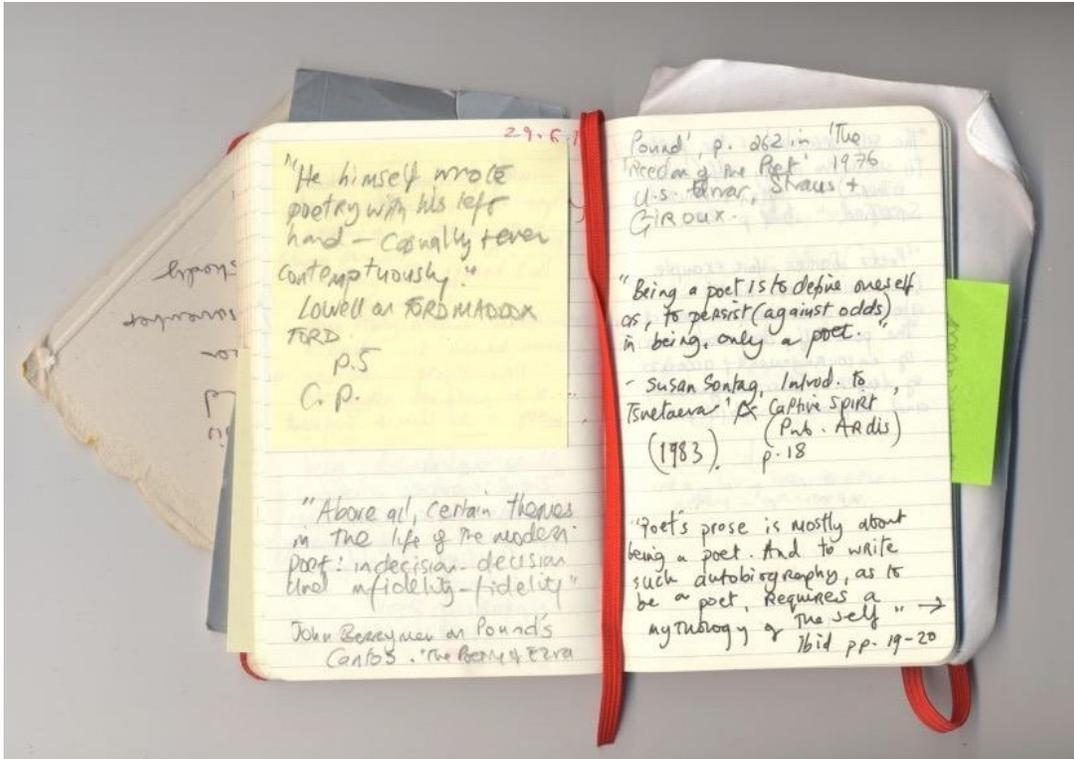


Figure 10 Diary method



Figure 11 Scrap booking method



Figure 12 Research conversation method



Figure 13 Small group discussion method

At the end of the session all four young women chose diaries as the method they would like to use and one stated that she'd also like small group discussions (focus group method) after which the others said they'd like that too. They asked me to go to the local Pound Shop and gave me a list of things that they wanted such as stickers, coloured pens and "bits and bobs" (Sunshine) and told me to meet them at a set place in the school grounds at the end of the school day. At subsequent group sessions the young women asked me for other materials and told me that the glitter was messy and the coloured pens were too thin to colour anything in with. Being 'told' what to do, where to shop for the materials and what to buy demonstrates a positive engagement in the project. I interpreted this as a way that the young women tested boundaries and saw to what extent they could take control and ownership over the project. I had provided them with having the choice of methods, so could they also then choose other things and make modest demands? The answer was yes, and I happily responded and felt confident that the young women would feel a greater sense of investment in the research as a result.

The next activity was a 'body activity' (Figures 14, 15, 16 and 17). Body activities are used a lot within youth and community work. They provide a framework by which workers can prompt thinking and ideas on a particular subject. For example, in the past I have used this activity for young people involved in recruitment to generate interview questions for potential new youth and community workers, as well as in sexual pleasure workshops for participants to think about pleasurable and exciting activities involving the whole body and senses. I gave the young women an A4 piece of paper along with some pens, coloured felt tips and stickers etc. I asked them to draw the outline of a body and to think about how the HPV vaccine affects them starting from the head and working downwards. I also drew a body and gave an unrelated example to start. This activity was the beginning of gathering information from the young women about how they engage with the HPV vaccination programme. Having an initial focus that distracted from the participants' personal experiences was chosen

specifically to help them ease into the process of providing feedback. It detaches from the focus being on their personal experiences. Using the body activity or external resource, in addition to the young women and me, is often referred to as the 'common third' in social pedagogy practices (www.socialpedagogy.co.uk). This allows both the researcher and the researched to collaborate in a shared experience, which develops the relationship between me as the researcher and the young women as those being researched. This creates the potential for both to learn and be equal in the doing of the activity.

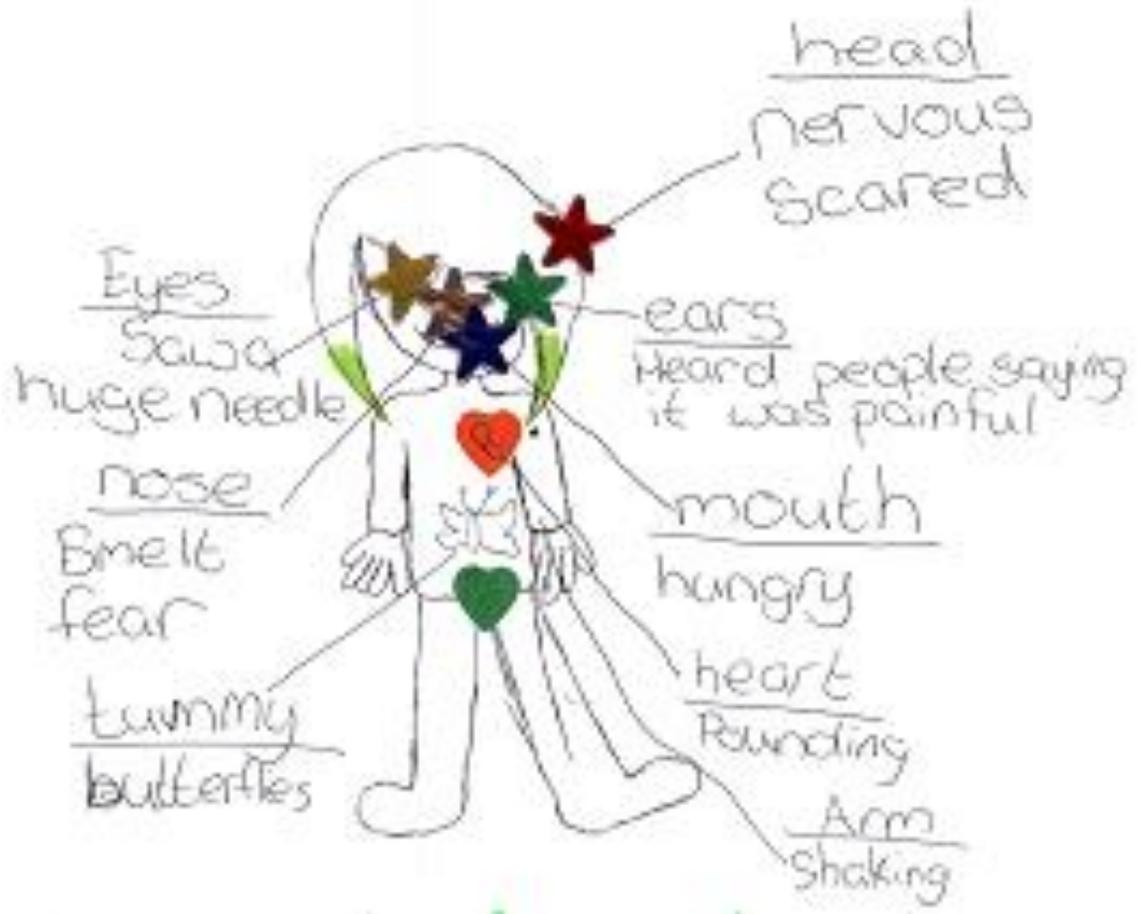


Figure 14 Sunshine's body drawing

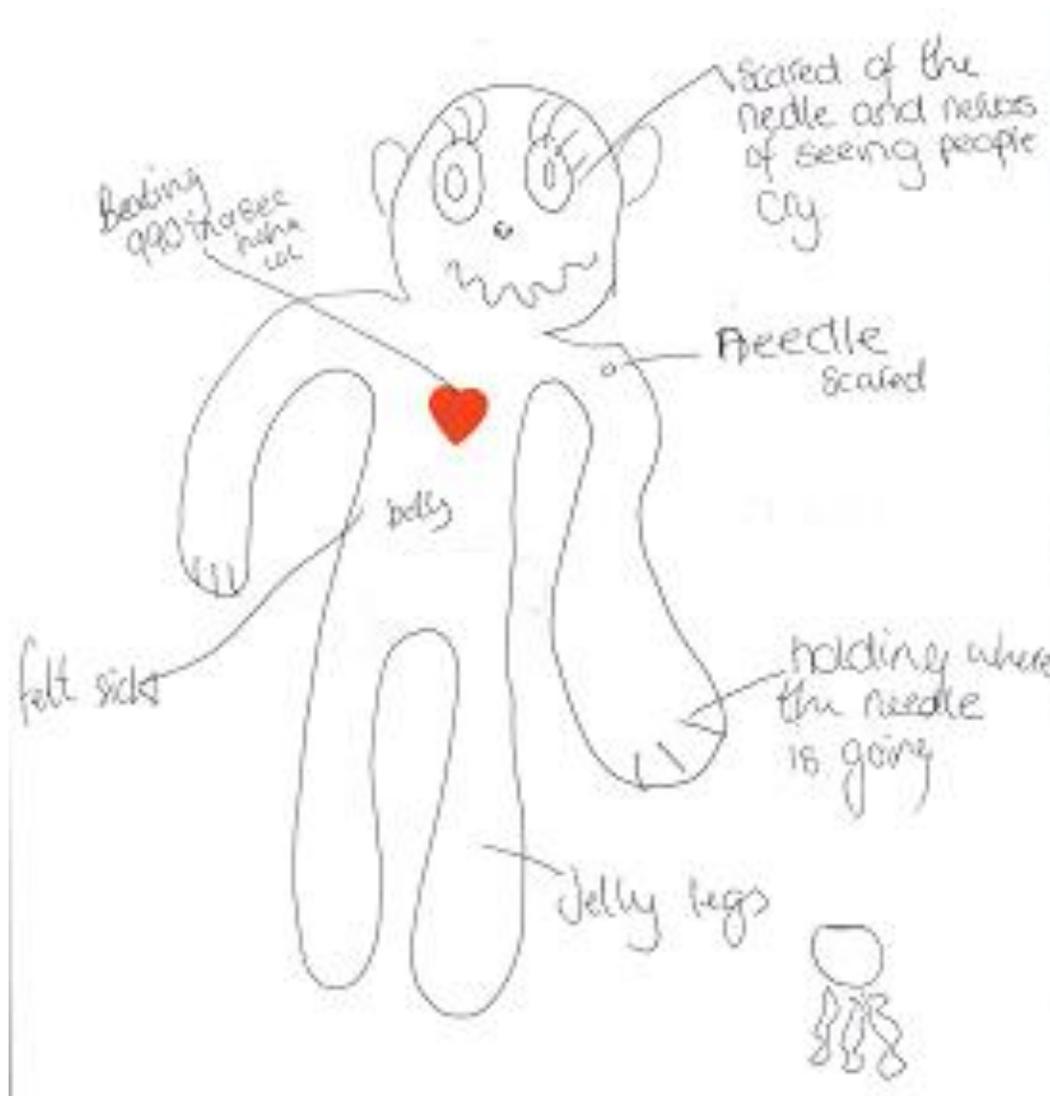


Figure 15 Emily's body drawing

The second small group discussion

I was in contact with the young women between the session in December and March via Facebook messaging, email and/or text message, whichever way they had asked me to be in contact. Based upon the observations I had made during the vaccine administration sessions I sent messages with prompts and questions to guide the young women to create their diaries. Also during this time the school had re-allocated the meeting room we met in during the first workshop and so we were allocated the video-conferencing room upstairs above the

reception area. This room was locked and was in the area next to the staff room and staff toilets. We met there at lunch time and it seemed as though the



Figure 16 Ainsley's body drawing



Figure 17 Lexi's body drawing

young women were apprehensive but felt cool being in a usually restricted area only meant for staff and other 'important adults'. During this session at Wendy Chicken Shop school I planned a 'bin it, keep it' activity (Figure 18) as a way of the young women having the opportunity to shape the direction of the research.



Figure 18 Bin it, keep it activity

I prepared the coloured stars with 'bin it' and 'keep it' written on them and then gave lots of blank coloured stars to the young women. They then wrote down the different things that they wanted to bin or keep doing the diaries. This allowed me to plan activities that were more relevant to their interests and those which would, hopefully, help to retain their involvement in the project. There wasn't necessarily a consensus of feedback but it did give me the insight to prompt fewer written tasks and more creative tasks. For example, from the audio recording of this session two young women disagreed about the writing tasks:

Ali: What do you think is nice, what have you been enjoying, what do you want to keep? And what do you think is annoying and you think 'I can't be arsed with that, I don't want to do that anymore'? So write them on there and then you put them next to bin it or keep it and then I'll keep them separately.

Ainsley: What can we bin?

Lexi: Writing.

Ainsley: No, coz you have to write.

Ali: But if you don't want to write as much, or you'd rather do drawing ones or something like that?

Ainsley: Like more creative tasks.

Sunshine: Yeah. (March, 2014)

I asked a key question during this session: "if you were me, what would you ask?" This elicited insightful responses such as focussing on the role and questions asked by the nurses. The young women agreed that the nurses asked them 'silly' questions and they all seemed keen to share this with me. As a follow on question to this, I also asked them:

Ali: So if you were going to be asking somebody else, what kind of questions would you ask them?

Ainsley: Like you could do a mini survey. Or something.

Ali: But who's going to create the survey?

Lexi: Us

Ali: Would I create it or would you create it?

Ainsley: Us

Ali: So there's four of you, how many questions would you create each to make a survey?

Ainsley: Ten.

Ali: Ten each?

Emily: That'd be hard.

Ali: That'd be forty, if there's four of you in this group.

Ainsley: Oh no! (March, 2014)

Asking the young women these questions provided subsequent questions and prompts for the diaries. It also led to a survey that was created during the sessions but which it was decided that I would type up, print out and send two copies in the post to each of the young women. The young women used these surveys to varying extents and, where they had them completed by friends, they also glued them into their diaries. The key interest of the survey is that it was instigated by the young women themselves. So the 'bin it, keep it' activity provided information that allowed me to understand what mattered most to the young women. This is just one example of the way in which I facilitated the young women's participation and investment in the project which mean embracing an organic and unanticipated trajectory for the research.

The third small group discussion

This session started with the young women describing to me the diary entries they had made since the last session. It was planned as the final session and one where we could review the tasks and look to finish off the diaries. They listed reasons why people have and did not have the vaccine. During Ainsley's reading aloud these reasons, I asked follow up questions to the reasons why

people do and do not have the vaccines. However, Ainsley was more interested in assessing the levels of creativity and colour in her diary than engaging in a discussion of the list she'd prepared stating "I'm guna jazz mine up tonight, it just looks boring".

Emily quietly but unashamedly told me she hadn't done the previous task and then took to rifling through the latest selection of craft materials I had brought along. I had sent Emily a sheet of all the tasks I had set for her to tick against when she had completed them. Emily had moved house in the interim period and wasn't sure where she was up to. She had that checklist with her and we went through it. At each task she hadn't done, Ainsley would tell her what she had written. For example, after listing who is involved in the HPV vaccination I asked Emily:

Ali: Can you think of anybody that Ainsley might have missed out?

Emily: Yeah, the tall nasty black-haired one.

Ali: Who? The tall nasty what?

Emily: [mumbles to mimic the health care assistant] 'Go to your class'

Ainsley: That's the one that I said...

Ali: The one that gives you the...

Ainsley: Yeah, the papers. (April, 2014)

Whilst Ainsley had completed all of her tasks first (and spoke of decorating the diary as a secondary interest), Emily showed more interest in decorating her

diary and chatting. She showed me what she had done and seemed pleased with the extra things she had included in her diary:

Ali: Look at you with ribbons!

Emily: Great I am, yeah? (April, 2014)

Again, this signifies the differing ways that the young women participated. Whilst it is the experiences of the HPV vaccination as an intervention that I have a particular focus and interest in, these young women are more willing and readily able to share their individual hobbies and stories from school, weekends, gigs and holidays than their experiences of the vaccination, as we will see more of later. Here, they show greater interest in decorating their diaries and making them aesthetically appealing than in focussing on the entries themselves and their experience of the HPV vaccination.

Collecting the diaries

Together with the young women we arranged a date for me to come to the school and wait in the reception area at lunch time to collect the diaries. This was based on them leaving enough time to complete their diary tasks, decorate them and finish school work before the summer holidays began. Sunshine and Ainsley returned theirs without problem or issue. Lexi had forgotten her diary and so we arranged that I would collect it from her home after school. Emily sat with me in the reception area, on the 'naughty seats', and went through the diary with me as she wanted to make sure she had done everything we had agreed. Each of the young women received a £20 voucher for a shop of their choice (New Look). They had also received a £10 voucher mid-way through the process. They were also told that I would return their diaries if they wanted me to.

I detail these methods in order to bring to life the research that the young women and I undertook. It evidences the ways in which my participatory orientation to the research was practiced. It suggested ways in which skills from youth and community work can be merged with academic research to build a permissible and positive research space.

A chance encounter: recruiting a 'refuser'

As much as I celebrate the participatory approach and methods I used here, I also recruited two young women through a chance encounter whilst I was running a workshop at the 'Adventure and Empowerment' Girls' Work Conference at Manchester Metropolitan University (September, 2013). At the end of the conference I caught up with Suzzanne who also worked in a sexual health setting as a youth and community worker and we chatted about common experiences and issues in the workplace. We started to discuss my PhD and she said she was concerned about the HPV vaccination as her daughter had just been offered it but she had not had any previous vaccinations. Following this discussion I asked Suzzanne if she'd be willing to be involved in my project, and whether her daughter (Beth Hester Who) would be too. I explained that the young women from Wendy Chicken Shop school had selected the diary methods and I offered Beth the chance to be involved too. Beth said yes and also asked if her friend, Celia, could do it too. I embraced this chance opportunity which offered the project the experiences of an additional two young women through unexpected means.⁹ At this stage I now had six young women interested in being involved in the research project.

Home visit

⁹ Despite some initial involvement in the project, Celia later withdrew from the process and I have no research materials from her.

I met Suzanne, Beth, her younger sister and their dogs at the local train station. We walked to their home and Beth made me a coffee apologising for the soya milk and rolling her eyes at her parents' veganism. Luckily, because I knew Suzanne, I had brought vegan chocolate brownies and Beth seemed to settle and feel less embarrassed at what she had anticipated I would think was an 'unusual' lifestyle. During this meeting I had planned to introduce myself to Beth and discuss the project, much in the same way that I had done with the young women at Wendy Chicken Shop school. As there was only one young woman, the planning for this visit mainly involved discussion prompts and mental reminders to cover the topics of consent, incentives and general interest in the project. Beth and I chatted alone in the living room, occasionally having to stop and shoo her younger sister away. Beth told me that she doesn't see Celia outside of school but that she'd pass on the information about the project the next day. After our chat, I was invited to see her bedroom and was treated to a duet of 'In The Jungle' on ukulele, which Beth had been teaching her younger sister to play. I left Beth with the project information sheet as well as a diary and various craft materials similar to those that I had given to the young women at Wendy Chicken Shop school.

Paired research conversation at work

I kept in touch with Beth via text message to Suzanne's mobile phone. I sent Beth the questions and prompts that had been generated via the sessions at Wendy Chicken Shop school in an attempt to keep the materials fairly consistent. Suzanne and Beth both told me that Beth felt more articulate when she speaks and she had skipped a few of the prompts. I decided therefore to ask her if she'd like to chat with me rather than focus entirely on completing the diary and asked if I could audio record it. We arranged to meet at my new place of work (LGBT Centre) as it is a place familiar to Suzanne and somewhere that has a small comfortable library that could be used privately. Suzanne and Beth came and I had prepared a loose set of questions and themes to discuss, some of which

were based on the diary questions and prompts and others were in relation to Beth's experiences of being a 'refuser'. It was a paired research conversation with Suzzanne, but Beth also asked her to leave the room during one part of the discussion.

Dropping off the diary

Once Beth had completed the diary we arranged for me to collect it. It was the school holidays and Beth, along with her younger sister, best friend and her Dad were in the vicinity of my workplace on a particular day. They agreed to visit my place of work again (and to have lunch at the community café there) and drop off the diary at the same time. During this visit, I chatted with the group, offered them merchandise such as stickers and badges from my workplace and also provided Beth with the vouchers (Forbidden Planet) for her involvement.

At this stage I now had five diaries returned and I could begin my review and analysis of them. The recognition and appreciation of them as used by the young women to practice gender and femininity started here too.

'A life worth recording': practicing femininity through diaries

The use of diaries by young women is often seen as being a private activity that captures 'social evidence' of everyday life. I suggest that diaries are a gendered activity, often thought of as being confessional in nature, sometimes coded, yet hidden from public view.¹⁰ There are many famous diaries that could be called upon here but I focus on diaries during adolescence as they are much more closely associated with the social worlds of young women. As Barbara

¹⁰ The diaries of Anne Lister serve as a good case in point here. The nineteenth century industrialist from Yorkshire kept coded diaries of her relationships with other women using algebra and ancient Greek. Her diaries were later decoded in the 1930s (Whitbread, 1992).

Crowther has suggested in her investigation into the diaries of 10-14 year old girls from the 1950s to 1970s:

[Diary writing] concerns a practice and a product of early adolescence, a time when, as girls' independence grows, a public face, and an acceptable one, is increasingly being demanded of them, but a public voice gets little encouragement [...] Girls detect early that men's voices are heard more and culturally valued more than women's are. There are very few cultural texts or products that reflect and engage specifically with little girls' experience, before they are addressed by the ideologies of heterosexual teenage femininity and romance. (1999: 199)

The fact that the young women selected this method could be seen as reflective of them having an awareness of the disparity offered to the views and opinions of young women and young men. Using a diary to write one's thoughts and experiences is a way of externalising – albeit in a private and controlled way - and putting forth into the world one's feelings, whether there is an actual audience or a reluctant one. In this project, the young women knew that I would be reading their entries; I was to be their audience whether imagined or 'real' during their writings. The diaries provide research materials through which to consider Crowther's argument of the implicitly gendered nature of voice and the cultural value of women's public display or practices of identity and experience.

Crowther, who has written on many issues in relation to culture, language and on-screen depictions of women (it appears that Crowther has only written this one chapter on diaries), highlights how the use of a diary is indeed a public performance. She suggests:

If no one knows, or no one is intended to know, what is inside a girl's diary, yet they know she keeps a diary, the writer is communicating to those

close to her that she has something of her own to say – she has feelings, responses, opinions, or, at the least, a life worth recording. (1999: 201)

The ‘life worth recording’ is of interest here as it resonates with my motivations for taking on this research project as a way of creating and affording time and space for the articulation of the young women’s thoughts, feelings and reflections on the HPV vaccination programme. The written entries of a diary exist in a different material space to the audio recordings of voice or the transcriptions thereof. By creating a diary Crowther suggests a young girl is:

Putting on an act about her autonomously articulated life, communicating through an activity and through the maintenance of an exclusive and excluding relationship between herself and her unfolding text. (1999: 201)

Writing a diary with a set purpose, i.e. for my research project, brings another dimension to the diaries of Lexi, Sunshine, Emily, Ainsley and Beth. As we will see below, some of the young women’s entries appear to be explicitly written to me; the dynamic of the research relationships is presented to the reader and can be analysed as another facet of the materials that have been generated. Despite this insight of the ‘audience’ and the responsibility felt towards me and the project, the diaries help us to learn the details of the various ways in which the HPV vaccine impacts upon and affects the lives of these young women. We can learn about the HPV vaccination programme in a new way, by virtue of the participatory nature of the project.

Mary Jane Kehily and colleagues carried out a study at a UK primary school during which Kehily uncovered a social ‘diary group’ which was a “self-styled network of eight girls who met in the school playground to discuss issues that interested and excited them” (Kehily, Mac An Ghail, Epstein and Redman, 2002: 167). Kehily has provided a great reflection of her role during this research:

During this period I was treated as an 'honorary member' of the diary group and was expected to abide by the convention of the group [...] my presence as researcher and 'grown-up girl' was quickly integrated into the structure and ritual of diary group meetings. Within this space I could be called upon by the girls at different moments as group member, invited audience, moral arbiter and source of knowledge about the adult world. (2002: 168)

This reflection from Kehily has prompted me to consider my role as the researcher with this group of young women. When I present the diary materials I highlight some of the instances whereby my position is seen to be indicated through the diary entries. In particular, and most clearly, this is seen with Emily's diary entries. Similar episodes to those described by Kehily occurred during the group discussions at Wendy Chicken Shop school. For example, Sunshine was counting the time shown on the audio recorder for how long we'd been recording, she then instigated the group to "say goodbye" to me when she was switching it off. Emily also spoke 'to the recorder' when I asked her if she'd used "the c-word" in the knowledge that I would be listening to these recordings in the future.¹¹ Using such expletives in the setting of the school where this would usually be challenged and/or punished provides insight into how Emily has assessed that I am a different type of adult to her teachers at the school.

I found watching the progress of the diaries being created at the group sessions delightful. Seeing how each young woman kept her diary and her materials, whether she had remembered to bring her diary, whether she opened the pages and publicly displayed the entries to the other young women, and whether she chose to read excerpts to the group. These active decisions and semi-public displays are demonstrative of the processes of meaning-making that the young women were going through. This sense of young women figuring

¹¹ Here I refer to the word 'cunt' which is a derogatory word often associated with female genitals.

things out has been described by many scholars working in youth studies and studies of girlhood and/or childhood and adolescent femininities as an aspect of their empirical research relating to friendships, culture and consumerism, schooling and sexualities (Kehily et al., 2002; Hey, 1997; McRobbie, 1978; Walkerdine, 1990; Ringrose, 2010).

These practices of young femininity occurred in a space that I specifically created as an opportunity for exploring the key questions of the research project: How do young women engage with the HPV vaccination programme in the UK? Next I discuss my understanding of the language used around construction in relation to the narrative accounts of young women's identities, as demonstrated through the young women's diaries.

Narratives of identities in practice: developing the language of construction

Here I explore the nature and extent to which the diaries can provide insight into the identity formation and practices of 'figuring it out' that the young women engaged in to 'do' 'young woman'. And more specifically how their identities are practiced and negotiated through their engagement with the HPV vaccination programme.¹² Jo Woodiwiss, Senior Lecturer at Huddersfield University, has worked for many years with Women's Aid and with women who have memories of child sexual abuse. Her work tells of the ways in which the language of therapeutic storying of women's lives, of overcoming the trauma of early sexual abuse, constructs a circumscribed range through which the stories available to women are limited. The dominant framework envisages women as troubled and thus in need of rescuing which, in turn, will lead to a successful, happy and healthy version of an adult woman.

¹² Specific scholarship exists in relation to diaries, drawings and images used as qualitative research methods chosen by the researcher. See Coleman, 2008; Harvey, 2011; Elliott, 1997; Kenten 2010.

During the 'Troubling Narratives' conference at Huddersfield University (June, 2014) Woodiwiss suggested that people use narratives as a way of making sense of the world. We bring meaning to our experiences through the storying of our lives and those of others. We can justify, explain and gain insight into our lives through telling them in particular ways. In order to draw upon and use narratives, there are dominant stories which are available to us and limit us. Woodiwiss suggests that we are not free to tell any story we choose (2014; Woodiwiss, Smith, and Lockwood, 2017 forthcoming). This is particularly so of women, and in particular, those who have experienced sexual abuse in childhood or who experience sexual 'problems' in adulthood. I argue that the 'options' of femininity available to the young women in this project are similarly limited. The construction of future ill-health is explicit in the justification for vaccinating girls and young women at an age that is assumed to be pre-sexual debut. Not only for those who accept the vaccine, but also to those, like Beth, who decline and thus are deemed at higher risk of an almost inevitably diseased future.

I find the focus on narratives useful in understanding and framing this project. There are many HPV narratives that circulate and I am contributing to those through this project. Young women are learning which narrative options they have. These options are made available and shaped through the social and cultural scripts offered and presented to them in their home lives, their friendships, cultural engagements and popular depictions of what it means to be and 'do' 'young woman'. The young women being offered the HPV vaccination are often presented with a version of femininity through promotional materials, school assemblies and letters sent home. This is a narrative that depicts HPV as a common sexually transmitted infection linked to the development of cervical cancer and an almost inevitable future of ill-health. Indeed, genital warts – one type of HPV virus – is the second most common STI (www.nhs.uk/conditions/sexually-transmitted-infections/Pages/Introduction.aspx accessed 17th March 2013).

Narrative redemption is offered through the framing of the vaccine as the saviour of health in the NHS leaflets promoting the HPV vaccine. Young women must simply practice resilience in the face of HPV and cervical cancer through accepting the vaccine. As Ronan and I argue the notion of the resilient young woman is a narrative template that is becoming increasingly commonplace in youth and community practice and policy (Hanbury and Ronan, 2014). We suggest the use of the term resilience:

Occludes questions of gendered, classed and raced inequalities and becomes part of a wider neo-liberal agenda that shifts responsibility for dealing with crisis away from the public sphere and onto the individual. (2014: 81)

A central focus in the narrative framings of the HPV vaccination programme is the focus on the bodies and the sexualities of young women. They are expected to act in a way that will avert or respond in specific ways to ill-health. The practices of young womanhood require identification with this framing. It is such identity positions that are formed through the use of narratives and are demonstrated in the diary entries of the young women in this project.

Indeed using autobiographical writing, or self-narration, is a way of constructing identities and meaning making that helps the writer to work through difficult and painful experiences. As Kehily (2010) has written in a later reflexive article on an early writing exercise, she uses 'well worn' stories from her past and critiques them through a feminist lens. In her article *Self-narration, Autobiography and Identity Construction*, she states that autobiographical writing can allow people to describe the world as it is and create it in a way that it could be. As such I view the diaries as an exercise of possibility and a vehicle for processing something new and uncertain. Both Kehily and Woodiwiss pay attention to the documenting of hardship and the subsequent response to this which is often packaged into a survivor's story of overcoming adversity. Indeed Kehily reflected

on her 'well-worn' story of her first relationship with a man as "a quaint little tale about getting the clap" (2010: 25).

The significance of this is two-fold. Firstly, Kehily is reflecting on her 'well-worn' story that described a past relationship as she saw it at the time. Through reflection some time later she can view this as a constructed identity which involves romance, aspirations and heart-ache, thus a new interpretation and articulation which now suggests to the reader a construction of a current identity in relation to this relationship; one which is more hardy and critical of the gender imbalance. The interpretation of a 'well-worn' story can thus change; as do, therefore, the identity constructs that are practiced through narrating an event in the past. Secondly, it is the sexual story that is significant. The use of humour regarding a sexually transmitted infection (in this case 'the clap' refers to gonorrhoea) is rare to read in academic articles (particularly where the incidence of STI relates to the author herself), where the 'seriousness' of infections and risk-taking are usually viewed more earnestly.

I understand Woodiwiss and Kehily's work in several ways. First, Woodiwiss' assertion that narrating one's life, specifically traumatic experiences, often comes with a narrative template beyond which it is difficult to move. There are specific framings within which the young women can know, understand and practice their gendered identities. Second, Kehily develops the potential of the storying of women's lives. Not only can life stories describe what has happened but they offer the potential for young women to create different versions of how things might be. This is a key point for my research as the opportunities to engage with the HPV vaccination programme and to share stories of experience, provides opportunities for creating these different versions and breaking from the narrative template. I return to the possibilities for young women to narrate a sexual story in Chapter Three, where young women's sexualities are explored more explicitly, and techniques such as humour and dismissal are used in specific ways.

Introducing and analysing five young women's HPV diaries

Five young women completed HPV diaries. Lexi, Sunshine, Ainsley and Emily all attend Wendy Chicken Shop school in a small town in North Wales, and Beth Hester Who attends Bazinga school in a city in the North West of England. The former four young women all received the three HPV vaccines Gardasil during school year 8 in 2013-2014. Beth and her parents chose not to accept the vaccine during this same school year. These research materials do not conform to the usual criteria of diaries. Entries were made following my prompts via the selected method requested by the young women. This included private messaging on Facebook, email, by post and via text messages to their mobile phones. The diaries could be more accurately termed note books or scrap books but, as diary is the term utilised by the young women, this is what will be used in the thesis.

I have gone through each diary in turn in order to analyse this material. This is so that I keep a sense of the young woman herself rather than splitting her accounts into separate episodes. The collective experience which became increasingly apparent will be represented through analysis of the group discussions alongside some of the diary entries which reference the collectivity of the vaccine process. My analysis is a tactile and emotionally engaged practice and, I suggest, suitably so for a project which involves the diaries of young women. Despite my attempt to photograph the materials and analyse these images using Atlas ti software, I soon realised that a computer package was not best placed to assist in the analysis. Atlas ti, I found, distorted the image on the screen and carved them up into isolated pieces. Instead I sat with the diaries on my desk or knees, with photographs of the pages and with post-its and note paper slowly trying to engage with themes that come from them. My analysis has to be useful and of significance to the project as a whole. Specifically, drawing

out recommendations to practice are of paramount importance to me as this was my foundational concern.

Each young woman will be introduced according to the formation she has provided about herself in her diary. This is instead of a strict and formulaic infatuation with demographic information. The diaries elucidate research materials which contribute to knowledge surrounding HPV vaccinations and its programme. These research materials explicitly attend to my research question: how are young women engaging with the HPV vaccination programme in the UK?

Lexi, Wendy Chicken Shop School

Lexi is twelve years old and is a season ticket holder for Manchester City Football Club. Lexi kept a very neat and orderly diary. She decorated it with many stickers and small drawings. Lexi drew or wrote many things that she is interested in at the front of her diary. They are; sport, art, pizza, jokes, iPad, rides, money, scary movies, Pizza Hut and chocolate. During the first group session we had at Wendy Chicken Shop school, Lexi brought her friend Sunshine. Sunshine explained that she was there because Lexi was nervous to come alone. This is how Sunshine became involved with the group.

Lexi wanted me to be in touch with her via email so this is mainly how we communicated about the project. During half term I told the group they could use the diary to add more things about what they liked and what they'd done during their time off from school. Lexi, on page 10 of her diary, drew her name in the centre of the page in bubble writing and coloured the letters alternately in red and blue. She wrote other things around this that she liked, such as shopping, New Look, money, swimming, football, chocolate and clothes. In a red section in the bottom corner of the page she wrote her dislikes which was "Hospital, bcos I had to have a cast on my finger for 3 weeks". Lexi had broken her finger playing

football and told me about this in one of the lunch time sessions we held at the school. Here, Lexi is developing an account of herself as a young woman. She is identifying the things she enjoys and likes, albeit in list form, then providing a small episodic account of an incident which she later recounted during the group discussion. Despite this being a negative story of a broken finger, it provides a real-life example of her interest in sport and the bodily investment she makes in it (along with attending regular Manchester City games). Therefore, we are testament of these two 'public' spaces within the parameters of the research project (and others outside of this) – the diary and the small group discussions - in which she is practicing her identity (Kehily et al., 2002).

Another example of the diary entries is the body activity which was repeated by the young women from Wendy Chicken Shop school when they received their diaries and materials later that same day. Lexi's body drawing, both from the first session (Figure 17) and when it was repeated in her diary (Figure 19) shows uniformity and symmetry of the body. The arms appear by the side and are suggestive of a normative and passive body similar to body diagrams found in medical or biological text books. The body is facing the viewer; initiating an analysis. The writing around the body is in orderly boxes and framed bubbles that help the reader see what Lexi is referring to. She is referencing the world outside of the body; the other people in the hall at the time of the vaccination (other people crying), the surface of the body where the vaccine is given (upper arms) as well as the physical and physiological effects that she is reporting as a result of the vaccine (nervous, shakey, eyes water, hot, everywhere felt weak).

I joined in with drawing during the first body activity. Without speaking, I placed a star sticker between the legs of the person I drew. My intention was to see whether the young women had knowledge that the vaccine they had just received was related to the diseases it is claimed to protect against i.e. genital warts and cervical cancer. Lexi was the first person to notice this and started to

giggle. At this point Emily also looked at where I had placed the sticker and asked why. I replied by asking them why they thought I'd put it there. Ainsley then said fleetingly that it was about cervical cancer and Lexi quietly placed a sticker between the legs of the body she drew too, as did Sunshine (heart shaped sticker).

Lexi's description of what the vaccination does to the body mainly involves pre-vaccination embodied feelings. The post-vaccination feelings she accounts for are "everywhere felt weak after the vaccine" and "a little hot after the vaccine". However, the severity of these negative affects is limited and coupled alongside the depiction of a butterfly and a jellyfish, which are well-used metaphors for physical feelings.

Lexi's drawing of the hall where the vaccine was given is also of interest to me (Figure 20). Most notable for me is the lack of colour in the drawing and that it takes up two pages of the diary. In most of her diary Lexi has put colourful stickers on the left hand page and made her entry on the right hand page. I read this as being indicative of the size of the hall, which may also represent a large imposing force that exacerbates her fear. Lexi makes reference to this through the comment next to the clock; "watching the clock hoping it would go fast" as well as the comment next to the nurse's forms; "pile of forms hoping mine wouldn't be first". Despite there being several nurse's stations from where the vaccines were administered, Lexi has drawn only one nurse and one "injection chair". The fine black pen was used to draw the chair and with it drawn facing the "waiting seats" brings to mind an executioner's chamber with electric chair and viewing gallery.

This task was given to the young women after they had completed the body drawing activity which was after their first vaccine, therefore the fear that comes through from Lexi's drawing of the hall is still something that she was feeling. Despite, or because of having had, the first injection Lexi's feelings of not

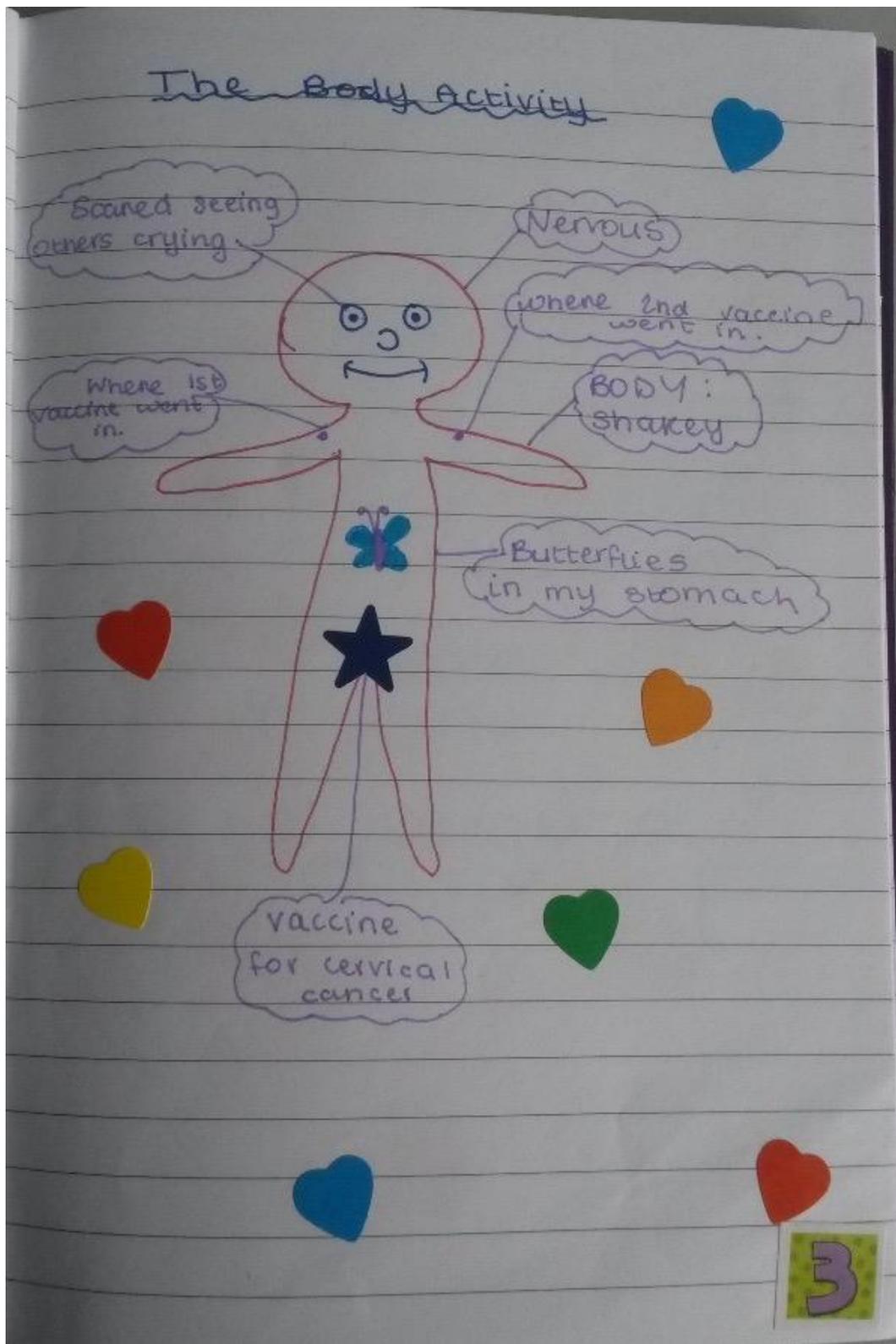


Figure 19 Lexi's diary body drawing v.2

wanting to be first and wanting it to be over quickly remained. Following the second vaccine Lexi said that it “stung more this time tbh”.¹³ She also wrote in her diary “I don’t think I’ll be nervous for the 3rd one at all because I’ve already had 2”, and furthermore, they did not result in any severe or lasting negative side-effects.

Sunshine, Wendy Chicken Shop School

Sunshine became involved in the project through her friendship with Lexi. She was more vocal than Lexi and actively took a lead in responding and chatting in the group. Sunshine called her diary “My injection diary” and on the page where she decorated it about herself she spelled her name at the top in gold alphabet stickers and glued glitter on the page too. She used coloured pens to write about herself and heart-shaped stickers or hand-drawn hearts to highlight the things she likes. These things are; I love Animals, I love Dancing and next to a love heart she wrote; “maths, IT, science”. She also wrote her pets’ names and the names of her parents and siblings.

Like Lexi, Sunshine reflected on the differences between having had previous injections. Sunshine wrote that for the second injection she “sat down feeling fine still a bit nervous but fine” (Figure 21). After this she states the repetition of the first vaccination: “the nurse asked me the same few questions” followed by “[the nurse] did the injection then I went back to class and was feeling good”. No issues or temporary feelings of being hot or shaky (like Lexi) were given in her account.

¹³ Tbh is used as an acronym for ‘to be honest’.

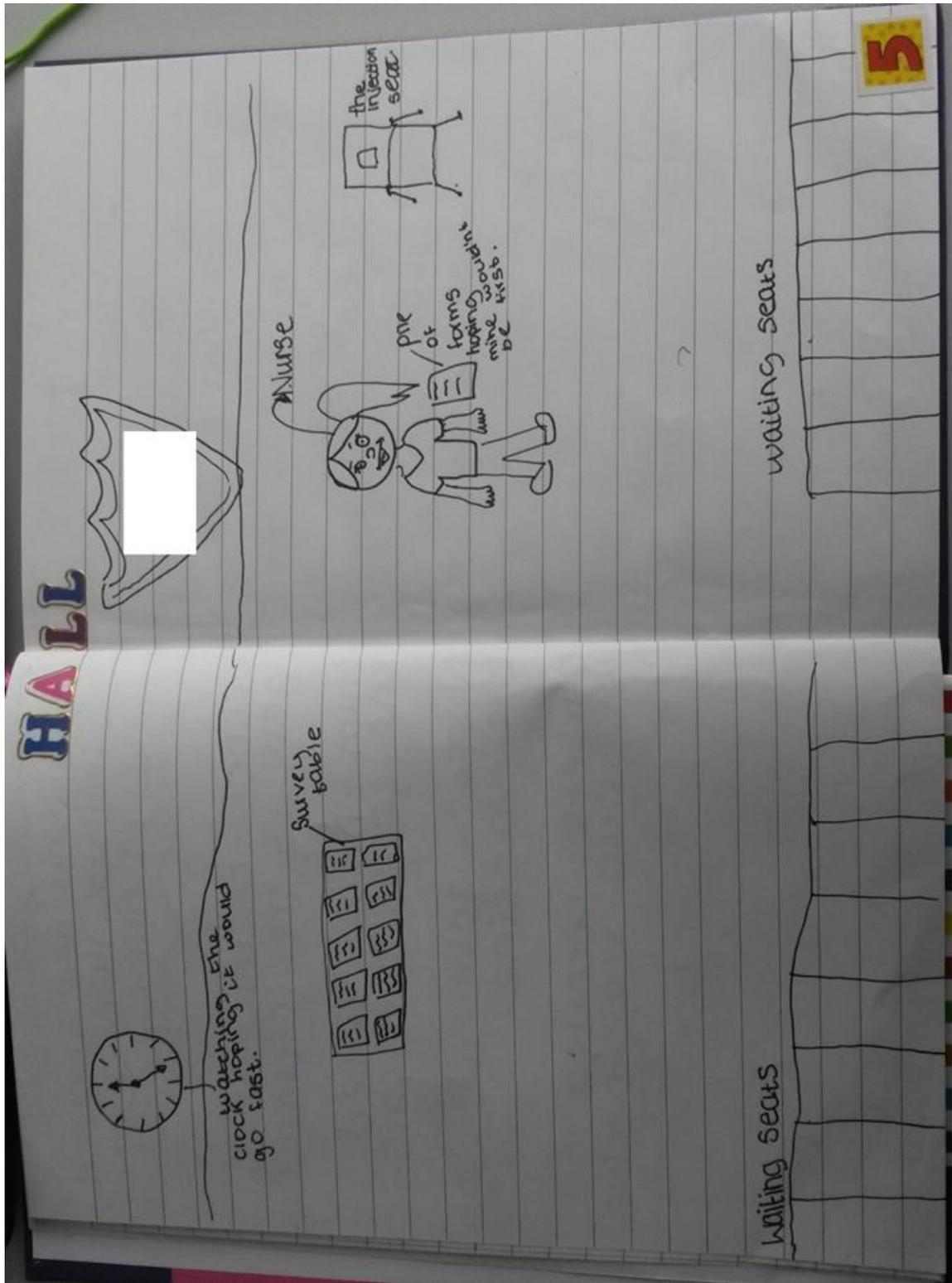


Figure 20 Lexi's diary entry of the school hall

Sunshine has written three separate accounts of her experiences of having the three injections. On the first day she used five negative words and two positive, on the second day (as shown in the image above) she uses three negative words and seven positive words, and on the third day she uses no negative words and seven positive words. This, rather conventional style of writing a diary entry (that I had somewhat prompted), represents how Sunshine's feelings and approach to having the injections has changed over time and the way in which the fear and anxiety she experienced at the start has dissipated as she knew what was going to happen, how the injection would feel and that the pain went away after a while, with nothing untoward happening, Sunshine's negative feelings were gradually replaced by entirely positive ones (Figure 21).

As with Lexi, Sunshine refers to the seat at the nurse's station as "injection seats" (Figure 22). This image comes before the pages where Sunshine describes each injection. Sunshine writes next to the injection seats "people nervous" and next to the seats where they were waiting she writes "people scared". This reflects upon the feelings of the group as a whole rather than an individual feeling. This sentiment of being part of a collective group is often spoken about by both the young women and the adult professionals. Indeed, as an excerpt from my field notes indicates, some professionals fear that the collectivity of the experience will lead the young women to react negatively and become concerned if they see their friends or classmates reacting in a particular way.

One girl during the day did not have the vaccine. She stated that she wanted it at her doctor's surgery. Helen tried to explain that it was exactly the same vaccine, needle etc., but then conceded that she was old enough to make that decision, completed the paperwork and told her to take that to her doctor. The nurses discussed this between themselves and Eryl said that if you "pander" to them, the rest of them will start playing up and you could spend a lot of time messing around. (November, 2012)

DAY 2 Feeling nervous
Fine
okay.

Today I felt much better than the first day I felt a bit nervous but also quite okay.

I sat down feeling fine still a bit nervous but fine. The nurse asked me the same few questions did the injection then I went back to class and was feeling good.

Figure 21 Sunshine's diary entry, day 2, second injection

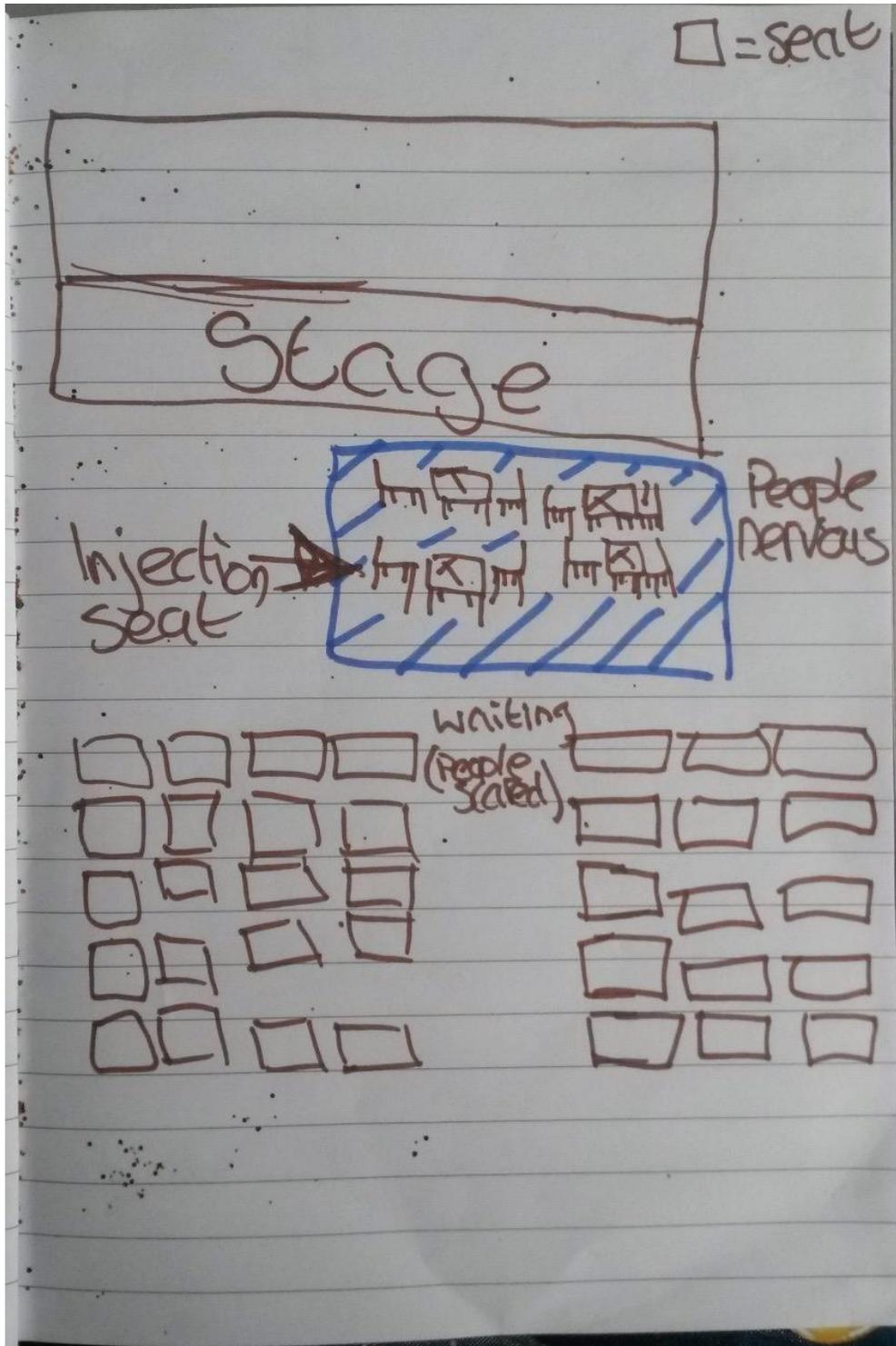


Figure 22 Sunshine's diary entry of the school hall

Indeed, when two young women experienced some dizziness or feeling unwell during one of my observations, a teacher's comments appeared dismissive of the

young women's fear and 'problematic' responses. A further excerpt from my field notes reads:

After the break I was speaking to one of the female P.E. teachers who had come into the hall. She asked me why two young women were lay on the crash mat. I said they must've felt faint and she told me that they were "drama queens". She also joked with one of the young women that her arm would fall off soon. And she said that a lot of them had tried to get out of doing P.E. with her because of having had the vaccine. (April, 2014)

Anticipating pain and discomfort is factored into many of the narrative accounts of the young women. Indeed where she was asked to tell me who is involved in the HPV vaccination Sunshine's diary entry included a drawing of a black needle and syringe with a red feather stuck to the tip of it (Figure 23). The use of the red feather could be seen as representing blood.

I see this as indicative of Sunshine's preoccupation with the injection itself. Sunshine has stated that the people involved with the vaccine process are parents, the school and the nurses. There is no mention of herself or her peers indicating a potential hierarchy of those people deemed to be more expert or important in the programme. As such, this indicates a sense of being less knowledgeable about the vaccine and the programme and the recognition of a lack of representation or importance within the process (Gilligan, 2011). This is precisely my motivation for ensuring that the young women's diaries are the central research materials within this thesis.

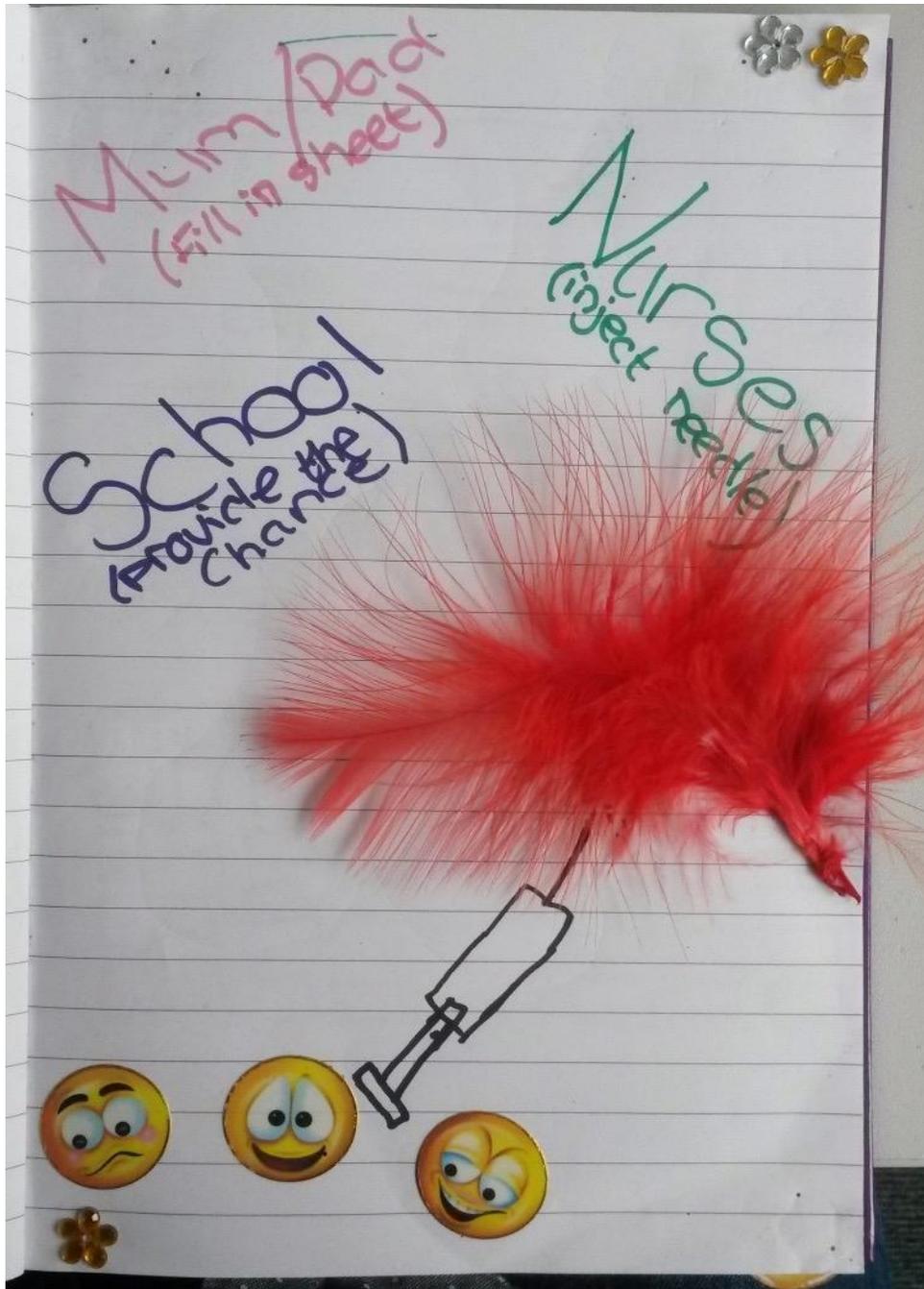


Figure 23 Sunshine's diary entry of who's involved in the HPV vaccine

Ainsley, Wendy Chicken Shop school

During the research process, Ainsley was the most consistent member of the group to attend and respond to me. She would often take a lead role in communicating with some of the other young women if they did not respond to

me directly. Ainsley also added me as a friend on my PhD profile on Facebook. The front of her diary was decorated with the words “Ainsley’s HPV book” written in silver stickers. She placed star and heart shaped stickers around it. Ainsley wrote “This is my ‘HPV’ diary. My name is Ainsley [surname] I am 12 years old, 13 on February 12th!!! Things I enjoy are listening to MUSIC. Playing the guitar and listening to One Direction x”. Ainsley drew a large guitar and stuck two pictures of the boy band One Direction in her diary. She drew arrows from each of the boys and wrote their names, then “My favourite is Zayn!” with a smiley face below it. Ainsley drew coloured lines, music notes and underlined some parts of the text. She also used stickers and a red feather. In a later session when we were reviewing the diaries Ainsley and Lexi discussed their love for One Direction and that they had seen them live in concert.

As indicated with Sunshine, there was a recurring theme present in Ainsley’s diary entries. She often referred to the other people involved in the process and the injection itself, and in particular, the sense of the HPV vaccine being a group process that her and her year group were going through collectively. She drew nurses, needles and used face stickers to represent people’s role within the process (Figure 24).

In Figure 24 Ainsley has drawn the school nurse and the health care assistant (although Ainsley shows some scepticism about the nurse)! She also identifies the school and her mother as people involved in the process. Ainsley does reference herself as she states “within the first few weeks I had my injection” and below this she has drawn a large needle with detail at the tip of the needle. Indeed she draws two needles as part of this diary entry; one close-up and one in the hand of the nurse. Again with detail at the tip possibly representing the sharpness or the common depiction of nurses expelling the air from the syringe. On the following page Ainsley completed the task referring to the hall where the vaccinations were administered.

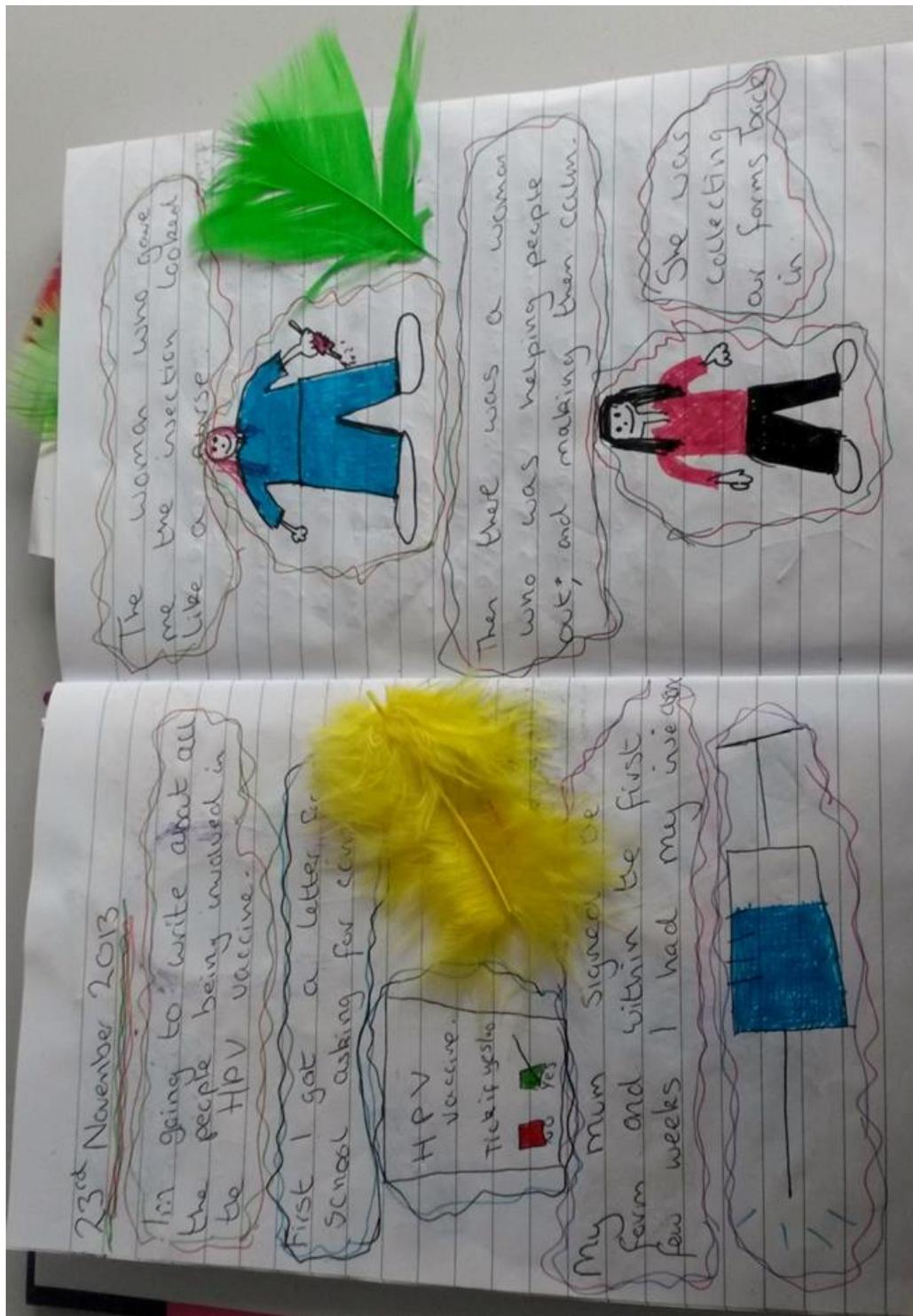


Figure 24 Ainsley's diary entry of who's involved in the HPV vaccine

Ainsley draws from left to right, me (Ali), herself, a friend, a "victim" and the nurse (Figure 25). The drawing of Ainsley, her friend and the victim are all

dressed in school uniform with the jumpers removed. Ainsley has indicated the injection site of the victim by drawing a small black spot on the upper arm. I am depicted as wearing a different colour to everyone else, and with my tongue sticking out. I suggest that this is in reference to the conversations we had about my tongue piercing. Ainsley has again drawn the nurse in blue “scrubs” yet the nurses and health care assistants do not wear these or any other form of clinical uniform. Rather than drawing the entire set-up of the school hall Ainsley is focussed on the people and the separation of those behind the blue screen from those waiting. I am positioned as separate from the clinical staff and, both figuratively and physically, on the side of the young women.

Early in her diary Ainsley’s body activity drawing has a face sticker too. She also states during a small group discussion that she likes the face stickers and is using these to represent the feelings or position of the people involved. We can see the faces of the young women are depicted as fearful whilst the nurse’s face is represented as smiling and almost manic in her anticipatory delight at giving the injections.

Ainsley’s diary entries often referenced the other young women in her year. In various tasks in her diary Ainsley reflected on how she felt on the three injection days. For the first injection she describes being “nervous” and “quite scared” as well as “I felt like dieing the morning of them because I didn’t know what it was all about”. Ainsley states not having had an injection before but I believe that she has had her childhood vaccinations but could not remember those. She also referenced the other young women by writing “some people were crying, upset/happy”. In relation to the second injection Ainsley wrote “I was excited for the injection because I knew that was the last one until April!” She also noted that the nurses “were less thorough and was trying to get the job done quicker”. Whilst Ainsley said she was feeling OK about the second injection, as she knew what to expect, she also recognised other young women in her year when she writes “some were still upset” (Figure 26).

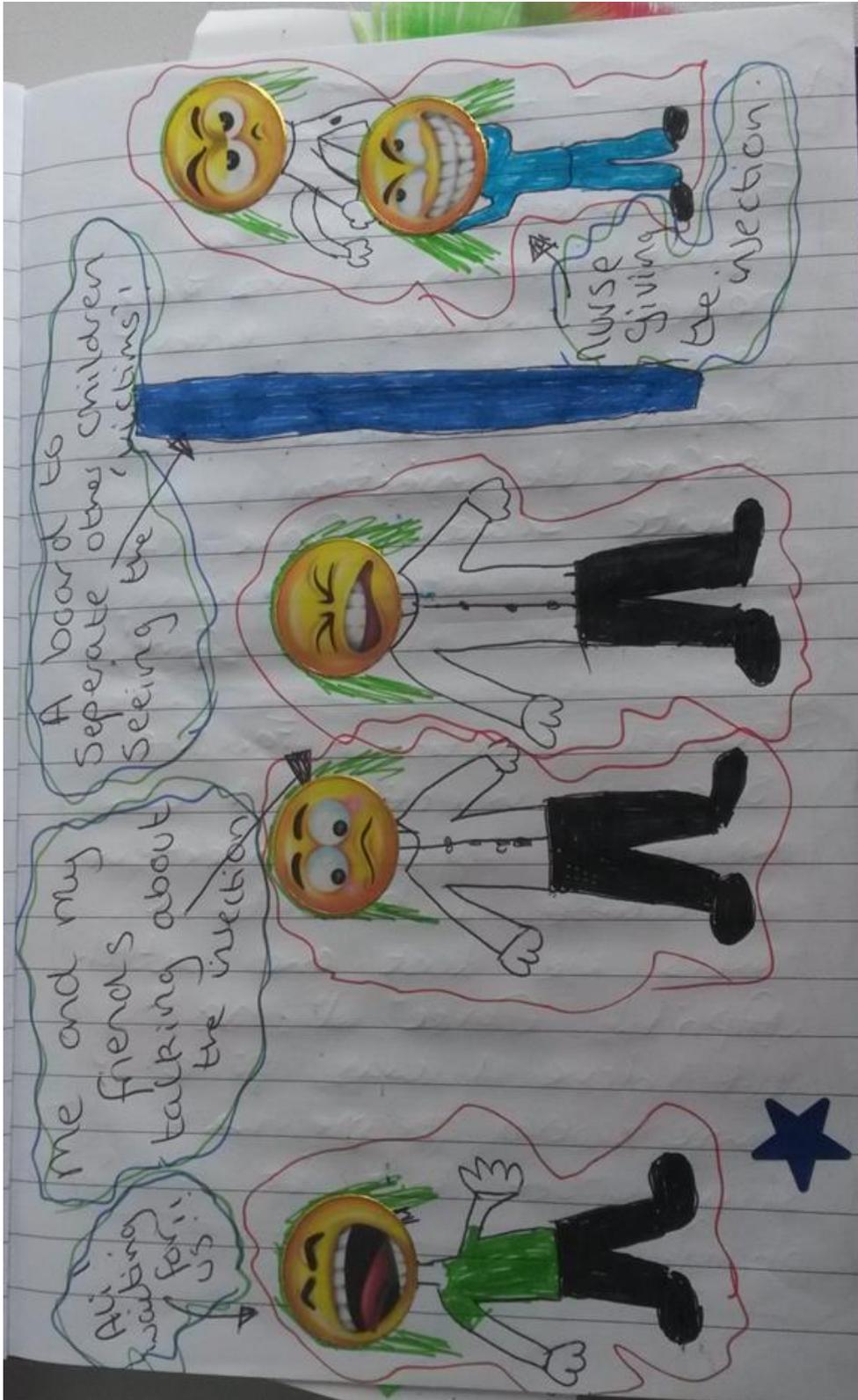


Figure 25 Ainsley's diary entry of the school hall

Ainsley has retrospectively given the HPV vaccination a score from ten (Figure 26). She has given it a nine. Her reflections post-vaccination completion is positive, stating:

Everybody couldn't wait to get these injections over and done with because these were the final ones. This injection was fine because we'd already had it twice before! (Figure 26).

Again, Ainsley references the other young women in her year group. Ainsley reflected positively about the vaccine, particularly after the first and second injections as she then knew what to expect and had time to see that nothing negative or adverse had happened to her thus previous fears had been allayed. Despite this, the images she drew throughout the diary would focus on the needle and blood. Indeed the last image she drew in the diary, also focuses on the needle.

Figure 27 sees a smiling face of a young woman in the injection chair. Both arms are depicted as bleeding following the injection. This represents the fact that the arm the vaccine was administered into alternates, as Ainsley has written "The first was on the left, second on the right [...] My third injection will be on my left arm". Ainsley has used feathers decoratively in Figure 27 but it is unclear why Ainsley has used the feathers here. Perhaps the red colour represents blood or hair for the young woman depicted, although this would be an unusual addition given the drawing is of a simple 'stick person'. This serves as a further example that the needle is the focus and primary concern of the HPV vaccination.

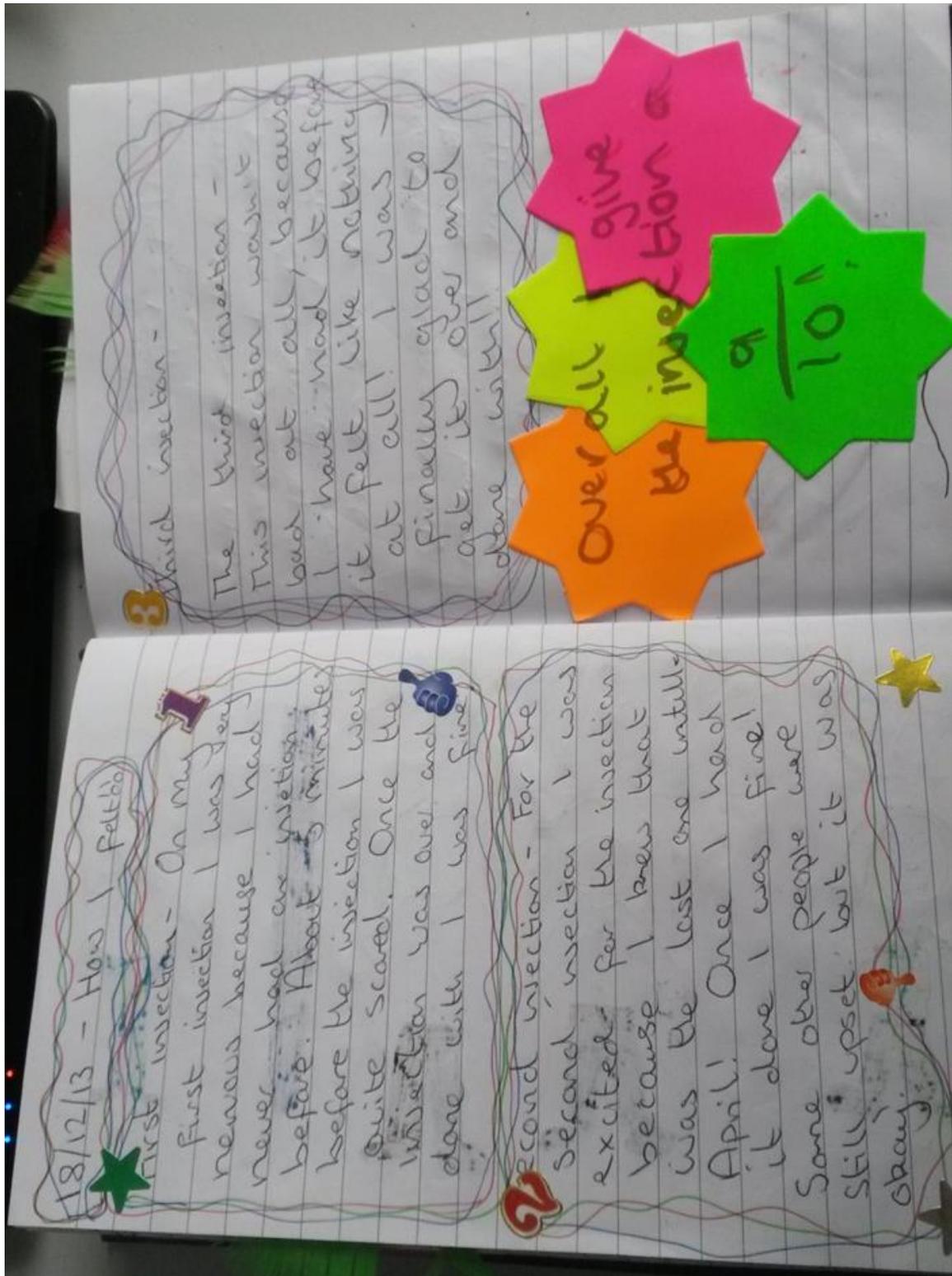


Figure 26 Ainsley's diary entry of 'how I felt'



Figure 27 Ainsley's diary entry, final drawing

Emily, Wendy Chicken Shop school

Emily is 13 years old and has a Palomino horse named Molly; “she is amazing and I love her she is the best horse ever!!” Emily used some of her horse ribbons to decorate her diary. In the front cover of her diary Emily has stuck a black and white photograph of herself from 2007 and has apologised, in writing next to it, for not having a more recent photo. She has stuck coloured feathers along the top edge using heart shaped stickers. On the right hand page she has written in large text “Things about me” and drawn a smiley face. At the end of the text in which she describes her horse, Emily signs the page with her name and a heart sticker. This is suggestive of her completing the diary at my request; she is purposely signing off as you would a letter or note to a known recipient.

Emily’s diary was the one which had most additional materials and self-made elements such as the horse ribbons, the photograph and her certificate of immunisation. At the back of the diary she had made herself a ‘pocket’ out of folded paper in which she kept sheets of stickers, feathers and notes I had sent her. At the back of the diary Emily had also spelt out in silver alphabet stickers “good luck Ali” underneath which she had stuck five differently coloured heart shaped stickers with a circle and cross through the green one (Figure 28). She later told me this is because she hates green. She had also applied red lipstick to her lips and transferred this to the page under which she wrote “my lips” and drew lips and an arrow.

My analysis of Emily’s use of the lipstick is that it represents a positive sentiment and well wishes. I feel, given the way in which Emily interacted with me, that it can be read as an expression of affection, and one which may reflect Emily’s enjoyment and appreciation of being a part of the project. Emily often spoke of her poor attendance record at school and she seemed to lack any great investment in academic achievements or additional school activities. This, along



Figure 28 Emily's diary entry, good luck and lips

with her fractious relationships with her mother (elaborated below), may provide some insight into her affectionate expression towards me as an adult woman. The use of the lipstick and her enjoyment of a project that was *at school* but not a

part of school is similar to what Anoop Nayak and Mary Jane Kehily (2006) suggest is part of the paraphernalia of girlhood:

Informal student cultures are saturated with objects such as lipstick, magazines, stickers, stationary and collectables of various kinds [...] these items constitute the paraphernalia of gender in school, the ephemeral stuff of boyhood and girlhood that exists in the margins of life in school – in the playground, between lessons, in the corridors and washrooms. (2006: 470)

Emily's diary was the only one which had missing pages taken from it with torn edges close to the spine. She also repeated some of the tasks, particularly on the day when we met for her to return her completed diary to me. We sat on the 'naughty seats' in the school reception area with Emily writing the answers she thought she'd missed. Some of this confusion over which tasks she had completed could be down to her having moved house during the period of the diary work. Her mam had moved out of the area and Emily moved in with her granddad. Emily often used strong expletives when she spoke about her mam. Despite this, her diary made it with her to her granddad's house and she updated me with her new address for me to send her things in the post. She also scribbled out the earlier references to her mam and mam's boyfriend and also wrote her old and new address in the diary too, indicating that she used this medium as something other than her HPV reflections and perhaps took solace in having the diary as confidante.

In keeping with her scattered style of entries there are two written entries about the hall. The second one has then been scribbled over. Twelve pages on from the first description (Figure 29) is a drawing of the hall and over the page is the scribbled out hall description.

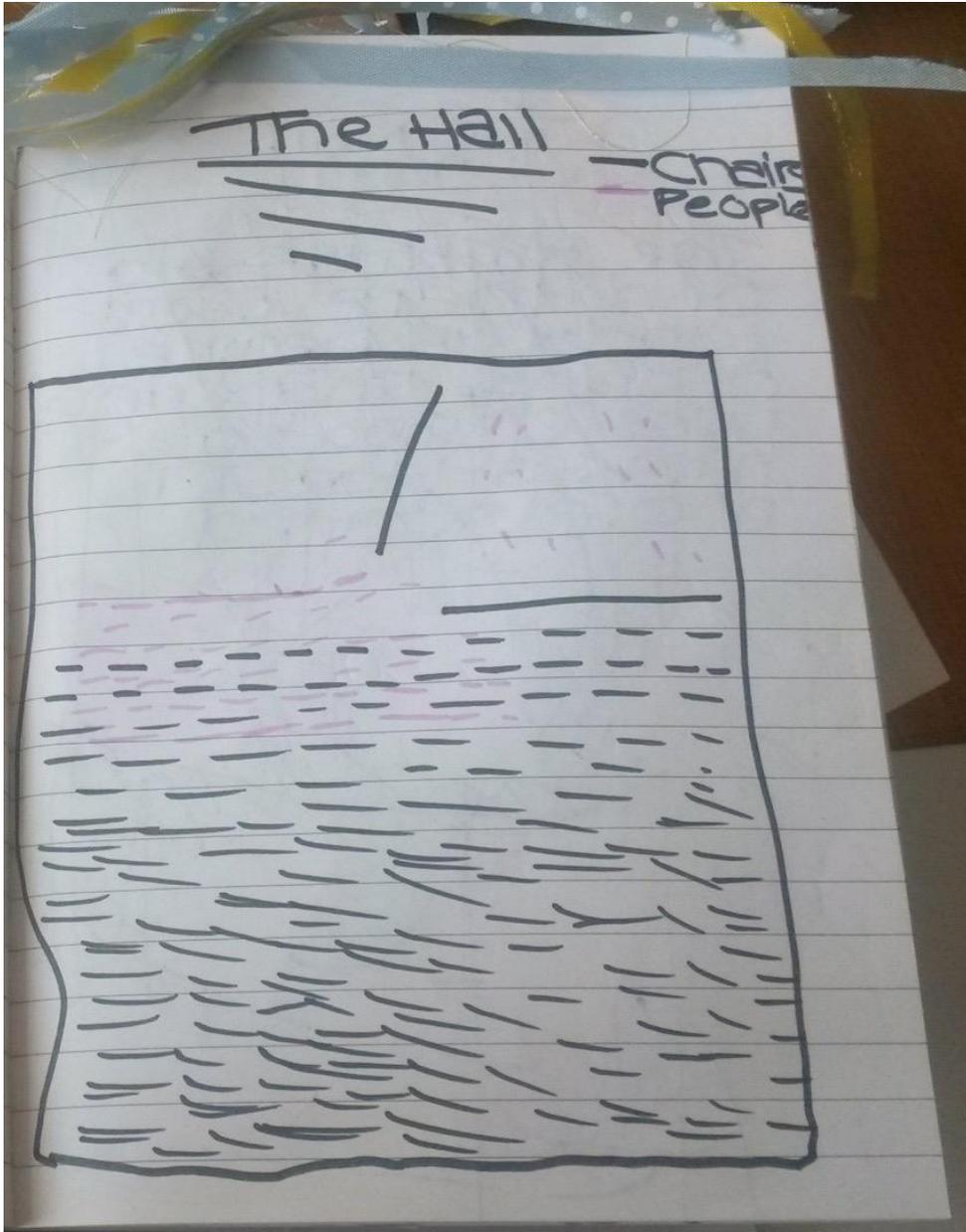


Figure 29 Emily's diary entry of the school hall

It is difficult to see the colour pink that Emily has used as part of her 'key' to the people. There are pink dashes to the right of the black line (representing the blue screen) at the top of the hall and in the first four rows of chairs. At the end of the written description for this task Emily has again signified that she is writing the diary for me. She has written "when I walked into the hall the first time there was you and loads of over people [...] then I seen you so I came and talked to you" and at the end of the description; "hope I am doing okay" then her

name and two stickers (Figure 31). I read this as a concern that Emily wanted to perform well for me and my research project.

Other direct references to me include a page on which Emily has written “Monday with ali march” (Figure 30). In the centre of this page is an orange star glued down in which she has written “things that happened”. She has drawn round the star in various colours to outline it and on the rest of the page she has drawn pink and purple hearts. This is one of the pages where you can see she has torn out sheets. Perhaps the things that happened were written on this page. The page that remains and is opposite has a large drawing looking to the future and “my next needle” (Figure 32). This entry shows the isolated area of Emily’s upper arm where the needle is administered. There is a red dot to represent the injection site and the liquid drug is shown in the “needle holder”. Emily has simply used red pen and pencil to create this diary entry which may be indicative of the straightforward way in which she views the needle; something that has to be done and which does not have any additional niceties related to it through the use of colours, stickers, ribbons etc. At the bottom of the page is a smiley face she has drawn with a wide mouth possibly representing shock or being scared. In this task Emily does not relate the answer or the situation to me as her audience.

Emily directly references me or uses my name five times in her diary and she also stuck in two of the notes I have sent her in the post; the first is a checklist of tasks which she asked me to send her and the second is a note I sent when I was sending her a folder, that the young women had requested, to keep all their materials in. I see this as interesting and important for several reasons. Firstly, Emily does not directly reference me when she is drawing the ‘needle’, showing that she recognises me as separate from the vaccination administration (as with Ainsley) thus she is narrating a more pleasurable relationship that she has with me through the programme. Secondly, Emily is directly referencing me as the key person to whom the other diary entries are directed; it is therefore



Figure 30 Emily's diary entry, Monday with Ali March

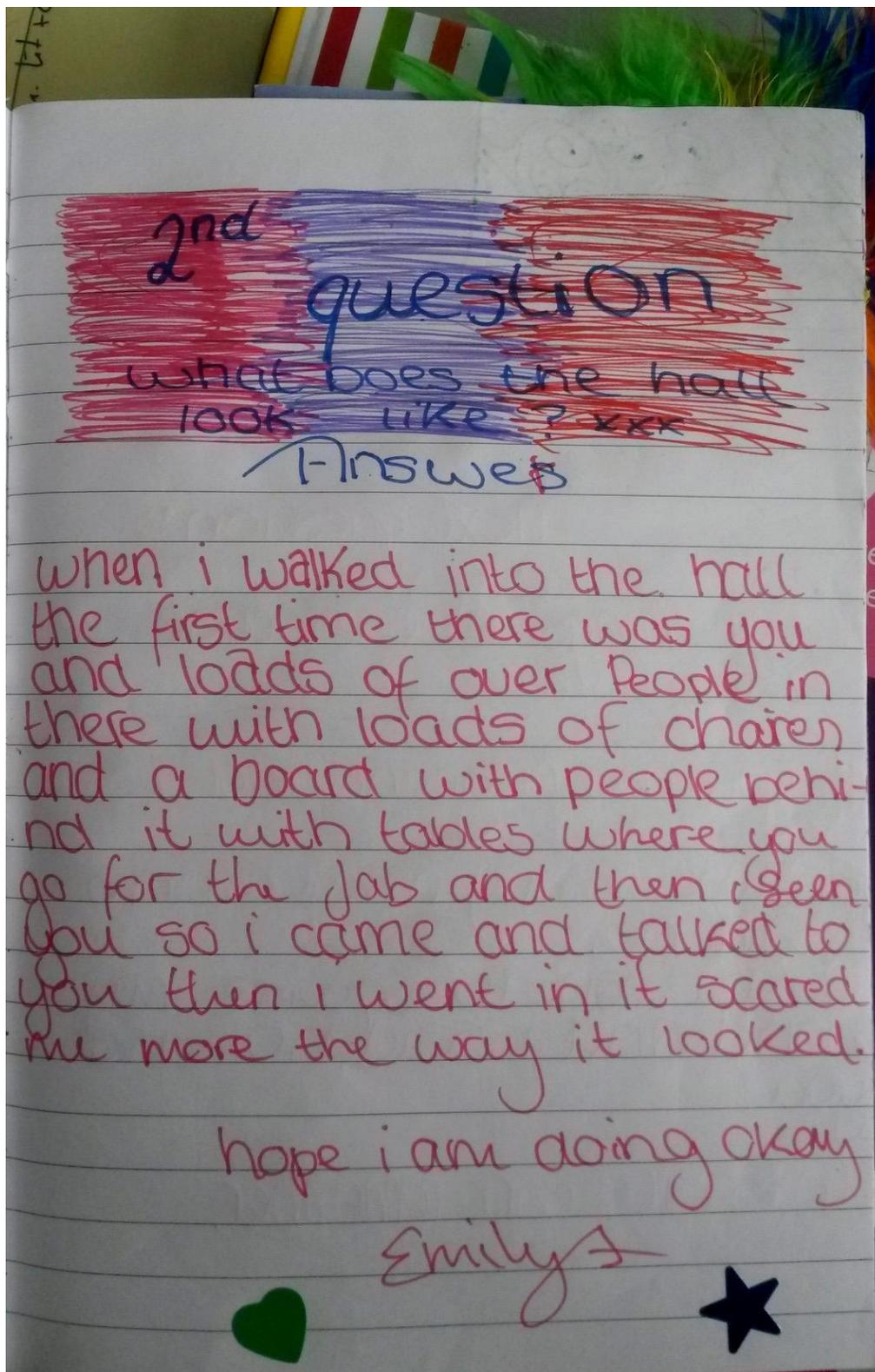


Figure 31 Emily's diary entry, 2nd question

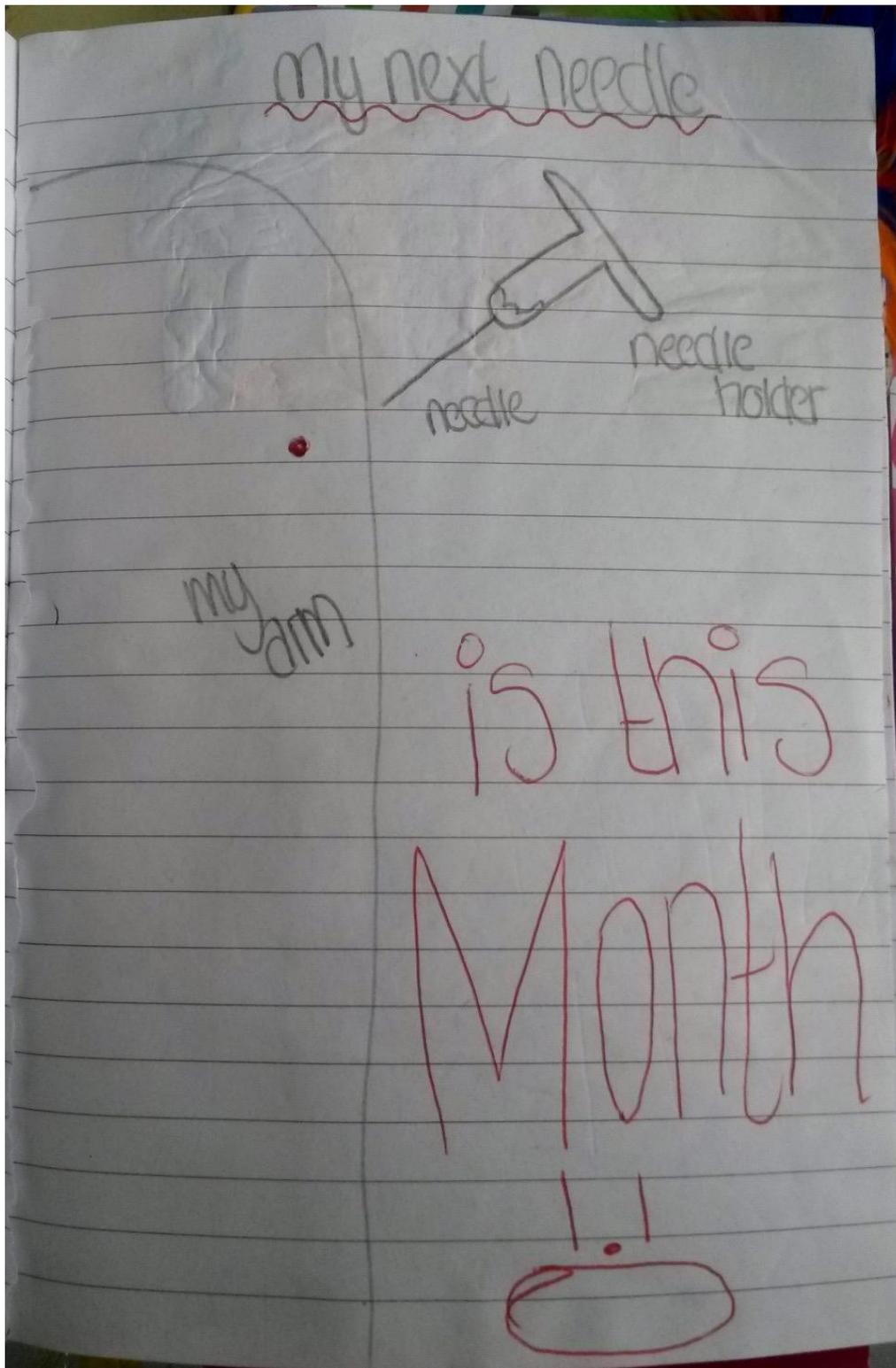


Figure 32 Emily's diary entry, 'my next needle'

something she is undertaking as a favour to me as I will be the beneficiary of the diary. But this is maybe not so easily the case when I consider this alongside the level of self-investment and direction Emily has displayed in order to add to her diary. I find the juxtaposition of these both intriguing and indicative of the world outside of the vaccine diaries.

Emily uses eleven pages of her diary for entries that do not relate to the tasks of the HPV vaccination. I prompted the young women twice to decorate the diary and make it about themselves; once at the start of the project and once during the half term. Emily has additional entries which include “my best films”, “things I have done”, “more things about me” and two separate pages with hand drawn calendars and key dates.

In contrast to Ainsley and Sunshine’s account of the vaccine becoming less painful and easier to deal with, Emily states the opposite; that it became more painful. She writes about the third injection that; “it did hurt the most and I felt it loads more it was scarey and I felt like crying but I let it stay in so it wouldn’t hurt”. Practicing their versions of young woman in response to the vaccine follows from the assertions above regarding the parameters within which they are able to form their identity. Having these differing responses is permissible within the HPV vaccination programme as they are accepting the vaccine and unproblematic to the programme’s success. They are ‘doing’ ‘vaccinated young woman’ differently but successfully and thus rendering the programme a success too. As Angela McRobbie (2009) has stated, in another context, young women are ‘free’ to ‘choose’ how to respond, as long as this response is within the confines of having accepted the vaccine. My key point here is that Emily’s responses do not threaten the success of the vaccination programme or of her own feminine practices.

Often when differences are experienced in relation to a medical intervention, these are put down to the individual rather than the intervention

affecting people differently. For example, the common assertion is that most people 'deal' with the injections well and do not have any adverse effects. This prioritises medical adverse effects as opposed to social and emotional trauma experienced by the young women. The vaccination has been easily integrated and subsumed in the lives of these young women. The negativity experienced was short-lived and tangential to the other concerns and things going on in their lives e.g. a broken finger, One Direction fandom and moving house.

Beth Hester Who, Bazinga school

Beth's favourite band is Fall Out Boy and her favourite singer is Ed Sheeran.¹⁴ On the front of her HPV diary she has written musicians/band names in a neon star which she has stuck on. She has placed smiley face stickers around the star and has spelt her name and age in alphabet and numbered stickers beneath it. Perhaps quite obviously by the choice of name and school name, Beth is a fan of both Dr. Who and The Big Bang Theory ('Bazinga' is a catchphrase used by the main character Dr. Sheldon Cooper in the USA TV show). Beth became involved in this project through a chance discussion I had with her mother Suzanne at a conference (detailed earlier). Suzanne works in sexual health and is also involved in LGBT community work and activism.

When asked about who is involved in the vaccine process, Beth is the only young woman who mentions 'scientists' and mentions safety (Figure 33). Beth also explicitly states that the young women or 'pupils' have to 'agree' to have the vaccine.

¹⁴ After I had analysed the diaries I contacted each young woman and sent them the paragraph which introduces her (used in this chapter) based on the diaries, asking them to check and see if they wanted to change anything. Beth asked me to change the name of her favourite band from the one that originally appeared on the cover of her diary to the one which is now written above; Fall Out Boy.

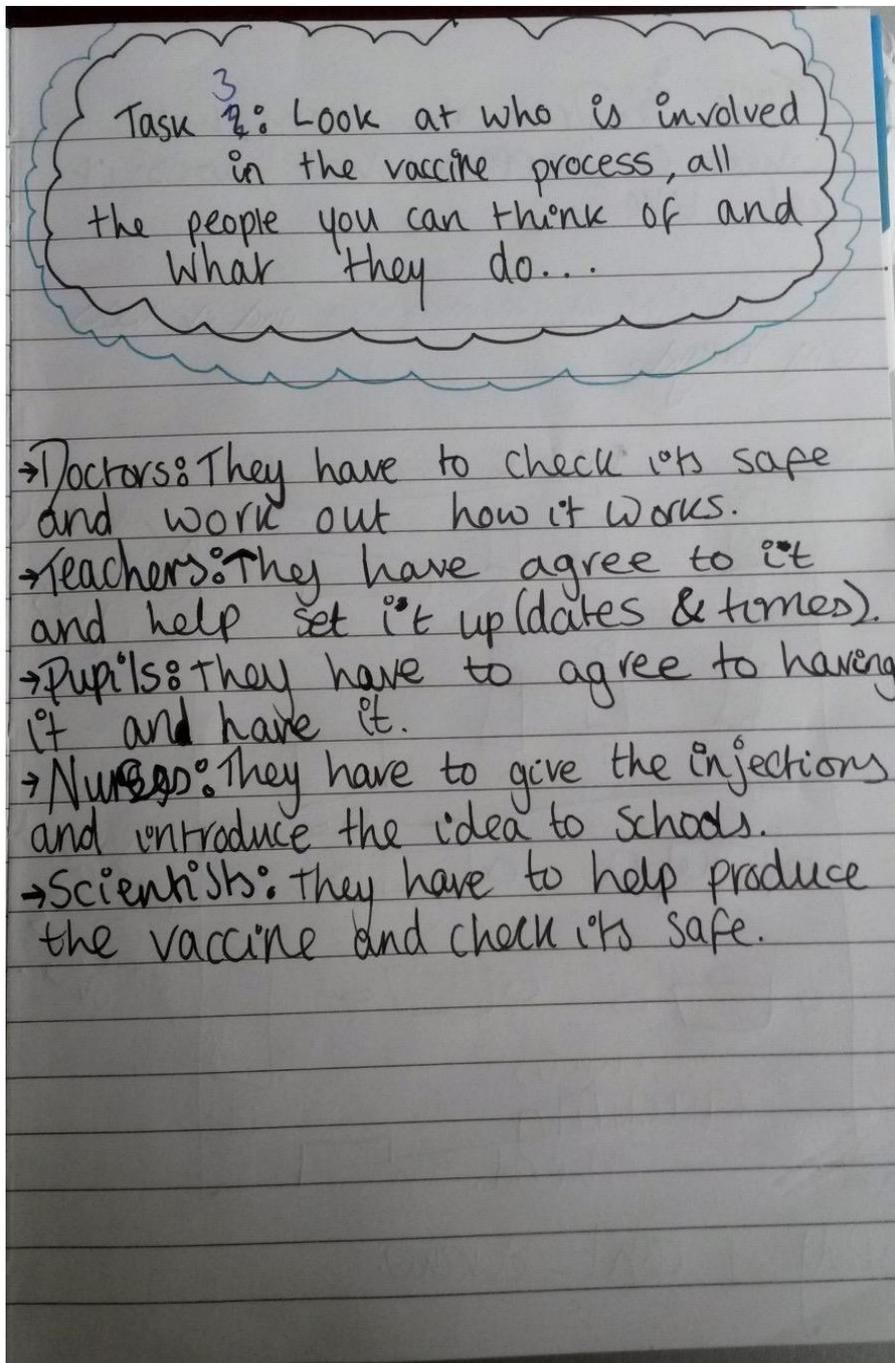


Figure 33 Beth's diary entry, task three

To me this suggests that she has been privy to information regarding the vaccine that is in addition to the standard HPV information provided by the school nursing team or in the NHS vaccination leaflet. This could be demonstrative of the fact she attends a different school, but I feel it is more reflective of the approach her

parents have to discussing issues with Beth and providing information and rationale for not vaccinating. Such rationale and justification is something that is not required if the parental decision reflects the norm of accepting.

Beth is the only young woman who completed a diary who did not receive the HPV vaccinations. She started the process by also involving a friend Celia. However I never met Celia or received her diary. In addition to sending Beth diary tasks via text message, I also met with her on three occasions detailed earlier. Beth is a white British young woman who attends a girls' school with a predominantly Asian Muslim demographic. During the audio-recorded research conversation with Beth and Suzanne she reflects upon her position as being different. It was towards the end of the research conversation, once she and Suzanne had developed a rapport and a more trusting environment with me that I asked specifically about whether Beth felt different having not had vaccines in the past, being a non-Muslim and having two mams and a dad. She replied:

Beth: I'm just genuinely different, I'm just an outcast; have short hair, listen to punk rock. I don't like Justin Bieber, have lesbian mums, I'm for gay marriage, I'm for independence for Scotland, no-one else is. I like Dan and Phil, that's a thing that no-one else likes. I'm one of the only white girls, like there's only fifty white girls in the whole school, or not even, 20. I'm not exaggerating.

Ali: Does it feel like you're really different all the time?

Beth: I quite like being different, you know, I do. Even if I like a One Direction song I make myself not like it because I don't want to be normal.

Suzanne: I suppose you've got enough friends who are similar to you outside of school. Some people just have school and their family [...]

You've got plenty of friends with alternative ideas, you've got friends who are home schooled.

Ali: So there's lots of stuff that makes you different anyway, so not having a vaccine just adds to it generally?

Beth: I don't mind not having a vaccine though, I genuinely, I used to really find it hard in primary school but now I don't care, I genuinely don't actually. (September, 2014)

Being different to the mainstream seems to be an identity position which Beth is happy to practice, develop and work on. A clear distinction, other than vaccine acceptance/decline, between her and Ainsley and Lexi is their thoughts on the boy band One Direction! Beth noted in her diary that the school staff and nurses use the term "refuser" to describe her and others who declined the vaccine (Figure 34).

During the research conversation with Beth she elaborated further on this term by saying:

By the way they called me a refuser, it makes me think that they don't really like the people that say no and they think that we're arrogant and stuff like that but we're not really so, it's a bit silly. They're just a bit silly. [...]. Yeh they put 'refuser' [on the notes] and it's a bit weird like. It's like they're negative, I mean obviously they're negative about it, they don't treat you very nicely, like 'she's a refuser, you can go [back to class] now'. (September, 2014)

Task 5
I can't remember the details of each time but I can remember some stuff. I remember that the first injection was quite unknown and everyone was scared and talking about it. I also know that in either the first ~~and~~ or the second vaccine one of my friends got stopped and was made to ring her dad because she wasn't having the vaccine and to check ~~whether she~~ whether she was definitely having it or not. Then I remember the third one to be a much different and mainly because it was in a different ^{class room} but for different reasons. Another reason was they didn't make as much of a fuss if you weren't having it. If you weren't having it then they just told you to go back to class, which otherwise I would have had to wait. But they did call you a refuser if you weren't having it which wasn't ~~that~~ ^{very} nice.

Figure 34 Beth's diary entry, task five

By being sent back to her class by the nurses she was made to be unfeminine, transgressing or subverting the strict gender binary that the HPV

vaccination programme constructs. Beth explained that there were other consequences besides her feeling like she wasn't liked. Once the nurses had established she was a "refuser" she was told to return to class. Arriving back at class earlier than expected she "then got questioned by my teacher why I was back so early. Coz everyone wants to know". Beth has been situated as problematic; she is a refuser who returns back to class 'too early' and undergoes questioning again from her teacher. It is these such seemingly insignificant examples, of the non-normative experiences of engaging with the HPV vaccination programme, that expose the hegemonic version of how to behave as an appropriately successful feminine young woman that is hidden within the practices of the programme.

The term refuser suggests a problematic position to hold, with a decidedly pejorative quality to the label. At the bottom of Beth's diary entry she has added three lines of text in black ink where she states "But they did call you a refuser if you weren't having it which wasn't very nice". In the text above this Beth has described the three different vaccination administration days. She recounts a situation where her friend was "made to ring her dad because she wasn't having the vaccine and to check whether she was definatly having it or not" (Figure 34). This additional measure, which is carried out by the nursing staff in order to check whether a young woman is having the vaccine or not, is of interest. This additional measure is not carried out to ensure that the consent given is indeed the true wishes of the parent or carer. This is likely because the act of signing and returning a consent form is seen as an active choice from an invested adult.

In the materials provided to me by Mary, the School Health advisor states that clinical staff will telephone the parents or carer if consent forms have not been returned. This is in an attempt to gain 'telephone consent' for which Mary stated there was a separate telephone consent form. According to Beth's story her friend was not having the vaccine, but whether her dad had asserted this through not completing the consent form or through actively notifying the school

is unknown. Telephoning therefore may be undertaken as a way of increasing uptake, meeting targets or indeed, as a way of ensuring that as many young women are vaccinated in the belief of the clinical staff that it is to the benefit of the young women's health.

Conclusion: creating vaccination success through practicing femininity

This chapter is a visual and material space for the young women's diaries, in photograph form, to be seen. My hope is that the diary entries will prompt thinking about the HPV vaccination programme which is not usually undertaken when the dominant messages, campaigns and media or political arguments around the issues of young women's identities and the HPV vaccination programme are observed by the reader of this thesis. By prompting the young women to include personal interests and information about themselves, be that through the decoration on the diaries or the questions about their activities during school holidays, the diaries provide a space for the articulation of a broader self, a fuller picture of these young women than the health intervention makes visible. This broader self is of significant interest to my professional commitments of creating a space for the young women to engage in meaning-making of their worlds. And whilst there is significant scholarly interest in the HPV vaccination and its programme, for these young women it signifies a brief and peripheral part of their schooling and wider social worlds. I argue that this shows that the HPV vaccine is simply not a big deal in the lives of these young women; what the diaries show is that if they don't have the vaccination or don't experience side-effects it's just not that important to them. I saw this evidenced through the limited and recycled, parrot-fashion responses they repeated, as well as their focus on hobbies, interests and 'jazzing up' their diaries other than writing about and representing the vaccine. Once the injection is done the young women were relieved and forget about it. This shows that the HPV vaccination is not a big part of the lives of these young women. It is a momentary worry that is quickly surpassed by their interests in other things. I suggest that the HPV vaccination is

inconsequential to these young women. But, I argue, the vaccination programme has very real and demonstrable negative effects that I will explore in Chapter Five.

The key question that opened this chapter was; how are young women engaging with the HPV vaccination programme in the UK? The diaries are an intervention; a conscious mediation between me and these young women based upon my own commitments to acknowledging and promoting young women's voices and experiences through a difficult and unknown process that is the HPV vaccination programme. I have provided an analysis that has expanded what is included in answering the key question. It is a feminist and social justice concern to broaden my focus from the vaccine as a biomedical offering to the social and sex/gendered characteristics of the programme. As such, this project has been an extension of my critical feminist youth and community work practice with the aim of promoting and permitting broader versions of what it means to be a young woman and how this is 'done' as part of a supposed 'everyday' health intervention that reinforces strict gender orders. The diaries and research activities created a different kind of space for the young women to experience and make meaning of the vaccination programme. The young women engaged in a reciprocal activity with me through which they could make sense of their experiences and develop their identity practices. This was done in a positive and permissive space where otherwise 'challenging' or 'off-topic' discussions were allowed.

The self-narration that is offered by the young women hint at many gendered issues (Kehily, 2012; Crowther, 1999; Gilligan, 2011). First, I see the selection of the diary method as significant given the historical trend of autobiographical narration favouring the lives and achievements of men and other dominant forms of life (Kehily, 2010). Second, I claim that the use of the diaries is a way of publicly displaying a private life, one which is note-worthy and valued through there being a dedicated reader. I am clear that these are not

private diaries found and voyeuristically pored over by an academic; they are carefully planned and crafted objects for study within a youth-led participatory project. They demonstrate identity practices of the young women's lives e.g. through information regarding their peers, their families, their pets, their pain and so on.

I have drawn upon scholarship from researchers with a strong empirical basis and who use a language of construction. I am keen to develop this in relation to identity construction and have instigated in this chapter the use of the term 'practice' in relation to identity. For me this term suggests an act of doing which is always in development (with the association with a repetition of 'well worn' stories borrowed from Mary Jane Kehily) and the idea of the occasional conscious effort involved in learning, developing and practicing one's identity. The feminine identity practices of these five young women vary but fitted within specific cultural and social parameters. Having different experiences of the HPV vaccination and programme is allowed and not seen as problematic because they are accepting the vaccine. Despite finding it painful and scary, the young women may not like having the injection but they are practicing femininity in acceptable ways that do not threaten the success of the vaccination programme.

The HPV vaccination programme carries normative assumptions about gender and (hetero)sexualities. In the next chapter I build upon the feminine identity practices demonstrated here and examine gender and sexualities, which are discussed as inextricably linked elements of personal identity. Chapter Three considers two main factors that construct and affect young women's sexualities: the de/sexualised culture of schools in the UK and the pharmaceuticalisation of young women's sexual health in the UK.

Chapter three: Young women's sexualities in the HPV vaccination programme

“We probably don't equate having sex with cancer”

“Doing this [vaccinating] at 13 is great but often by the time they become sexually active [...] I can't think of any 12-13 year old girls who'll then remember when they get their boyfriend at 16-17 whatever, that they're going to think back and remember about this virus [and] that they need to protect themselves against [it] even though we may have said it. We said it in one assembly when all they're thinking about is the needle [...] I think [it's important] to educate around HPV and condom use and safe sex etc. as well as other STIs. I mean anything that we [sexual health services] produce doesn't talk about HPV. [But] everybody knows about Chlamydia and Gonorrhoea and Syphilis but HPV isn't [included]. So we talk about genital warts but we don't talk about how it's caused and we could prevent it [...] I think we probably don't equate having sex with cancer.”

Mary, School Health Advisor & Sexual Health Nurse, April, 2012

HPV is often spoken about as a 'sexless' infection that causes cancer; its etymology is not, as told by Mary above, equated with having sex. In this chapter I explore the tensions relating to young women's sexualities during the period commonly known as 'adolescence'. I have always been surprised that the sexual nature of the HPV vaccination programme is not more explicitly discussed and that the HPV vaccination programme is not seen as a positive opportunity to introduce conversations and educative messages about bodies, relationships, sex and pleasure. I use my experience in a sexual health charity to guide my route through this chapter, often referencing my concerns about the focus on young women being prescribed hormonal contraception as a priority of sexual health services. In this chapter I specifically ask how young women's sexualities are constructed within the HPV vaccination programme. The research materials presented in this chapter suggest that there are opportunities where sex and relationships education could be introduced during the administration of the HPV vaccination. However, the focus is firmly placed on constructing compliance through docility. To get to this point, in this chapter I detail two key framings of women's sexualities that converge to make the HPV vaccination programme

work in practice. These framings are; the de/sexualised culture of schools in the UK and the pharmaceuticalisation of young women's sexual health in the UK. Working through empirical materials, I interrogate the combined effects of these approaches, and suggest that those institution's cultures, and those working within them, construct young women's sexualities as inherently at-risk and in need of saving from an inevitably diseased future.

Broader definitions of sexualities

I also address my second research question in this chapter; how are young women's sexualities constructed and practiced through the HPV vaccination programme? The starting point for doing this more explicitly within the thesis is by utilising the research materials and a broad definition of the term sexualities. Sexuality is a central concept within this chapter. And furthermore, sex, as an embodied act is a second focus as it is intrinsically bound up with the notion of human sexuality. Holland et al. (2004) refer to sexuality as:

Sexual practices but also to sexual identities and the varied historical and cultural forms which sexual identities and practices can take. Sexuality implies sexual beliefs and desires and also how these are socially negotiated and constructed in social relationships. Sexuality is simultaneously variable bodily states, desires and physical practices, and also culturally variable understandings of this embodiment and its meanings. Sexuality is embodied in the sense that it entails bodily activity: there is a physical aspect to sexual experiences, desire, and reproduction. But this is always both material and social, since what is embodied and experienced is made meaningful through language, culture and values. (2004: 21)

This definition is taken from the WRAP and MRAP projects introduced in Chapter One. As such it is underpinned by empirical work carried out with young people. I

am interested in the ways in which young women's sexualities are constructed by education and medical practices, which is often in contrast to the broad definition above. The World Health Organisation (2006a) offers a definition of key concepts related to sexual health:

A central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors. (www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/ accessed 17th March 2015)

The term sexuality therefore refers to a broad concept that is interlinked to many factors both within oneself and externally. Sexualities is a particular element or sense of self, an element of identity that is shaped, constructed and practiced in everyday situations and an on-going facet of women's biographies. It involves negotiation of our relationship with our own bodies, our personhood and relationships that are socially, romantically, sexually and otherwise mediated such as those with school and health staff.

The de/sexualised culture of schools in the UK

I use the term 'de/sexualised' to argue that there is indeed a sexualised culture of schooling but that there are also attempts to desexualise young people in schools in the UK. The practices I explore in the following chapter catalogue many examples of both, but for now, we should keep in mind that there is a fundamental tension relating to sexualities of children and young people. On the

one side there is a normative sexuality that is seen as innocently de-sexual; it is promoted through banal practices of schooling and through constructing children and young people as heterosexual. The other side is a non-normative sexuality that is seen as risky and sexual; it is avoided and requires management through practices that construct children and young people as at-risk. The young women and the school nurses are negotiating this difficult terrain in and through the HPV vaccination programme as part of the wider de/sexualised culture of schools.

During my first research conversation with the School Health Advisor Mary, I was keen to explore the level of direct acknowledgement of the sexual nature of the HPV vaccination by those involved in its administration and thus the extent to which the young women have the opportunity to learn about HPV as a sexually transmitted infection. Our conversation went as follows:

Ali: When the nurse asks them [young women] about their health on the form, is there a question about sex on it?

Mary: There's a question 'is there any chance you could be pregnant?' Coz pregnancy is a contraindication so we can't give it if there's a chance there's a pregnancy. Which usually causes great hilarity with the year 8s but we do ask them, supposed to ask them.

Ali: So you don't ask 'are you sexually active?'

Mary: No, we ask 'is there any chance you could be pregnant?' (April, 2012)

The question that is asked as a part of the nurse's script for establishing suitability or any contraindication for vaccinating assumes a particular level of knowledge on behalf of the young women; that they know how they might become pregnant. Whilst the assertion that 12-13 year olds may not know how

pregnancy occurs may seem naïve, the formal education curriculum in the UK for this age group does not mandatorily teach students about reproduction (I detail the sex and relationships education requirement in UK schools later in this chapter). I find it interesting that the question is asked because pregnancy is a contraindication for vaccination. The question is not a way of establishing whether sexual activity has occurred, which would indicate the possibility of an exposure to or existing HPV infection.

The 'great hilarity' that Mary suggests the 'pregnancy question' can cause was also mentioned by Ainsley from Wendy Chicken Shop school in her diary entry. Ainsley, who was introduced in Chapter One, included a script of the exchange that she had with the nurse (Figure 2). In it she suggests more of an incredulous, possibly even offended, response than one of hilarity. Such a response from Ainsley may suggest knowledge but also something that she wishes to avoid discussing, knowing that sexual activity is discouraged and could lead to trouble for her.

In Figure 2 you can see that the nurse asks "And are you pregnant?" to which the 'pupil' answers "WHAT!!! NO!!!" Within this script Ainsley refers to the young woman, or herself, as 'pupil' rather than using her own name or the first person. This may be a tactic utilised to distance herself from this exchange in a way to further imply she could not be pregnant, or it could demonstrate her belief that none of her peers could be pregnant at their age. The response from Ainsley is a way of showing a particular version of successful femininity for her age group; her loud, disbelieving response providing the weight of certainty that not only is she not pregnant but that it is an unimaginable possibility for herself or others of her age. I think this may also be a way that Ainsley indicates a lack of knowledge and an expected level of sexual 'innocence', as is often cultivated within British school cultures for this age group of 12-13 year olds (Robinson, 2012; Allen, 2007).

Interestingly, the specific wording of the question varies between Mary and Ainsley. Whereas Mary suggests the nurses ask 'Is there a chance you could be pregnant', Ainsley recalls being asked rather more bluntly 'Are you pregnant?' This was also mirrored by Lexi in her diary entry (Figure 34). Unlike Ainsley however, Lexi has not provided her responses.

Beth Hester Who from Bazinga School, who declined the vaccine, spoke to me about sex more explicitly than Lexi and Ainsley. Our conversation took place in her home - and at points on her own without her mother Suzzanne - which may be why she spoke more openly and directly:

Beth: I think also they [nurses] assume that you're going to have sex when you're older, which you most likely are but like it's a bit silly.

Ali: Do they talk about safer sex or [...]?

Beth: No not really but obviously they assume that you're going to have [sex]. I don't know.

Ali: So they assume you're going to have sex coz that's how it's passed on?

Beth: Well most likely yes, well you most likely are [going to have sex] but like it's a bit silly sometimes. (September, 2014)

Nurse questions

- Are you pregnant?
- Look at the wall pretending your watching your favourite program.
- There it's all done.
Yay!!! (haha)

Figure 35 Lexi's diary entry, 'nurse questions'

I suggest that describing the assumption of future sex as 'silly' acts as a mechanism to express a similar sentiment to that which Ainsley expresses; sex is, at their age, something that doesn't happen, or at the very least is not something they have knowledge of happening at their age. It is not a part of their life. For Ainsley, then, it is an almost unbelievable question; for Beth, who didn't get as far as being asked it, it is 'a bit silly'.

Establishing whether or not there is a pregnancy in this way assumes the sexual knowledge of these young women that penis-in-vagina (hetero)sex can lead to pregnancy. I argue that it also demonstrates the institutionalised heterosexuality that is present within the school and health systems (Holland et al., 2004) i.e. that the focus is upon the assumed current and future heterosexuality of the young women and their male partner/s. By asking this question 'is there any chance you could be pregnant?' the school nurses assume that the sex which the young women may have experienced is penis-in-vagina penetration (consensual or otherwise), as the only form of sex which would lead to this outcome. It also works on the assumption that their future sex will be with unvaccinated male partners who will benefit from the young women's immunised status.

I argue that in schools there is a pervasive adult discourse of innocence and vulnerability surrounding the sexuality of children and young people, and one which attempts to desexualise them. Louisa Allen has studied schooling in New Zealand in relation to the denial of students' sexualities. Allen states:

A protective discourse around young people's sexuality forms part of many New Zealand schools' 'official culture'. This discourse suggests young people need protecting from the (potential) dangers and negative consequences associated with sexual activity (Fine, 1988). Such a discourse draws on essentialist ideas about sexuality as biologically determined and hormonally driven, with student sexuality constituted as

dangerous because it can propel young people to act in ways that are detrimental to their health. Young people are seen to be especially susceptible to their bodily urges as they negotiate the period defined as adolescence, which is characterised by emotional volatility. This perceived 'turmoil' renders young people less capable of making decisions that will support their sexual well-being, increasing their vulnerability and thus 'need' for protective guidance from school and family. (2007: 224 – 225)

She asked students "how could the sexuality education you have received so far at school be improved?" (2007: 223). Their responses included:

Same-sex attraction, homo-phobia, transgender issues, teenage parenthood, pregnancy, how to make sexual activity more enjoyable for both partners, as well as emotions in relationships. (2007: 226)

These suggestions demonstrate that schools' discourses construct young people as 'childlike' therefore lacking sexual subjectivity and thus the capacity to act as sexual agents. Schools, Allen suggests, are a place primarily focussed upon academic pursuits and achievements, therefore to concentrate on the body and the 'pleasures of the flesh' are seen as contrary or distracting to the focus of schooling. She states:

In the case of the school's 'official school culture' around sexuality, the 'practical tendency' is typically the regulation of students' sexual identities in ways that do not disrupt the academic purpose of schooling. (2007: 222)

I suggest that school culture positions students' education as at risk from their sexualities but does not provide them with education about sexualities. Through such practices, Allen suggests, the school culture in New Zealand desexualises the young people and actually heightens the risks involved. Allen concludes by stating:

The schools' provision of sexuality education acknowledges young people's sexuality, but its typically de-eroticised format concomitantly desexualises them. (2007: 231)

Although the school culture in New Zealand fails to provide sex education and condoms, it also actively promotes messages about sexuality hence the tension for young people in negotiating and expressing their sexualities. Allen suggests that this tension communicates that "schools have a preferred student identity" (2007: 231). Allen argues that a discourse of young people as sexually at-risk constructs them as vulnerable, lacking autonomy and sexual subjectivity. This limits their ability to pursue pleasure and be more active in engaging in safer practices. I argue that it also creates an environment in which it is easy to introduce 'protective' pharmaceutical measures such as the HPV vaccination.

In the UK, there is a care structure in place through the school system that surrounds the healthy development of children through adolescence and into adulthood. Examples include free school meals for those in need, mandatory physical education lessons and benchmarks for age-appropriate developmental markers. Like Louisa Allen, I suggest that the school environment and culture focuses on academic success as a key priority; as such I argue a culture of compliance through docility is constructed in order to enable conditions under which this can be achieved. Holland, Renold, Ross and Hillman (2010), discussing participatory research methods, highlight the issue of 'schooled docility'. This relates to the way in which young people are coached into performing academically according to the school's rules and expectations for behaviour. I propose that this not only applies to the classroom expectations of listening, following teacher instructions and so on but it also applies to the regulatory norms that construct the sexualities of the young women. It constructs a culture of passivity meaning that the young women are discouraged from being active, vocal and asking questions on their own terms.

I have witnessed a sense of fear - and arguably a well-intentioned one - amongst some professionals who work with young people that they may be sexually active at a young age. More specific however, is the fear of the outcomes of them being sexually active. For example, a possible pregnancy would mean the HPV vaccine could not be administered and HPV infection could be present. And furthermore, should a HPV infection be present, the fear of it increasing the chances of genital warts or cervical cancer is a possible reality.

In relation to this fear, in November 2012 I observed the HPV vaccination being administered at Wendy Chicken Shop school. I wrote the following field note to capture the questions one young woman asked of the nursing team and the nurse's actions that followed:

As the final group were coming to the end, one young woman went to Eryl [nurse] who was sat on her own and asked why they didn't give the vaccine to you if you're pregnant; "Does it kill the baby?" she asked. Eryl said "We don't really know. We don't think it'll affect the baby though". She went on to explain that only the flu vaccine is given if a woman is pregnant, otherwise they avoid giving vaccines to pregnant women. I overheard this conversation and Helen [nurse and sexual health project co-ordinator] then came and asked me if the young women were asking about being pregnant, I said yes. Helen was helping administer the vaccine today and also runs a sexual health clinic for young people. Helen then spoke to Eryl about the young woman's query, in an attempt to ascertain whether Eryl had a concern about a potential pregnancy. (November, 2012)

I wondered if Helen was reading the student's question not as an interested query but as an indication of possible pregnancy. For me, this response from Helen indicates or reflects a national fear of teenage pregnancy and a compulsion or professional requirement to be seen to respond in a particular way.

In the context of the HPV vaccination programme Eryl will have known that the young woman had answered 'no' to the question 'is there a chance you could be pregnant?' and as such did not view this query in the same light as Helen who runs a local young people's sexual health project (and thus works frequently with young women who access her service for pregnancy testing and pregnancy advice). Helen could have had concerns about a pregnancy of a 12/13 year old which would likely be the result of an illegal and/or abusive relationship. By approaching the nurses and asking this question, the young woman is constructing herself as a potentially interested 'consumer' of the HPV vaccination (and the fact that it is sexually transmitted); and possibly more problematically, a potential critic.

I argue that this interaction highlights the nurses' lack of willingness or inability to engage the young women in educational opportunities to discuss either sex and/or the risks of pharmaceuticals. By responding with 'we don't actually know' this takes away the focus on the effects of the drug (desired and adverse) and instead places the focus, seemingly, with the knowledge deficit of the nurse. It also says we don't know or think it harms, and what is implied therefore is that they do know it does good! The fact that a drug designed to be life-saving could potentially limit or prevent life from occurring (in the case of the 'unborn baby') is a difficult idea to comprehend. This directly relates to one of the core concerns I identified in the Introduction chapter; that health professionals are trusting the vaccination with blind faith, and do not have the capacity or perhaps the feeling that any critique of it is possible or useful. This interaction is one such way in which I consider the diverse ways in which feminists can support, engage with, and critique, the HPV vaccination programme. As such I would promote this young woman's question as a youth-led opportunity for engaging in a learning opportunity and an exploration of topics such as underage sex, teenage pregnancy and vaccine safety. These opportunities could be used to enhance the limited focus that is afforded to sex and relationship/s education in schools in the UK.

Sex and relationship/s education in schools

The most recent update and guidance document specifically for Sex and Relationship Education (SRE) for schools from the then Department for Education and Employment (DfEE) was written and issued in 2000. In this guidance, which outlines 'good practice' rather than mandatory requirements, schools were provided with information that outlined ways in which SRE could be delivered in light of the revised national curriculum, the Social Exclusion Unit's report on Teenage Pregnancy (1999) and within the Personal, Social and Health Education (PSHE) framework. The guidance states:

The objective of sex and relationship education is to help and support young people through their physical, emotional and moral development. A successful programme, firmly embedded in PSHE, will help young people learn to respect themselves and others and move with confidence from childhood through adolescence into adulthood. (2000: 3)

Here the assertion is that delivering SRE within a PHSE context will enable young people to develop confidently into adulthood. Sex and sexualities figure here as key boundaries between childhood and adulthood. One of the key messages that the document recommends is taught to young people is for them to delay their first sexual activity. This is repeated in the guidance ten times, despite the assertion below that suggests that quality SRE does not prompt young people to enter into sexual activity earlier:

Research demonstrates that good, comprehensive sex and relationship education does not make young people more likely to enter into sexual activity. Indeed it can help them learn the reasons for, and the benefits to be gained from, delaying such activity. (2000: 8)

In addition to the inclusion of research that supports the positive effects of SRE, and the focus on delay messages, the guidance also highlights the broader themes that should be taught in secondary schools that are within the PSHE framework and in addition to the national science curriculum's teachings:

Secondary schools should:

- teach about relationships, love and care and the responsibilities of parenthood as well as sex;
- focus on boys as much as girls;
- build self-esteem;
- teach the taking on of responsibility and the consequences of one's actions in relation to sexual activity and parenthood;
- provide young people with information about different types of contraception, safe sex and how they can access local sources of further advice and treatment;
- use young people as peer educators, e.g. teenage mothers and fathers;
- give young people a clear understanding of the arguments for delaying sexual activity and resisting pressure;
- link sex and relationship education with issues of peer pressure and other risk-taking behaviour, such as drugs, smoking and alcohol; and ensure young people understand how the law applies to sexual relationships. (2000: 10)

This section of the guidance recommends the school's focus on love, respect and self-esteem as foundational principles, to move towards more pragmatic advice and guidance, concluding with a cautionary sentiment of the association of sex with teenage parenthood, sexually transmitted infections and other risks including the use of drugs, smoking and alcohol. The final point makes reference to the law regarding sexual relationships. Three years after this guidance, the Sexual Offences Act (2003) was passed in November 2003 and eleven years later the

Equality Act (2014) was introduced leading to significant changes that would affect the teaching of SRE. The guidance on SRE has not changed for schools although there has been further governmental guidance on sexual health, curriculum updates and Ofsted reports that are related to its delivery.

In 2014, three leading sexual health non-government organisations (NGOs) in the UK - Brook, PSHE Association and the Sex Education Forum - produced a supplementary document, *Sex and relationships education (SRE) for the 21st century* to sit alongside the 2000 guidance. This responded to the growing demand for comprehensive and statutory SRE as well as the update in the Sexual Offences Act (2003). This report provides a summary of the SRE requirements that are placed upon state-funded schools in the UK.

ALL STATE-FUNDED SCHOOLS		
	MAINTAINED SCHOOLS	ACADEMIES AND FREE SCHOOLS
WHOLE CURRICULUM	Must be balanced and broadly based, with a statutory duty to promote pupil wellbeing. Schools must publish details of their curriculum, including PSHE and SRE.	
PSHE	The Department for Education states that all schools should make provision for PSHE education, drawing on good practice. Schools are free to develop their own PSHE programme to reflect the needs of their pupils.	
SRE	It is compulsory for pupils in secondary education to have sex education that includes HIV and AIDS and other sexually transmitted infections.	
SRE GUIDANCE	Any school that provides SRE has a statutory duty to have 'due regard' to the Secretary of State's Sex and Relationship Education Guidance (DfEE, 2000)	
NATIONAL CURRICULUM	Statutory sex education in science programmes of study at Key Stages 1 to 3.	
SRE POLICY	The Secretary of State's 2000 guidance states that all schools should have an up-to-date policy for SRE, which must be available for inspection and to parents/carers on request.	SRE policy advisable but not compulsory.

Figure 36 SRE requirements, Blake et al., 2014: 4

Figure 36 shows that the only compulsory element to SRE currently required is for young people to be taught about HIV, AIDS and other STIs, and that there is some SRE delivered within the science curriculum. I argue that situating the development of sex and relationships knowledge within a scientific

and biomedical framework significantly affects the ways in which teachers, parents and young people view this topic. It suggests that a specialist or 'scientific' lexicon is required, and that it is a topic that has an expertise attached to it. Given this focus, it does not consider the embodied pleasure, joy and excitement that can be part of sexual relationships which is experienced outside of this biomedical framing. It does not recognise that embodied experiences of sex and sexualities are sources of knowledge and information that are insightful and useful. Rather than encouraging young people to feel confident in their own embodied experiences of what it is like to be a sexual citizen, the necessity of a scientific lexicon distances young women from the knowledge that they could and should be generating. It also limits the arguments from those who disagree with its inclusion, by utilising the language of science and detachment as a tool that cannot be (easily) argued against. However, later in the document the organisations do state:

Science teaches about the biological facts relating to human growth, puberty and reproduction. It may also include teaching about contraception and STIs. PSHE helps pupils to think about the different social contexts, influences and beliefs that affect personal behaviour. PSHE also develops a positive vocabulary and the strategies and skills children and young people need to stay healthy and safe. (2014: 8)

Here, a clear distinction is made between scientific knowledge and the broader awareness of societal and other factors on the skills 'young people need to stay healthy and safe'. I see this use of language as framing education about sexuality and sexual health as an endeavour which is about protecting young people from the potentials of ill-health and being at-risk.

Having worked for Brook and witnessed many professional conversations on this topic, I argue that the cautious tone of this document is employed to pre-empt negative responses and to limit the accusations of young people as being

hyper-sexual and of sexual health professionals corrupting young people (Hanbury and Eastham, 2015). It therefore situates sexual health educators alongside others who are trusted and deemed to be responsible for the welfare and safety of children and young people. However, I also think that this discourse is reflective of a concern that young people are at risk of negative outcomes as a result of early sex. Here, the organisations position themselves as moral guardians at the vanguard between young people and the risks of (adult) sex. They are the experts who know the risks and they promote themselves as being advocates of young people, but in so doing they use the reassuring habitual embrace of a safeguarding discourse; whether it leads to the safeguarding and protection of young people or not. Robinson articulates this point by referring to sexuality as a critical boundary:

Sexuality has become representative of adulthood and it is perceived to be a critical boundary differentiating adulthood from childhood. Normative life markers of human development not only operate to constitute and reinforce the culturally defined boundaries between childhood, adolescence, and adulthood, they are the socio-cultural, political, and economic organizing principles of relations in society. Children have ultimately become markers of the heteronormative status quo. (2012: 261)

I contend that constructing 'sexuality as a critical boundary' is therefore a necessary manoeuvre employed to construct young women's sexualities in this risky way. This results in the opportunity for intervention being constructed in a particular way. Specifically, with young women's sexualities being viewed as in need of intervention and protection, institutions such as school, DH and pharmaceutical companies, can intervene in ways which are promoted as 'for their own good'. Pharmaceutical products are often the 'chosen' interventions for protecting sexual health leading to the pharmaceuticalisation of young women's sexual health in the UK.

The pharmaceuticalisation of young women's sexual health in the UK

The vaccination schedule for children and adolescents in the UK is available for free (and encouraged) on the NHS. As I previously referred to in the Introduction, between the ages of two months and eighteen years young women will receive 22 vaccination injections if they accept all vaccinations that are offered. This includes booster jabs and some combined vaccines that are given in two or three dose regimes. The vaccines are thought to offer protection against a variety of diseases including the combined 5-in-1 (DTaP/IPV/Hib) vaccine given from two months old which “contains vaccines to protect against five separate diseases: diphtheria, tetanus, whooping cough (pertussis), polio and Haemophilus influenzae type b” (www.nhs.uk/conditions/vaccinations/pages/vaccination-schedule-age-checklist.aspx accessed on 6th April 2014). Women are also vaccinated during pregnancy, further increasing the pharmaceutical input absorbed by the soon-to-be child, as well as the mother. From adolescence, young women aged 13 and over can be legally prescribed hormonal contraception (without the knowledge of her parents) if deemed competent under the Fraser Guidelines, as assessed by a nurse-prescriber or doctor (Larcher, 2005). Women can continue to be prescribed a hormonal method of contraception throughout adulthood, often seen as “more of a default than an active choice” (Hanbury and Eastham, 2015: 6). Upon becoming menopausal women may be offered, or seek out, hormone replacement therapy (HRT) which is taken for several years to assist with the symptoms associated with the decline in hormone levels during this period of life. With such proliferation of pharmaceutical input in women's bodies, it is interesting - but perhaps not altogether surprising - to note that:

There are no vaccine studies in existence using a true non-vaccinated control group [therefore] the natural incidence of a disease, as well as the true risks of a vaccine cannot be effectively assessed.

(www.greenmedinfo.com/blog/hpv-vaccine-maker-s-study-shows-natural-hpv-infection-beneficial-not-deadly accessed on 6th May 2015)

The authors of this article, Brogan and Founder, make this assertion when critiquing the assumption of the HPV vaccination programme “that HPV causes cervical cancer, that cervical cancer causes death” following a study by GlaxoSmithKline that reported findings to the contrary (Castellsagué, et al., 2014).

This reliance on pharmaceutical products as a way of mediating and ensuring that a healthy girl develops into a healthy adolescent and adult woman is one that is accepted in a banal and ostensibly celebratory fashion. Indeed, displaying any anti-vaccination sentiment is often met with ridicule, disbelief and an articulation of medical rationality. For example, Suzanne, Beth’s mother stated that when she ‘confessed’ to her father, who is a GP, that she had not vaccinated Beth against Measles, Mumps and Rubella (MMR), he replied with “I can’t believe you’d be so irresponsible [...] I’ve seen children in iron lungs, have you got any idea?” Suzanne’s account of this exchange brings to light the ways in which choosing not to vaccinate is seen as an irresponsible thing to do. Suzanne felt that her dad uses his experience as a GP to add weight to his accusation of irresponsibility. Suzanne is not a medical professional; she is a youth worker who uses homeopathic treatments and diet as a key source of health and wellness for her family. I suggest that the strength of feeling in the assertion from Suzanne’s father relies upon a strict normative medical framing of health and exemplifies the pharmaceutical necessity.

Further examples of the ways in which young women’s sexualities are deemed risky and are offered a pharmaceutical response include when some girls will experience what is deemed to be the ‘problematic’ issue of early pubertal development, which can result in hormone-blockers being prescribed to them (Roberts, 2015). And, once puberty is established and sexual activity is a

possibility young women can experience the prescription of hormonal methods of contraception (for both contraceptive and other purposes). I argue that the pre- and adolescent sexuality of young women is often viewed within biomedical contexts as in need of pharmaceutical mediation. This contemporary timeline of vaccinations and pharmaceutical offerings comes following a history of the “scientific turn of sexology” (Marshall, 2002: 135) whereby sexology has attempted to assert itself as an authoritative science. Barbara L. Marshall, Professor in Sociology argues that:

Sexology though, has always had problems of legitimacy, and one of the strategies used historically to establish itself as an authoritative science has been to assert a physiological basis for sexual problems within a medical paradigm of diagnosis and treatment (Bullough, 1994; Irvine, 1990; Tiefer, 1996). Thus sexuality has become medicalized, rendering it amenable to intervention and management according to a biomedical model. (2002: 134-135)

In her article ‘Hard Science’: Gendered Constructions of Sexual Dysfunction in the ‘Viagra Age’, Marshall describes the “rationalization and medicalization of sexuality” (2002: 146) that forms part of the complex “cultural event” of Viagra (2002: 131). This modern concern with sexual dys/function and the biomedical (and indeed cultural) event of a pharmaceutical response (Viagra) has consequences not only on the body, but also for social/sexual relationships and the future development of pharmaceutical ‘treatments’ for sexual ‘problems’. Marshall argues that as well as being biomedical, “drugs are social products” (2002: 132) and that “Viagra is one of the most commercially successful prescription drugs on record” (2002: 133). She argues that the discourses of biomedicine construct “gendered, sexual bodies and responsible individuals” (2002: 133). Marshall’s work is useful to my analysis of the HPV vaccination programme as it is the practices within this that also rely upon and construct the responsible individuals who are expected to behave in particular normative ways.

Similar strategies are at play within the HPV vaccination programme as with the Viagra case that Marshall uses when she attests:

Universalized bodily norms are constructed against which individuals can be measured and compared, and which provide a context whereby we not only understand our bodies, but *experience* them – as sick or healthy, functional or dysfunctional. (2002: 135, original emphasis)

Therefore the socially constructed ‘universalized bodily norms’ by which we understand our bodies rely upon the markers and measurements of health that have been constructed. We utilise these markers as a tool to assess our health, by which to know and experience our bodies in limited ways. Unlike sexual dys/function however, the HPV vaccination does not depend upon any physiological symptoms, rather it is based upon the fear of the future possibility of cervical cancer.

I argue that education and societal views on sexualities remain governed by this perennial biomedical discourse, and are seen in phallo-centric ways. The idea that ‘real sex’ occurs between a woman and a man, with penis-in-vagina penetration being the marker of losing one’s virginity, is a limited yet a pervasive and powerful sexual currency which is often the basis of many sexual health interventions and indeed of the ‘Viagra Age’ (Marshall, 2002; Marshall, 2009; Barker, 2013; Cacchioni, 2007). Sociology Professor Thea Cacchioni found the pressures of heterosex to be a key factor in the lives of women (2015). In her book *Big Pharma, Women and the Labour of Love*, her respondents stated they felt “traumatized by many aspects of heterosex, and yet felt immense pressure from several sources to be actively, frequently, and orgasmically heterosexual” (2015: 67). Pressures to be sexually available and to perform and achieve in sexually ‘desirable’ ways has also captured the interest of some pharmaceutical companies, with several companies vying to be the first to bring a ‘treatment’ for female sexual dysfunction to market following the success of Viagra (Marshall,

2002; Teifer, 2008; Canner, 2009). Pharmaceutically orientated views often focus on problems to be solved and dysfunctions to be treated. Indeed, in August 2015 the USA's FDA approved flibanserin (marketed as Addyi) to treat Hypoactive Sexual Dysfunction Disorder (HSDD) in premenopausal women (www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm458734.htm accessed on 19th September 2015) despite major opposition and the uncertainty around identifying any treatable physiological cause of sexual disinterest and aorgasmia (Teifer, 2008).

The focus on female sexuality as a physiological issue sees women's bodily performances and sexual availability as in need of correcting for the benefit of herself and for her (male) lover/s. Cacchioni describes how various pharmaceutical companies were fighting to construct a diagnostic label for the unsatisfying sexual encounters experienced by women which could be remedied by their profitable pharmaceutical products. Estimated at a US\$1.7 billion dollar market, sex drugs for women is seen as an area that will provide excellent returns on the investment of the main pharmaceutical players.

I contend that pharmaceutical companies have a limited version of what is included in their definitions of sex and sexuality. And I argue that these parameters limit the opportunities for focussing on the various related topics outlined in the broader definition that I quoted in the introduction to this chapter, taming the scope of sexualities into manageable and medically-orientated data. As such, I argue that the biomedical and pharmaceutically orientated ways of viewing sexuality is, in part, an expression of the legacy of sexological thinking which relies upon medical discourse and frames the ways in which researchers and youth and community practitioners and others approach sex and sexualities. This discourse sets a particular view of sexualities that has been co-opted by many practitioners and sexual health services. I further develop this argument by next turning to interrogate materials from the HPV vaccination publicity, and

examine how medical language is used in order to construct the case for vaccine acceptance.

Relying on the language of science in HPV vaccination publicity

A similar legacy is evident in the HPV vaccination. Scientific knowledge – of which medical knowledge is a part - as inherently legitimate has long been critiqued by feminist activists and scholars (Ehrenreich and English, 2005; www.ourbodiesourselves.org accessed 30th November 2014; Moore, 2010). The traditionally male environment of ‘hard’ science is one which pursues particular versions of knowledge and generates information that is often inaccessible to those to whom it refers i.e. ‘patients’. In Chapter One I introduced Andrea, the pharmaceutical representative. During my telephone research conversation with her she explained:

When we generate our own *data* around *cost effectiveness* for instance; that’s all done internally but we have panels of *experts, clinicians* that *ratify* all the work we do and these people, they’re not on our books [in paid employment by the company]. We pay them honoraria for their *consultancy* time, but that’s all done within a set of *rules and regulations*. (July, 2012, emphasis added)

This is an example, in relation to health economics, that demonstrates the reliance upon the discourse of medical expertise and systematic procedures. Here, Andrea is using a specific language that creates a powerful image of the professionalism and proficiency of the work of the pharmaceutical company. Referring to experts, clinicians and consultancy suggests particular expertise that is authoritative. It also distances both her and me from this work, and furthermore, those who are offered the vaccine. Using terms such as ‘data’, ‘ratify’ and ‘cost effectiveness’ suggests a set of practices that are systematic, planned and objective. This presents a hierarchy of knowledge and expertise,

shutting out people from being able to understand and therefore challenge it. Finally, in a move which I suggest anticipates but shuts down any potential opposition or critique, Andrea clearly tells me that the experts are not employed by the pharmaceutical company (suggesting distance and neutrality) and the process is governed by rules and regulations that safeguard against any potential subjective investment or corruption, thus objective medical truths are created.

Sandra Harding's assertion of "strong objectivity" is an example of a feminist critique of scientific knowledge claims. She highlights that history has shown there to be a delusion of the social production of knowledge. She argues that "modern science has again and again been reconstructed by a set of interests and values – distinctively Western, bourgeois, and patriarchal" (1993: 145). Harding states:

The fact that feminist knowledge claims are socially situated does not in practice distinguish them from any other knowledge claims that have ever been made inside or outside the history of Western thought and the disciplines today; all bear the fingerprints of the communities that produce them. (1993: 57)

Harding therefore argues that the claims to value-neutrality as a key characteristic of scientific knowledge production is absurd, highlighting that scientific knowledge is always socially situated. The relevance to my arguments is that all knowledge is socially situated. However particular sources of knowledge communicate in ways that make their claims seem superior and unquestionable. It is the hierarchy of legitimacy into which different knowledges are placed that result in difficulty and precarity. As such, I return to elaborate more on information, knowledge and decisions in Chapter Four.

Keeping this in mind, in the following section I make a close reading of the leaflet that was issued to young women and/or her parents who were offered the

HPV vaccine. In this reading I critique the publicity on the grounds of its use and reliance upon a (language and practices of) science and medical superiority as providing unquestionable truth claims about the risk of cervical cancer and the efficacy of the HPV vaccination.

Frequently asked questions about the HPV vaccination

I missed my vaccination, can I still have it?
 Yes. If you missed any of your vaccinations, for whatever reason, you should speak to your nurse or doctor about making another appointment. It's best to make your appointment as soon as possible after your original one. The most important thing is to have all three doses – it's never too late to catch up.

But hasn't the vaccine changed?
 Yes. From September 2012, the HPV vaccine is changing but stocks of the vaccine that was used when the programme started in 2008 are being held back, so you can still complete your course if you missed out on one or two of your appointments in the previous school year.

Now I've had the injections, will I still need to go for cervical screening?
 Yes. All women should decide to go for cervical screening (smear tests) when they are old enough (25 and over in England). The vaccine protects against over 70% of the human papillomavirus types that cause cervical cancer, so you still have to be screened to try to pick up cervical abnormalities caused by other HPV types that could lead to cancer.

Should girls who have already had sex bother with the vaccination?
 Definitely. If you've had sex, and are in the relevant age group, you should still have the vaccine.

Please don't forget that cervical screening (smear tests) will continue to be important whether you have had the HPV vaccination or not.

Having this vaccine will also protect you against the two types of HPV that cause the majority of cases of genital warts. It won't protect you against any other sexually transmitted diseases such as chlamydia and it won't stop you getting pregnant.

Missed your appointment?
 Speak to your nurse to arrange another one. It is important that you have all three doses to get the best protection.

More information
 Visit www.nhs.uk/vaccinations where you can download a question-and-answer sheet that gives more detailed information on the topics covered in this leaflet.

For more information about cervical screening visit www.cancerscreening.nhs.uk

Ordn against cervical cancer

Immunisation
 The national immunisation programme

NHS
 Immunisation information

Your guide to the HPV vaccination from September 2012

Beating cervical cancer

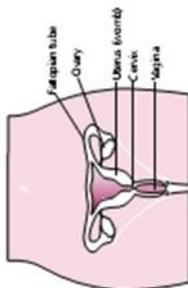
Figure 37 HPV vaccination leaflet, 2012, front and back

What is cervical cancer?

Cervical cancer develops in the cervix (the entrance to the womb – see diagram below). It is caused by a virus called the human papillomavirus or HPV.

Cervical cancer can be very serious. After breast cancer, it is the most common women's cancer in the world. In the UK, around 3000 cases of it are diagnosed every year and about 1000 women die from it.

For more information, visit www.nhs.uk/vaccinations



HPV and how it spreads

The human papillomavirus is very common and you catch it through intimate sexual contact with another person who already has it. Because it is so common, most people will get infected at some point in their lifetime. In most women the virus does not cause cervical cancer. But having the vaccine is important because we do not know who is at risk.

The HPV (cervical cancer) vaccine

There are many types of human papillomavirus. The HPV vaccine protects against the two types that cause most cases (over 70%) of cervical cancer.

Because the vaccine does not protect you against all of the other types, you will still need to have cervical screening (tests that pick up early signs of changes in the cervix) when you are older.

Most girls who have the vaccination will reduce their risk of getting cervical cancer by over 70%.

Having the vaccination

You will need three injections over about six months to get the best protection. It's important that you have all three doses. The nurse will give you the vaccination in your upper arm.

Your school or local NHS will contact you when it is time for your vaccination.

Remember, the HPV vaccine is recommended for all girls aged 12 and up to their eighteenth birthday. It is offered routinely to all girls starting in school year 8.

Side effects

Like most injections, the side effects of the HPV vaccination are quite mild. Soreness, swelling and redness in the arm are common but wear off in a couple of days. More serious side effects are extremely rare. The vaccine meets the rigorous safety standards required for it to be used in the UK and other European countries.

See www.nhs.uk/vaccinations or the patient information leaflet (PIL) given to you at the vaccination if you'd like more information on side effects.

Tens of millions of doses of HPV vaccine have been given to girls worldwide.

Giving consent

You will probably want to share information about the vaccine with your parents and discuss it together. If you are being offered the vaccination at school, you may be given a consent form that your parent/guardian or you should sign giving permission for you to have the vaccination.

Information about your vaccinations will be added to your NHS records.

The doctor or nurse will discuss the HPV vaccination with you at your appointment and will be able to answer any questions you may have.

Figure 38 HPV vaccination leaflet, 2012, inside

I suggest that the language used in this leaflet, although directed at young women aged 12 years and older, relies upon scientific terms and understanding. The mobile phone on the cover and the use of pink and flowers above some of the lettering are the main symbolic nods to younger femininity. Within the leaflet the information is 'translated' using bracketed text, into everyday speak e.g. "the cervix (the entrance to the womb – see diagram below)" and "cervical screening (tests that pick up early signs of changes in the cervix)". As is standard in many

scientific texts, the image of the area around the cervix is shown as a disembodied flattened image reminiscent of medical textbooks, and it uses medical language in labelling the fallopian tubes, ovary, uterus (womb), cervix and vagina. This is despite some of these words not being mentioned in the leaflet therefore potentially remaining a mystery to the young women reading it. This is indicated by the young women's repetition of the words verbatim from the HPV vaccination leaflet, rather than a critique or re-wording of it. I argue that this is suggestive of the complicity through docility in schooling I highlighted earlier. There was inconsistency between the young women as to whether they had seen this leaflet (or a bilingual language version in the case of the young women from Wendy Chicken shop school). But here Lexi has simply cut out and stuck selected paragraphs from the leaflet but offered no interpretation or her views on it. This suggests that she does not feel able to interpret or 'mess with' the authority of the leaflet.

As well as frequently referencing nurses, doctors and parents as HPV experts, the leaflet also provides the link to the NHS website, four times. This limits the possibility that young women would think of themselves as knowledgeable or having any 'expertise' in having received the HPV vaccination. In her diary, Emily writes out this website as well as the cervical screening website that is also referenced in the leaflet. She has utilised the truth claims of HPV vaccinations provided by the NHS and DH as part of a narrative template in order to reproduce the knowledge deemed to be important.

I suggest that the use of percentages, the image of the cervix and reliance upon medical language all create a version of the young women's bodies as ones which need pharmaceutical products i.e. Cervarix and Gardasil to protect and enhance their (sexual) health. Common-sense assertions such as assuming vaccine acceptance are made, and the language is expressed in ways which links this health behaviour with others in the future too. For example the leaflet

states “Because the vaccine does not protect you against all of the other types [of HPV] you will still need to have cervical screening” (Figure 38).

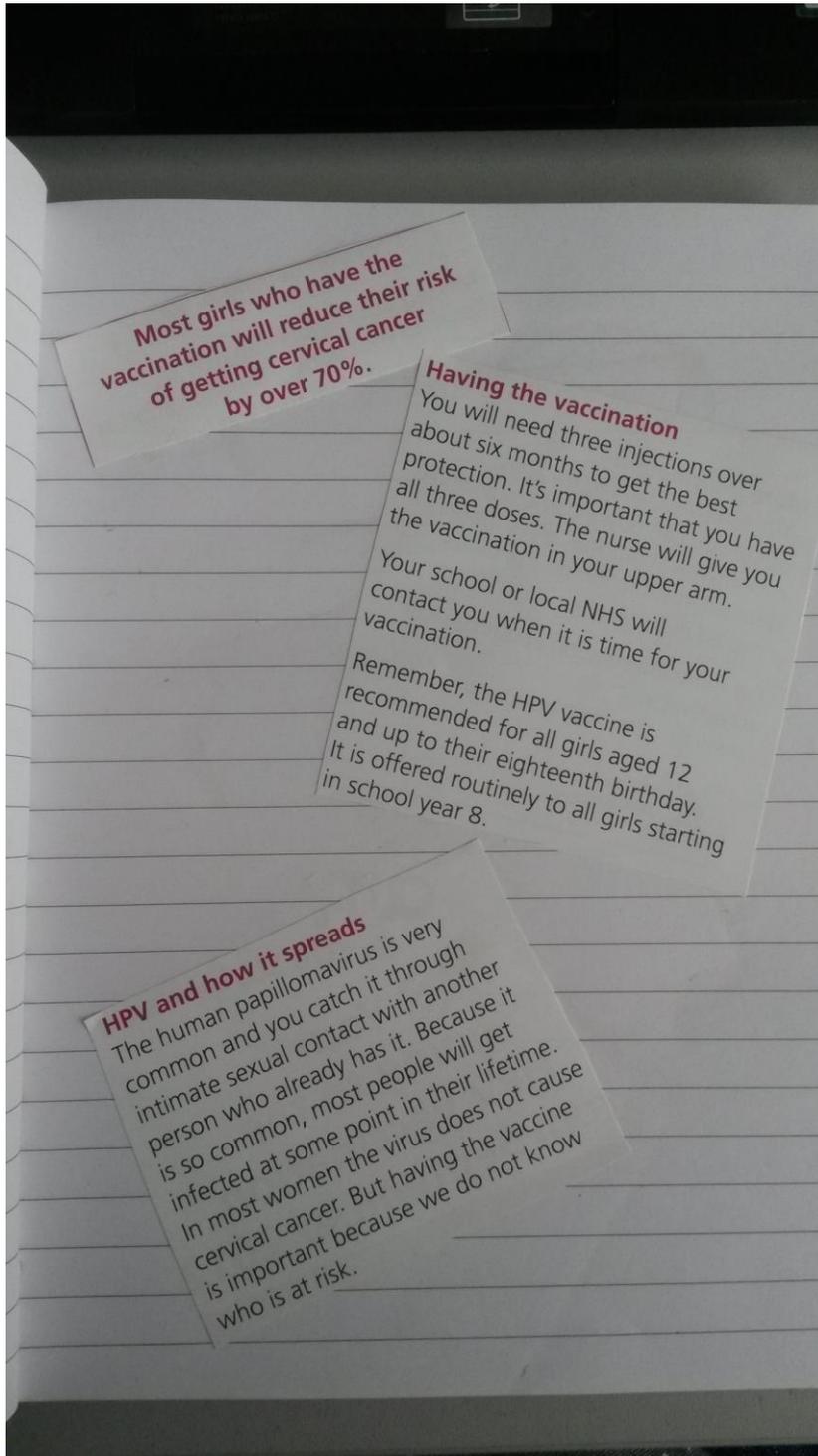


Figure 39 Lexi’s diary entry, cuttings from HPV leaflet



Figure 40 Emily's diary entry, website address

The risk of cervical cancer (and, tangentially, genital warts) is presented in a way that means it is understood only through this lens of pharmaceutically mediated knowledge and prevention. The possibility of a more nuanced

understanding of the body and its risks are not permitted. Despite the leaflet stating “in most women the virus does not cause cervical cancer. But having the vaccine is important because we do not know who is at risk” other factors are not included in this information, which could be considered when women consider their possible risks for developing cervical cancer. These factors include a broader range of considerations, some of which have been evidenced through embodied experiences and subsequent knowledge production through activist or citizen science (Dubriwny, 2015; www.ourbodiesourselves.org/ accessed 30th November 2014). These factors include familial history of cervical cancer, exposure to synthetic hormones and environmental factors such as smoking, alcohol consumption, poor diet and undiagnosed/untreated previous or persistent infection with the Human Papillomavirus.¹⁵ These factors are not included in the leaflet, instead the information presented to the young women is one of inherent risk that can be reduced only through the intervention and acceptance of the pharmaceutical product; the HPV vaccine.

In summary, the information provided is one which supports the use of the vaccination as the only option for reducing the risks of (genital warts and) cervical cancer. This is because it is a partial and socially constructed version of cervical cancer. It is a specific account of cervical cancer but the information leaflet has the truth claim that cervical cancer “is caused by a virus called the human papillomavirus or HPV”. This is factually questionable but a strategically powerful manoeuvre. Indeed, most cervical cancer diagnoses co-occur with a HPV infection but some do not. And there are other causes of cervical cancer than just persistent infection with a high risk HPV type. The information states that:

- HPV is the most common viral STI

¹⁵ Despite persistent HPV infection being largely seen as a negative indicator and risk to progressive ill-health, one study has shown that “natural HPV infectious exposures actually protect against the progression of HPV linked cervical changes to cancer” (Brogan and Founder, 2014, accessed online)

- Most sexually active people will have an HPV infection at some point
- HPV causes cervical cancer

Therefore this message is one of high risk. But, many of the types of HPV that most people are infected with do not cause cervical cancer. I argue that by limiting the information received and utilising a language of science to promote the link between HPV infection (general) and cervical cancer (specific) the desired health behaviour is accepted (vaccinating).

The HPV vaccination programme: combining the de/sexualised culture of schools in the UK with the pharmaceuticalisation of young women's sexual health in the UK

I now return to the key question of this chapter - how are young women's sexualities constructed through the HPV vaccination programme? I argue that the de/sexualised culture of UK schools is combined with the pharmaceuticalisation of young women's sexual health so to construct young women's sexualities as compliant, health-seeking and future-gazing. Jennifer Spratt, Janet Shucksmith, Kate Philip and Rebekah McNaughton (2012) conducted focus groups with teachers in seven secondary schools in Scotland to explore their accounts of their role in the HPV vaccination programme. They highlighted that compulsory school settings, since their inception in the late nineteenth century, have been utilised as sites for the delivery of large-scale health programmes. The school is an environment for the regulation and measurement of children's bodies:

In acting as a universal site of containment and control, schools are ideal places to implement nationally devised health interventions, particularly when physically administered to children's bodies. (2013: 84)

Through such health interventions in schools, teachers are - willingly or otherwise - agents who promote or are complicit in the dominant discourse of the national agenda regarding young people's health. As such:

In the contemporary context of the health promoting school, teachers are cast as active partners in the network of 'experts' guiding the health behaviours of children along the routes advised by the government. (2013: 84)

Despite this assertion Spratt et al. found that some of the teachers they spoke with were aware, and critical of, this role into which they were being cast. For example one teacher stated:

If they [health professionals] are delivering the government's wishes, then obviously there is an agenda, and you are going to be delivering that agenda to 13-year-olds and you can sell anything to 13-year-olds if you glamorise it. (Jocelyn, in Spratt et al., 2013: 87)

Jocelyn, who works at a Catholic denominational school in an inner city school in Scotland, articulates her displeasure at the assumed manipulation of information given to 13 year olds through 'glamorising' the messages. Her assertion that "you can sell anything to 13-year-olds" suggests her scepticism about the framing of freedom and choice. My key point here is that the culture of schooling and national health interventions such as the HPV vaccination programme, both have institutionalised practices of subjectification. Young women's sexualities are constructed and constrained so to compress and control the debates and complexities of the tensions that are felt and experienced. There is a wish to view them simultaneously as sexually innocent and vulnerable so to allow for the protective measures of health interventions and school culture to intervene as described above. This is further combined with, and complementary to, the neoliberal postfeminist version of normative femininities mentioned in the Introduction.

Writing in 2010, Janet Holland and Rachel Thomson suggest that there have been both changes and continuities in the ways in which research is undertaken and researchers and policy makers view sexualities. The changes reflect the new and emerging ways that sexual knowledge is being generated, i.e. through the campaigns of feminists, disability rights activists and LGBT people, through online resources and user-generated content (including pornography). Government interest in sexualities is also on the rise with significant investment in research and policy development into, for example, sexualisation of girls and young women (Papadopoulous, 2010) and child sexual exploitation (Jay, 2014). However the dominant policy recommendations have asserted that sexual health services should be mindful of the sexual risks to which young women are susceptible. So as I encountered at Brook, practitioners are encouraged to prescribe and promote hormonal contraception. From my practice experience, when young women are deemed to be 'vulnerable' through, for example leading 'chaotic' lives which means they will 'fail' to self-administer 'the pill', the knowledge that they have received a long-acting reversible contraception (LARC) method which limits 'user failure' is often hailed as a success and rewarded by financial incentives (i.e. 'payment-for-prescription') from commissioners of sexual health services. Guidelines from 2014 for contraceptive services delivered to under 25s produced by the National Institute for Health and Care Excellence (NICE) recommends that services "use CQUIN indicators and other arrangements and processes to improve the uptake of effective methods of contraception, as appropriate" (NICE 2014: 11).¹⁶

This shows a particular pharmaceuticals-as-saviour response to the sexual dangers that young women are deemed to be at risk of. Holland and Thomson quote Feona Attwood who suggests that there is:

¹⁶ See Hanbury and Eastham, 2015 for a discussion of the Clinical Quality and Innovation (CQUIN) payment framework.

A contemporary preoccupation with sexual values, practices and identities; the public shift to more permissive sexual attitudes; the proliferation of sexual texts; the emergence of new forms of sexual experience; the apparent breakdown of rules, categories and regulations designed to keep the obscene at bay; our fondness for scandals, controversies and panics around sex. (2010: 244)

Attwood writes about this 'contemporary preoccupation' at a particular time (mid-2000s) and within the context of the UK. Despite the changes that seem to have occurred in cultural representations of sex and sexualities, Holland and Thomson highlight continuities around the inequalities between women and men. They suggest that there is a "re-instatement of heterosexual normativity" and "the feminist language of freedom and emancipation [is] being taken up and used to sell lifestyles, to evoke sexualised hyper-femininity and conformity" (2010: 345). An example of this re-instatement of heterosexual normativity is the continued reliance upon the pharmaceutically orientated way of ensuring young women remain (sexually) healthy, as opposed to if they were to be a problematic refuser of the various pharmaceuticals that responsabilises them e.g. HPV vaccination and hormonal contraception. This point is re-visited and extended in Chapter Five in relation to the risks to sexualities of the vaccine-injured young women.

I argue that sexualities are an established element of neoliberal femininity in which young women are encouraged to engage in particular 'lifestyle' behaviours that contribute towards a publicly displayed version of their sexualities. These sexualities are lived out through the practices of prescribed hormonal contraception as well as the acceptance of the HPV vaccinations. These two specific examples also rely upon the role of the practitioners in the administration of the health intervention as well as the ideological culture of the settings in which they occur i.e. de/sexualised culture of schools and the 'payment-on-prescription' culture that is encouraged within clinical sexual health services.

Without the de/sexualised culture of schools in the UK and the concurrent pharmaceuticalisation of young women's sexual health the HPV vaccination programme would, I argue, not be as successful. This success means constructing docile young women through already-established practices of subjectification. This is done so to create complicit young women who will then accept the vaccination, which serves to achieve the DH target for numbers accepting the HPV vaccine. Imagine a situation whereby the HPV vaccine was made available and administered in more informal, community or leisure based settings, for example at youth clubs or sports centres. Or indeed, if we had a more homeopathic rather than an allopathic focus on healthcare, whereby there is a focus on non-synthetic products and lifestyle factors considered in the risk calculations surrounding women's health. By imagining such a scenario we can begin to identify the strength and necessity of the two key framings on the construction of young women's sexualities. The HPV vaccination programme is rendered successful through its reliance upon the imagined sexual risks of young women and the accompanied feminine behaviours of health seeking that the vaccine conveniently provides.

Conclusion: pharmaceuticals-as-saviour

The sexual identities of young women are a lived reality that relates to the many practices with which they are engaged, with a particular normative effect of gendered and sexual norms. The sexual nature of the various practices surrounding the HPV vaccination programme can often go unchecked but they contribute significantly to the construction of young women's sexualities.

In this chapter I have focussed on three key arguments. Firstly I focussed on the de/sexualised culture of the school environment. Practices within this environment are characterised by sexual and gendered norms. Often there are active attempts, in the name of child protection and fears of vulnerability, to limit

and reduce the sexual nature of young people's lives. At the same time, young women are positioned as responsible for the future health of themselves and their future male partner/s.

Secondly, in conjunction with the effects of the de/sexualised culture of schools, young women's sexualities are pharmaceuticalised. Arguably the steadfast presence of pharmaceuticals in the lives of girl children through their adolescence and into adult womanhood has a significant effect on the adult sexualities of these women and their health practices (Eastham, 2016). As well as accepting the promotion of pharmaceuticals-as-saviour and protector of women's health, a particular version of appropriate successful femininity is promoted.

Thirdly, I have demonstrated the ways in which the HPV vaccination programme is legitimated and made successful. Through the combination of being administered in the already powerful de/sexualised school culture, the HPV vaccination programme introduces a new addition to the heavily pharmaceuticalised framing of women's sexual health. The HPV vaccination programme is an easy-fit into these framings. It serves to create a complementary relationship of sexed differences and the gendered expectations of docility, compliance and required willingness to enter into feminised behaviours such as prophylactic health-seeking. Framing young women's sexualities in a pharmaceutically orientated way both relies upon and creates a particular version of the (sexual) distinction between childhood and adulthood. The tension between being 'desexualised' and 'sexualised' creates the optimum setting for introducing the HPV vaccination programme and making it successful i.e. there is a normative sexual world that is deemed so normal that it is viewed as not being sexual at all. This is in tension with a non-normative and risky sexual world that is discouraged and viewed as sexual. The former is promoted so to act to regulate the latter. The HPV vaccination programme constructs a fear of future disease

(and arguably of sex itself) and the desire to act to alleviate that fear i.e. by accepting the HPV vaccine.

There are more examples of the nuanced tensions that surround the practices demonstrated through the HPV vaccination programme which I will develop next. Continuing on from the identity practices presented through the diaries in Chapter Two, in Chapter Four I introduce research material demonstrating the various knowledge practices that occur in the HPV vaccination programme, which create particular tensions based upon the hierarchy of knowledge.

Chapter four: Young women's everyday activism

Risks of HPV vaccination:

It [HPV vaccine] was the unknown I think and then there was that incident where a girl had got sick and [...] she died didn't she? And it was reported that it was due to the HPV [vaccine], it was on the news.

Dilys, School Nurse Support Worker, April, 2014

During my research young women and school nurses engaged in practices that I consider as examples of everyday activism. An explicit aim of my research is to carry out a political project that acknowledges and values the knowledge practices women engage in with relation to their meaning-making and decision-making around the HPV vaccination. The construction and understandings of young women's gender, sexual health and futures were unpacked in the previous chapter. In this chapter, I present examples of the various knowledge produced and circulated by the multiple and differing perspectives of people involved in, and affected by, the HPV vaccination programme. Using research materials from four groups of participants this chapter highlights the different ways that knowledge practices are demonstrable in the HPV vaccination programme. I use knowledge practices to refer to the various engagements that are bound up when information creates knowledge and leads to decisions being made. I utilise scholarship from bell hooks and Joan W. Scott regarding women's experience and contributions to knowledge before considering Tasha N. Dubriwny's concept of postfeminist healthy citizenship. I then consider Robinson's work on difficult citizenship as well as Mark Smith's concept of young people as 'creators not consumers' against which to analyse some of my research materials.

Young women's accounts are often not present in mainstream HPV materials. As I will argue, they are often marginalised, sometimes discredited or

deemed to be unimportant by the DH, in school and by the pharmaceutical companies that control and administer the HPV vaccination programme. Furthermore this chapter considers how the knowledge that these people and institutions create shapes the ways in which women negotiate their ways of participating in the HPV vaccination programme and various institutions that surround it. Thus, knowledge is linked to the notion of citizenship, but specifically 'difficult citizenship' (Robinson, 2012). As a result of the relationship between these knowledge practices and difficult citizenship, I suggest that everyday activism is evidenced through various engagements with the HPV vaccination programme.

I frame this chapter with the question: how do knowledge practices of HPV vaccinations shape sexual citizenship? I provide research materials gathered from young women, their parents and health practitioners about their experiences of the HPV vaccination programme to demonstrate the wide range of practices that constitute HPV vaccination. Including materials from several sources provides insight into the hierarchy of knowledge and examples of everyday activism that is practiced through the programme. I explore how different understandings of HPV and the practices that construct these understandings are multifaceted and collective endeavours that take place within this hierarchy of knowledge. Developing arguments from the previous chapter on sexualities, this chapter analyses the young women in this research project's contributions to knowledge. It develops Tasha N. Dubriwny's (2013) concept of 'postfeminist healthy citizenship' which suggests that women practice health behaviours through consuming products and lifestyles, and Robinson's 'difficult citizenship' (2012) which refers to children and young people who know 'too much' sexual knowledge ahead of what is marked out as adulthood. This chapter is split into three sections to interrogate this scholarship. The three sections are: 1) HPV vaccination programme's publicity materials; 2) professional youth and community work; and 3) materials gathered from the nursing team who administer the vaccine at Wendy Chicken Shop school.

I use the term 'knowledge' to refer to the information that those involved in the HPV vaccination programme base claims upon. Knowledge is constructed, utilised and circulated based upon different commitments and campaigning. These knowledges are born out of their positions in relation to the HPV vaccination and the programme, and the information they receive and endow with validity, be that from clinical trials, experiential knowledge or a political commitment to critique power structures. Some of these claims to knowledge, and the practices that shape them, are contested, particularly the testimonial and personal narrative accounts of HPV vaccinations as they are often seen as lacking in scientific rigour and as subjective (Brinth, 2015). Again, I aim to make visible such minority knowledge which links both experiential and contested knowledge. Many scholars have celebrated experiential ways of knowing and proactively seek out these versions in their work.

The passion of experience: women's contributions to knowledge

In 'Teaching to Transgress: Education as the Practice of Freedom' (1994) bell hooks reflects on her delight at finding the term 'authority of experience' in feminist writing. This term was particularly pertinent to hooks during her undergraduate studies. The universalising of women's experiences did not, in fact, represent or make visible the issues experienced by black and other minoritised women. Through her reflections on practice and learning, hooks was later troubled by the term and its silencing potential if used in ways which were one-sided or that closed down opposition from an 'analytical' way of knowing. By this 'analytical way of knowing' hooks refers to knowledge that is not based upon direct experience rather a critique or analysis of the situation and experience. Instead hooks calls for a term that privileges the standpoint of experience and the "specialness of those ways of knowing rooted in experience" (1994: 90). Through her practice as a Professor of English, hooks states she will:

Share as much as possible the need for critical thinkers to engage multiple locations, to address diverse standpoints, to allow us to gather knowledge fully and inclusively. (1994: 91)

My research endeavours are founded on similar professional commitments deriving from my professional youth and community work practice. Indeed Batsleer states that the “elements of informal learning in youth and community work are widely taken to include experiential learning [...] and making voices heard” (2013: 55). Hooks states that having a privileged standpoint from a combination of both experiential and analytical knowledge, comes from a “passion of experience” (1994: 90). This is a clear demarcation between the authority of experience, that is knowing through having lived it, and an emotional engagement and passion for that experience to be known and shared.

Whilst hooks does not cite the work of Joan W. Scott, I find some commonalities between the work of these scholars. Scott, Professor of Social Science, analyses written materials and cultural phenomena to highlight the hegemonic historical stories told about social worlds through the claims of ‘the evidence of experience’. Scott says:

Among feminist historians, for example, “experience” has helped to legitimize a critique of the false claims to objectivity of traditional historical accounts. Part of the project of some feminist history has been to unmask all claims to objectivity as an ideological cover for masculine bias by pointing out the shortcomings, incompleteness, and exclusiveness of mainstream history. (1991: 786)

Scott critiques any claim that experience be utilised in incontestable ways. Quite simply, Scott argues that experience should not be taken for granted. To ‘unmask’ shows collusion between different versions of historically powerful and dominant ways of knowing (Ehrenreich and English, 2005; Löwy, 2011;

Ramazanoğlu and Holland, 2002). The masculine bias within these accounts provides an incomplete and also a dangerous and discriminatory version which has real impact on the lives of women and other minoritised people. Scott therefore calls for methods that attend to the historical visibility of people's positions, rather than an articulation of identities that emphasise the historical forces they aimed to challenge.

Despite this, Scott goes on to suggest that experience in itself is not enough to tell stories of the world that usurp the hitherto dominant narratives of history and to demonstrate the existence of alternative/minoritised versions of society; instead they must be viewed and critiqued as themselves socially constructed and thus politically created. A particular example offered from Scott is her analysis of the autobiographical writing of black, gay writer Samuel Delaney whose memoir details and demarcates the 'otherness' of his identity and feelings of solidarity and collectivity with other gay men. Scott suggests:

The project of making experience visible precludes analysis of the workings of this system and of its historicity; instead, it reproduces its terms. We come to appreciate the consequences of the closeting of homosexuals and we understand repression as an interested act of power or domination; alternative behaviors and institutions also become available to us. What we don't have is a way of placing those alternatives within the framework of (historically contingent) dominant patterns of sexuality and the ideology that supports them. We know they exist, but not how they have been constructed; we know their existence offers a critique of normative practices, but not the extent of the critique. Making visible the experience of a different group exposes the existence of repressive mechanisms, but not their inner workings of logics; we know that difference exists, but we don't understand it as relationally constituted. (1991: 779)

Scott is therefore moving beyond the 'simple truths' of experience, or, as bell hooks terms it, the authority of experience, and instead insists that we develop a critique that will allow us to recognise and identify the 'workings of the system'. This assists my thinking as to the ways in which particular knowledge claims are afforded greater legitimacy and credibility than others. Neither the powerful institutions nor the experiences of people are mutually exclusive. Furthermore, Scott argues:

It is not individuals who have experience, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation, not the authoritative (because seen or felt) evidence that grounds what is known, but rather that which we seek to explain, that about which knowledge is produced. (1991: 779-780)

Knowledge and experience are interlinked. One does not pre-determine the other. Instead, people construct their identities as they construct their experiences. Indeed, Kehily's assertion (in Chapter Two) that we utilise 'well-worn' stories in the narrative accounts of our experiences, is sympathetic to Scott's argument. The work of hooks and Scott value the power of the testimony of those lived experiences. Yet they both advocate for acknowledgement beyond this, that we need an analytical critique. Attending to and eliciting experiential knowledge is a core commitment of this project, and in so doing it "exposes the existence of repressive mechanisms" (Scott, 1991: 779). In attending to the accounts of experience, I must also ask "how conceptions of selves (of subjects and their identities) are produced" (1991: 782).

A further example of feminist scholarship that values diversity of experience is Sandra Harding's (1986; 1991; 2011) work on the philosophy of science and knowledge. Harding provides insight into the historical, social and political relationships which create the ways in which individuals can contribute to knowledge in research. With a particular commitment to research which takes the

lived experiences of often marginal or oppressed groups as its starting point, Harding asserts that:

The truth (whatever that is!) cannot set us free. But less partial and less distorted beliefs – less false beliefs – are a crucial resource for understanding ourselves and others, and for designing liberatory social relations. (1991: xi)

Harding thus provides both a caution and a call for change based upon her recognition that distorted beliefs (i.e. those based upon partial and incomplete accounts but that claim to be otherwise) are problematic. Her caution is in relation to the notion of truth, our beliefs based on that truth and the subsequent freedoms we have as a result. Cautioning against this triad relationship, Harding instead calls for less partial and distorted beliefs, through which she promotes the development of knowledge based upon the experiences of a broader demographic of peoples and communities; specifically marginalised people who she believes can provide greater nuance and insight. This is something which both hooks and Scott also advocate. These more nuanced (and subjugated) experiences construct different meaning and can create several versions of more nuanced knowledge. I argue that these several versions of knowledge exist within the research materials I present below, but that they are constructed and ordered in a hierarchical fashion.

The critique of women's contribution to knowledge and experience has been well highlighted and critiqued elsewhere (Harding, 1991; Oakley, 1993; Ehrenreich and English, 2005; Stanley and Wise, 1993, and Walker, 1983) but remains a contemporary issue that warrants exploration in relation to the HPV vaccination and programme. I introduced five young women in Chapter Two, four of whom accepted the vaccine and one who declined it; in Chapter Five I will specifically look at another group of young women who accepted the vaccination and experienced ill-health afterwards. A question that arises here is whether the

young women's knowledge is seen as inconsequential and critiqued as being emotional and subjective? If, as Harding calls for, our pursuit of knowledge was characterised by strong objectivity, the young women's accounts would be valued more than they currently are by medical and school practitioners. This kind of project, that values and promotes young women's contributions to knowledge, runs contrary to the ways in which their compliance and docility is constructed as part of neoliberal postfeminism introduced in the Introduction. I want to create a space for these accounts to be visible and heard. This relates specifically to one of the key concerns in the Introduction whereby I highlight the HPV vaccination programme effects on young women's sexualities and femininities. I argue that young women have to be compliant with both the strict social scripts of femininity and the HPV vaccination's expectations. As such, can an exploration of sexual citizenship aid my critique of the practices promoted by the HPV vaccination programme?

Postfeminist healthy citizenship

Citizenship, in its broadest civic sense, refers to the reciprocity between individuals and the society in which they live. Individuals have rights and benefits as members of a particular society or country. Such rights and benefits include access to legal protection and the ability to engage in society. As such there are a number of expectations that are projected onto individuals in the reciprocal, or more critically, a compromising and constraining, relationship of citizenship (Bell and Binnie, 2000). Individuals, or citizens, are expected to behave in ways compliant with existing norms and functions of societal institutions and to contribute to social living in a way that is respectful of the culture and practices of the specific location. Bell and Binnie summarise their use of the term sexual citizenship by highlighting the compromise it entails:

The current nodes of the political articulation of sexual citizenship are marked by compromise: this is inherent in the very notion itself, as we

have already noted: the twinning of rights with responsibilities in the logic of citizenship is another way of expressing compromise – *we will grant you certain rights if (and only if) you match these by taking on certain responsibilities.* (2000: 2-3, original emphasis)

This means that any alternative, marginal and even radical ways of practicing as a sexual citizen are discouraged and policed within strictly ordered legal frameworks e.g. of monogamous marriage.¹⁷ I develop the notion of citizenship, informed by sexual citizenship, by using Dubriwny (2013) and Robinson's (2012) work. These scholars' current empirical research allows me to attend to the ways in which women engage with the 'opportunities' and health interventions made available to them in particular individualised and future-gazing ways.

Having access to the HPV vaccination is said to ensure young women's healthy life in which they can contribute to society in a normative way, safeguarded through their choice to be vaccinated. Young women must accept vaccination in order to contribute to positive sexual health, and the HPV vaccination programme delineates a specific version of what it means to be sexually healthy. In the Introduction I highlighted the problematic assumptions surrounding expectations that young women should behave in particular postfeminist healthy ways. Hence, citizenship in the HPV vaccination programme involves adherence to gendered social norms that could be problematic for young women (Ryan-Flood and Erel in Gill and Scharff, 2013).

Tasha N. Dubriwny's book *The Vulnerable Empowered Woman: Feminism, Postfeminism, and Women's Health* focuses on postfeminist health concerns. Dubriwny provides a compelling argument that women's health requires an "activist feminist approach" (2013: 16) by identifying that

¹⁷ There is a burgeoning literature on sexual citizenship and queer sexualities. See Plummer, 1995, 2003; Weeks, 2003; Berlant, 1997 and McNicholas-Smith, 2014.

contemporary concerns surrounding women's health lack attention with feminism. Dubriwny theorises the notion of a postfeminist healthy citizen thus:

Postfeminism has usurped the position of feminism, bringing with it a representation of women as highly gendered individuals who are empowered to choose among medical treatments, manage their future and current health by altering their lifestyles, and increase or play up their femininity by taking advantage of ever-expanding opportunities to modify their bodies and lifestyles. I focus on how a postfeminist sensibility governs discourse about women's health through a larger rhetoric of risk in which women are represented as part of an inherently at-risk group that must engage in a constant monitoring and management of risk. (2013: 13)

Dubriwny utilises the concept of the 'at risk' postfeminist healthy citizen/woman to highlight the issues concerning women's health activism. She also highlights examples of the activism that has occurred as a result of such concerns. She draws on three key examples of controversies. These are campaigns around: 1) safety of various contraceptive methods, 2) radical mastectomies, and 3) issues surrounding disproportionate rates of sterilisation of racially minoritised and economically disadvantaged women. Young women are expected to attend to external risks; to their bodily and social weakness and vulnerability to disease. Yet there are significant tensions in this framing of young women's health.

Validity of embodied experience

Medical knowledge is frequently relied upon when making decisions about health. The common decisions are often reflective of dominant social norms i.e. that vaccines are accepted. Such norms have resulted in some women's health activists encouraging "a significant challenge to standard accounts of objective knowledge by insisting on the validity and importance of their own experiences" (Dubriwny, 2013: 17). The challenge and resistance to 'objective knowledge' is a

key characteristic of many campaigns within the various women's health movements. Dubriwny argues that the health behaviours co-opted, are not as a result of the woman's choice, but as a result of the dominant norms that medical knowledge creates, often without the woman's involvement. With contemporary health behaviours such as sexual health screening and HPV vaccination, women are often presented with information and health promotion materials prior to consenting. Health promotion materials are weighted in favour of accepting the intervention on offer. It is because of this that the arguments which oppose these interventions often critique neoliberal postfeminism as well as citizenship.^{18 19} Dubriwny calls for this activist feminist approach to involve three themes: 1) the politics of knowledge; 2) self-determination; and 3) contextualisation. I introduce and work with these frames below in order to organise my research materials and analysis.

The politics of knowledge

Knowledge and knowledge-production does not occur or exist within a vacuum. The ways in which we come to encounter and generate knowledge depend upon many factors. In Chapter Two, meaning-making surrounding the HPV vaccination programme was evident in the narrative and autobiographical accounts developed by the young women offered the vaccinations. Their knowledge of the vaccine differs significantly from the readily available medical and public health rhetoric surrounding the vaccination. From this group of young women knowledge claims about the vaccine include expressions/accounts of pain, anxiety and the fear of the 'unknown'. As Beth, who declined the vaccine, wrote in her diary, "I remember that the first injection was quite unknown and everyone was scared and talking about it". Milly, one of the vaccine-injured young

¹⁸ For examples of scholarship on sexual citizenship see Bell and Binnie (2000) and Plummer (2003).

¹⁹ See Singleton (1996) for a critique of the National Cervical Screening Programme.

women, told me what she now thinks of the HPV vaccination having experienced side-effects:

Ali: What do you think, if somebody said to you now, what's the HPV vaccine, what is it, what does it do, what would you answer me now?

Milly: Something sarcastic about how ridiculous it is and how awful it is. I don't understand what it is for, because I just thought it was for cervical cancer. I don't really want to look into it. Like, obviously I look into things on the internet, but if you like Google it, like HPV vaccination, it just pops up with like jabs and stuff, it doesn't pop up with, 300 girls disabled or some kind of story like that.²⁰ (February, 2013)

These young women have engaged in knowledge practices of seeking information and sharing and reflecting on experiences in order to create knowledge for themselves as a direct aspect of engaging in the current project. Milly states she uses Google to find different knowledge about the HPV vaccination. Given the opportunity, the young women engaged with the HPV vaccination programme in a way which was relevant and made sense to them. They engaged in practices through which they shaped their own knowledge and through which some of the young women came to challenge medical representations of the HPV vaccination as always positive. Milly describes how her early knowledge of HPV vaccinations related to prevention of cervical cancer, but that following her post-vaccination ill-health she engaged with alternative knowledge practices of others who claim the vaccine has disabling affects. This shift suggests that knowledge is political, it is constructed and utilised variably in accordance with particular interests, ideologies and experiences.

²⁰ See Brinth (2015).

An example of alternative knowledge that is constructed in particular everyday activism is from the Down There Health Collective. In December 2007 the Collective, based in DC, USA, produced a zine regarding HPV which focuses on a broader set of knowledge to that commonly circulated through the dominant medical and health promotion channels.²¹ Within their zine they include information that states:

- The HPV virus usually has no symptoms and *does not cause disease* — people usually don't know they have it
- If you contract HPV, don't blame yourself or your partner. Your HPV status is not an indicator of your sexual behavior or that of your partners
- HPV *is usually harmless*, but some types of HPV can cause cervical or other cancers in rare cases
- Most people will have HPV at some point, but *very few will develop cervical cancer*.
- The immune system of most people will usually suppress or eliminate HPV. Only an HPV infection that does not go away over many years can lead to cervical cancer.
(www.notjustskin.org/sites/notjustskin.org/files/HPV%20FINAL%20single%20page.pdf accessed 15th July 2014, emphasis added)

HPV is presented as an infection that is associated with a 'family' of over 100 infection types. That contrasts with the common presentation of HPV as associated with vaccination and 'cancer' (Robbins, Bernard, McCaffery, Brotherton, Garland and Skinner, 2010; Wailoo, et al., 2010). Indeed, of the

²¹ "A Zine (zeen) is a self-published, small press or homemade publication similar to a pamphlet. Zines often address specialized topics from an independent, controversial or alternative viewpoint. They can be a collection of random personal thoughts or expertly made political treatise." (www.douglas-ca.v1.libguides.com/content.php?pid=335220&sid=2742463, accessed online 24th April 2015).

twenty-nine young women I surveyed (see Chapter One) as part of my initial visit to Wendy Chicken Shop school, twenty-four of them responded that the HPV vaccine is for 'cancer'; fifteen specifically stated cervical or 'womb' cancer. As such, the most pervasive truth claim that is known to the young women when they are offered the vaccine seems to reflect the HPV vaccination programme's promotional materials.

These promotional materials celebrate the vaccine. They are prepared by those who support and make the vaccine, and reflect a specific set of knowledge and commitments. An example of the celebration of the vaccine comes from Andrea, the pharmaceutical company manager who had a lead role in the research and launch of the vaccine Gardasil in the UK. During our telephone research conversation she stated:

We launched Gardasil in 2006 [...] it was one of the fastest vaccines to ever go through the European medicines approval system [...] it was fast tracked through because of its superior efficacy and safety profile and it was deemed to be a vaccine that could make such a significant impact to public health they really couldn't afford to waste any time in bringing it to market. (July, 2012)

A similar story was relayed by three other health professionals I interviewed; Mary, the school health advisor and sexual health nurse; Iris, the Health Protection Unit manager, and Jessie, the manager with a cervical cancer charity. For these professionals, the HPV vaccine is viewed as an effective intervention and is celebrated for having been fast-tracked and having superior efficacy in clinical trials.²² To re-cap; Beth's diary entry tells us that the HPV vaccination is unknown and scary; Milly states that it is ridiculous, awful and disabling; the self-published zine from the USA presents HPV as an infection

²² There are many critiques of clinical trials. See for example McCartney, 2012; Davis and Abraham, 2011; Tiefer, 2008 and Moynihan and Cassels, 2005.

rather than a risk factor for cancer and is reassuring in its tone, taking the emphasis away from the inevitability of cervical cancer developing from HPV and thus the necessity of the HPV vaccination; and the pharmaceutical manager Andrea extols the unquestionable necessity and exceptionality of the vaccine and its efficacy.

In the four research materials presented above, there are clear differences in the meaning and sentiment between each. The focus on HPV shifts and practices differ depending upon context, situation and relationship to HPV vaccination. Dubriwny argues that the politics of knowledge is a key issue in women's health. Yet, although women's health issues remain a contemporary concern, they are only visible through being depoliticised. Dubriwny, like Gill and Scharff (2013), highlights the relationships between neoliberalism and postfeminism and how young women are constructed as being both 'vulnerable' as a result of at-risk femininity and 'empowered' through being coached into taking on a limited set of medical interventions.

These empirical examples suggest that there are struggles and contestations about what can and should be said about the HPV vaccination programme, while the dominant knowledge is that of its efficacy and life-saving potential. One of my initial research questions is: what are the diverse ways in which feminists can support, engage with, and critique, the HPV vaccination programme? And here I use various research materials to juxtapose different knowledges, which highlights the dominant knowledge that constructs and is constructed by the HPV vaccination programme's proponents. In raising this question, it allows for a more nuanced set of knowledges against which I can engage in a feminist debate about the HPV vaccination and programme. These varying knowledges could be utilised in Harding's call for 'strong objectivity'. Accessing and eliciting the knowledges of young women, who are sometimes subjugated and minoritised through the hierarchy of knowledge, has the potential to increase efficiency in administration and reduce the harm that has been a

result of administering the HPV vaccination programme based upon a limited version of knowledge and claims.

Self-determination

Dubriwny argues that her use of the term self-determination was in direct response to the many instances of women being absent from the decision-making process regarding their own health and medical issues. For example, the case of Ada Lovelace detailed in the Introduction (Löwy, 2011). Dubriwny provides various examples of feminist action that brought about changes in the health industries in the USA in relation to breast biopsies and hormonal contraception methods. As such, the self-determining health behaviours of women relate to both structural and personal, intimate engagements.

To a great extent the political feminist commitment of my project has been to provide an opportunity for self-determination surrounding the HPV vaccination, specifically for the young women who have been offered it, and more tangentially the women nurses and parents who have also been involved. Whilst Dubriwny focuses on bodily self-determination I extend this to refer to social and political self-determination. I believe this contributes to the rights that women can have over their own bodies. For example, being able to determine their own feminine and sexual identities, young women may then be able to determine bodily decisions differently. I was hopeful from my previous critiques of sexual health interventions throughout my career that I would uncover accounts of the HPV vaccination from young women which are considered peripheral and problematic. I ran a focus group of parents with daughters who had been vaccine-injured and this provided one of the most striking examples that self-determination was an important issue in this project. Many of their stories detail the trauma of being let down by the institutions they believed are there to protect and safeguard the health of their children. One mother, Vicky, told me: “You sort of trust the medical profession don’t you, you trust the doctors” (February, 2013).

Vicky was sharing her reflections on her and her daughter Pollyanna's post-vaccination treatment by health professionals. Following Pollyanna's first two vaccines she began to suffer from adverse effects. Vicky was alerted by a family member, who had seen a similar story reported by another parent in a women's magazine, that it may be the vaccine. Vicky recounted how she was reluctant to mention this to the health professionals. Rather, Vicky wanted to wait because, she claimed, she trusted the medical professionals not to have given her daughter a vaccination that would harm her. Being a 'good mother' and caring for Pollyanna in this situation was full of tensions. Vicky wanted Pollyanna to be well and she also trusted the doctors. However, following many referrals to different health professionals Vicky felt dejected and was dismayed by the claims of a medical professional that Pollyanna was self-harming. Vicky said:

My mum [...] she said, 'she [the doctor] obviously knows what she's talking about because she works at Great Ormond Street and she's been a dermatologist for 19 years' and I went, 'Well that's great, Mum' I said, 'but you know, I don't think she's right, I'm Pollyanna's mum'. (February, 2013)

Vicky's account suggests that she adopted various self-determined practices after the patient-doctor exchange. She challenged the authority of the dermatologist's truth claim through asserting her own knowledge of, and relationship with, Pollyanna. In this way Vicky resists the traditional hierarchy of medical power. However Vicky still engages with the medical profession in order to gain recognition of Pollyanna's symptoms as well as access to treatment. Vicky inverts the location of expertise in relation to knowledge of her daughter and she stakes her claim to knowing Pollyanna (and her symptoms) best, both to her own mother and in interactions with health professionals. We will return to the case of Vicky and Pollyanna in more detail in Chapter Five.

Contextualisation

For Dubriwny the term contextualisation refers to the emphasis that women's health activists have placed on the "social context in which individuals [a]re understood to be healthy or diseased" (2013: 19). In Chapters Two and Three I attended to the social and collective sense of experiencing the vaccination from the perspective of five young women and the often invisible sexual norms that are promoted through the HPV vaccination programme. The concept of contextualisation allows me now to focus on other determinants that affect knowledge regarding the HPV vaccinations.

Being understood as healthy or diseased is an important issue for many of the participants who provided accounts of vaccine injury. A specific example, of providing a social context to the effects of the HPV vaccination, occurs in the account shared by Milly. In February 2013 when I was invited to meet Milly and her mother Jackie at their home, Milly was 15 years old. I was told that for two years since receiving the HPV vaccinations Milly had been suffering on-going ill-health which she and her family believe has been caused by the HPV vaccines. Her symptoms include extreme fatigue, joint pain, dizziness, peripheral blindness, 'brain fog' and gastro-intestinal problems. These symptoms are sporadic and invisible to others around Milly; as such her illness could be seen as contested. Milly and others have experienced many struggles with daily living after the HPV vaccination. Her illnesses have meant she lacks the good health, energy and mental focus to be able to provide me with detailed accounts during the research project. As such her parents have taken on the role of carer and advocate and I rely heavily on her mother's accounts of Milly's experiences. Milly and Jackie told me of a shopping trip she was on with her grandparents. They said:

Milly: Because they're old, Grandad and Grandma, they want to stay and chat for hours with these people. So I'm stood at the side of Grandma and I'm going, ready to pass out, and I'm fidgeting, trying to move about a bit to take the dizziness, Grandma she's going 'stand still, stand still

[LAUGHING] stop fidgeting', so I'm trying to stand still and that was just it, I was off.

Jackie: She just passed out then [...] So it brought out to Mum and Dad how bad it was and of course they got her home and it's not just that she passes out, it brings on all the other symptoms. So that particular day I got a panicked call from Mum saying 'She's really really poorly, you've got to come straight through for her, she's so poorly Jackie! There's something wrong with her'. And I thought, well for two years we have [BOTH LAUGHING] been saying there's something wrong with her. (February, 2013)

The social context of Milly's illness is apparent here. Her symptoms, which are changeable and sporadic and often not visible to others, render her ill-health elusive. But the quote indicates how her family have come to understand health and illness, i.e. they have had to witness visible symptoms in order to know that Milly is unwell.

Accounts of vaccine-injury as an activist feminist approach to making positive changes in HPV administration

The narration of the vaccine-injured young women's experiences, their own and their parents, provides a number of accounts of both vaccine-injury and patient activism. The Sane Vax network (www.sanevax.org) campaigns for safe, affordable, necessary and effective vaccinations. However a large part of their work is dedicated specifically to supporting vaccine-injured young women following HPV vaccination and demanding recognition of their experiences from medical professionals, government and the pharmaceutical company. I include and analyse the cases of vaccine-injury in Chapter Five.

Dubrwin's framework of postfeminist healthy citizenship provides me with a lens through which to consider the political and gendered context in which

young women are being offered the HPV vaccination in the UK. It draws attention to the knowledge practices that are embodied and narrated by young women and their parents. The current controversy surrounding vaccine injury and side-effects (Rail, Molino, and Lippman, 2015; Maldonado Castañeda, 2015; Tomljenovic, and Shaw, 2012) has the potential in women's health activism to significantly change the ways in which the HPV vaccination programme is administered. Dubriwny helpfully attends to past activism, and brings forth a critique of the postfeminist environment in which women are being constructed as healthy citizens through being encouraged to co-opt measures such as the HPV vaccination. As such they must engage in practices that are healthy, safe and that contribute to the overall success and stability of civic life. As my research materials have alluded to, there are many examples of young women engaging in practices that trouble these expectations. Next, I consider a further articulation of citizenship, specifically looking at how young women are deemed to be 'difficult' in particular sexual ways.

The double entendre of 'difficult' citizenship

Kerry Robinson's (2012; 2013; 2008) work on constructions of childhood innocence was introduced in Chapter Three. I analyse issues of health and sexual citizenship, by utilising Robinson's scholarship regarding the constructions of gender and sexualities. She argues that children's (and I take this to also refer to young people) sexual citizenship is dependent upon the hierarchical relationship they have with adults. Through the protective practices of adults, children are positioned as vulnerable and innocent. This also situates adults as good citizens through both protecting and creating those younger healthy sexual citizens. In her 2012 article "Difficult citizenship': the precarious relationships between childhood, sexuality and access to knowledge', Robinson states:

Saving children from sex became increasingly articulated through age of consent laws and through formal and informal censorship and regulation of

children's behaviours and access to sexual knowledge [...] romantic notions of childhood innocence underpin children's continued precarious and difficult relationship to sexuality. Children have been successfully employed as regulators of normative life markers across human development. (2012: 260-261)

The precarity of young people's sexuality - as a distinguishing factor between childhood and adulthood - goes some way to explain the pervasive unease that some adults have when children and young people display sexually non-conformist development or sexual knowledge deemed to be non-age-appropriate (Robinson and Davies, 2008). The desire to reconcile the romantic notion of the innocent child with a sexual notion of a young person nearing adulthood results in some difficulty.

The term 'difficult' can be read as having two meanings; first, as something challenging or hard to accomplish and second, as someone who is being difficult or contrary to the behaviours deemed normal. This relates to the very thing which I am creating a space for within this project. This project itself may be putting young women at risk of difficult citizenship. I suggest therefore that to engage in practices that produce sexual knowledge is an example of difficult citizenship. The risk, or difficulty, is a result of it being *experientially produced* knowledge. Young women are engaging in a programme that is inherently sexual in its characteristics. I am encouraging and foregrounding the very thing that the HPV vaccination programme is downplaying; its sexual element. As I have stated previously, HPV is not platonic; it is the most common viral STI with over 80% of people thought to be infected at some stage in their sexual lives. Therefore all of those involved in the HPV vaccination programme can be deemed to be practicing difficult citizenship as a result of exposing 'innocent' children and young people to sexual knowledge, as argued in Chapter Three. Perhaps this is why a lot of information makes the link with cervical cancer, so as to draw attention away from focusing on sexual activity. As Dubriwny argues, in her

critique of Gardasil's "One Less" media campaign in the USA, which I present further below:

[T]here is no discussion of the details of how the HPV virus operates, most pertinently how it is transmitted. Audiences are instead informed that the vaccine protects against the "human papillomavirus that may cause 70 percent of cervical cancer." This careful construction of HPV as a virus of unknown origin and the emphasis on cervical cancer sidestep discussions of sex." (2013: 117)

Furthermore Robbins et al. (2010) found that many young women were unaware and confused about cervical cancer's relationship with HPV. Again this could be due to the strategy of avoiding speaking about HPV as sexually transmitted.

As Robinson argues, an organising principle of sexuality - delineating between age groups and their relational levels of maturity - is significant in thinking about the construction of young women's identities. It draws attention to the fact that young women's lives are mediated and regulated based around a central defining character. Whilst the HPV vaccination programme often ignores the sexual characteristics of the virus, my research highlights the impact and affects it has on young women's sexualities. As young women carry out various identity practices and knowledge practices they are dicing with the difficult citizenship that is built on their engagement in a world of sexualities. As expressed in Chapter Three, the expected health behaviours constructed by the pharmaceuticalisation of young women's sexual health affects their access to knowledge and their subsequent citizenship practices. Constructions of sexuality therefore have a significant impact on the lives of these young women. I argue that there is a difficult necessity for young women to publicly display their sexualities in ways that are considered to be positive and healthy.

The decisions available to 'responsibilised' parents

As presented in the Introduction, choice and decision-making are concepts inextricably linked to the notion of postfeminist neoliberal womanhood. Following analysis of the commercial and non-commercial discourses surrounding the HPV vaccine in the USA, Dubriwny (2013) suggests that choice is only available to young women who are privileged with regards to their class and racial positions. She also argues that the term 'empowerment' is limited to young women's ability to consume various health and lifestyle practices, such as vaccinating.

Decision-making links to my focus on self-determination. Being in receipt of the information provided by the NHS, parents are expected to have the appropriate knowledge they require in order to decide whether or not to vaccinate their daughters. As I will move on to analyse below, the parents are thus in a position of 'responsibilised' health citizens through undertaking decisions on behalf of their daughters. Parents therefore play an important part in the myriad health and citizenship practices involving their daughters. It is often the case, and demonstrable via my research materials, that mothers are responsibilised for making decisions regarding the health of their daughters. Arguably, during the period of adolescence, when the issue of sexualities is heightened, responsibilised parents are making difficult decisions in the best interests of their daughters.

An example of the decisions that parents are faced with comes from Julie. Julie was part of the focus group I conducted in the South East of England in February 2013 with the parents of vaccine-injured daughters. She received a letter from the Immunisation Team at the school attended by her daughter. The letter opens with bold text which states "**Beating cervical cancer**" and later "**This letter is to offer your daughter a vaccine to protect her against cervical cancer later in life**" which again appears in bold type. The letter states that the vaccine is "very safe and very effective" and after providing the three dates of the doses to be given to her daughter, the letter then suggests that "It would be most

helpful if on the day of immunisation your child could wear a loose fitting garment or short-sleeved shirt and have had breakfast” (Appendix 4). The letter thus far creates a case for the HPV vaccine which firmly centres the issue as one of beating cervical cancer.

There are instructions on how the young women should dress prior to the vaccines followed by the request for parents to “sign the form if you are in agreement for your child to receive this immunisation”. After this there is a statement warning: “**Please note that a young person can consent to an immunisation if they are deemed competent to do so**”, meaning that if the parent does not consent their daughter may choose to do so independently of their wishes. Could this be seen as an attempt to construct self-determination for young women? I argue it is not because the letter ends with the sentence “By having the HPV vaccine your daughter *will be* protecting herself and others against a very serious disease” (emphasis added). This marks the vaccine as unquestionably efficacious and directs the decision-making in favour of vaccine acceptance. It also constructs young women as successfully feminine in the role of conduit to good health between the vaccine and others; that is, her future sexual partner/s.

This letter ‘responsibilises’ parents to facilitate their daughter having the vaccine, and also for preparing their daughter properly - providing breakfast and ensuring she dresses appropriately. My key point here is that the parents are coached into making decisions on behalf of their daughters, but these decisions are based upon a limited set of options. Parents are led down the decision-making path of consenting to the HPV vaccination. The weight of the future potentiality of cervical cancer is made clear throughout the information they receive.

In the UK context it could be suggested that decision-making regarding whether or not to vaccinate, particularly with new and lesser established vaccines, has largely been presented to parents as a balance between weighing

up the risks and benefits; how likely is it that their child will experience side-effects (and how serious are they) versus what health problems will they avoid by being vaccinated? If it is believed by parents that the benefits (i.e. reducing risk of developing cervical cancer) is more serious a health concern and more likely to occur than the likelihood and seriousness of possible side-effects then vaccination is generally accepted. This argument however is one which Pru Hobson-West (2007; 2003) problematises. As a Social Scientist Hobson-West's work draws upon literatures on trust, ethics, public understanding of science and risk to explore decision-making in relation to vaccines. Her research concerning organised resistance to the combined Measles, Mumps and Rubella (MMR) vaccine controversy troubles this 'risk-benefit dichotomy', introduces alternative framings of the decision-making process, and provides examples of recent historical health activism.²³

Vaccination acceptance, as a prophylactic intervention, can seem counter-intuitive. Reynolds and O'Connell suggest that "unlike medical interventions for existing conditions, vaccination requires that a healthy child undergo an unpleasant procedure for an unseen benefit" (2011: 2). Indeed, the indicator of success of vaccinations is the overall reduction in the incidence of disease, but the benefit remains unseen, because whether the disease would have developed in the individual accepting the 'unpleasant procedure' will never be known. Despite this, vaccine acceptance is the established norm. The UK website NHS Choices, with its strapline 'Your health, your choices' states that the HPV vaccine is 'offered' as part of the NHS's childhood immunisation schedule. The website presents information and statistics about cervical cancer and genital warts, and promotes the HPV vaccination. Towards the end of the webpage site visitors are encouraged to "Now, read why it's so important for 12-13 year-old girls to receive

²³ Measles, Mumps and Rubella is a combined vaccine that is usually given in childhood in two doses. The controversy was sparked when a paper was published in medical journal *The Lancet* in 1998 by surgeon and medical researcher Dr Andrew Wakefield. This paper claimed that the MMR vaccines were associated with Autism and bowel diseases in some children. For more on this see Hobson-West (2007).

the HPV vaccination” (www.nhs.uk/conditions/vaccinations/pages/hpv-human-papillomavirus-vaccine.aspx accessed 23rd October 2014). My key point here is that rather than there being a choice between vaccinating or not, the decision is directed firmly and positively towards accepting the vaccination. This renders the option to not vaccinate as an unreasonable one.

Analysis from the USA suggests that accepting the HPV vaccine involves a very particular and limited acceptance of the vaccine potential; that is the pervasive biomedical discourse of reduced risk and better health. In their chapter ‘Re-Presenting Choice: Tune in HPV’, Giovanna Chesler and Bree Kessler (2010) explore the media industry and undertake a gender analysis to critique Gardasil’s “One Less” campaign, which uses the mantra “I chose”. They state that choosing to receive Gardasil based upon the dominant messages and positive promotion of the vaccine “involves choosing to agree to a limited understanding of human papillomavirus” (2010: 146). As I suggested in the Introduction the concept of choice should be highlighted as problematic, rather than the notion of agreeing with a limited understanding. Instead, I focus on the limited knowledge that is available upon which to base decisions. Furthermore, Reynolds and O’Connell found that:

In a qualitative study conducted in the United Kingdom [by Sporton and Francis, 2001], participants perceived that health education leaflets and campaigns exaggerated how effective vaccines are in offering protection from disease. (2011: 2)

The decisions presented in both the UK’s NHS Choices webpage and the USA’s Gardasil “One Less” campaigns are heavily geared towards vaccine acceptance. A further example of the UK shows how the HPV promotional messages extend beyond simply the parents accepting vaccination through a letter from the Immunisation Team. Elena Conis’ 2015 book *Vaccine Nation: America’s changing relationship with immunization* presents material from “teen[s] who

chimed in on the discussion groups and blogs channel[ing] Merck's ads" (2015: 240).²⁴ Despite there being many who "urged their peers to spread the word about HPV infection, talk to their doctors, get vaccinated, and order their Commitment bracelets online" (2015: 240) others were voicing concerns about the state mandates for HPV vaccination, as Conis quotes one online commentator: "F—K One Less! [...] It's all about 'Lot's more' (of 'Ka Ching in Mercks' bankaccount [sic]...)" (2015: 240).²⁵

Conis' analysis of the media savvy teens critiquing and parodying Merck's One Less advertising campaigns highlights how "teenage girls expressed a feminist demand for bodily sovereignty that was largely missing from conversations in mass media" (2015: 240). These examples of knowledge practices are context-specific to the USA where direct-to-consumer (DTC) advertising is a significant part of the repertoire of activities in which pharmaceutical companies engage. Whilst DTC advertising is not permitted in the UK, and the vaccine is free in the UK, the materials and mantras of the HPV vaccination programme, are displayed in schools, health centres and on London's Underground system as part of 'health promotion' activities. Conis suggests that the young women engaging with such debates were not only consumers of the media campaigns but also creators of particular versions based upon their critiques. These examples of young women engaging in a political critique of the HPV vaccine's media campaigns provide examples of everyday activism. If the information available is at odds with the young women's knowledge practices then opportunities for everyday activism are created.

²⁴ In the USA, pharmaceutical companies are permitted to advertise their products directly to the consumers. Merck's ads, refers to the advertisements on TV promoting the One Less campaign encouraging young women to accept the vaccination Gardasil.

²⁵ "Merck sponsored a program called "Make the Commitment" which distributed free "Commitment" bracelets (designed by a celebrity fashion consultant) to girls who took an online pledge to ask their doctor about cervical cancer prevention" (Conis, 2015: 236).

The information young women and parents receive affects the knowledge they have and this leads to the knowledge practices and decisions they make. From the research materials and the empirical work of Conis (2015) these decisions fall into two categories; either they accept the vaccination and are viewed as vulnerable empowered women (Dubriwny, 2013) in doing so, or they critique the vaccine and potentially engage in a particular version of difficult citizenship (Robinson, 2012) and everyday activism. As such I am advocating for ways in which young women and their parents can create their own knowledge and make decisions based upon more specific, nuanced ways that are relevant to their own lives. This is central to my commitments as a professional youth and community worker. In order to develop this line of argument I will now introduce youth and community work scholarship that advocates and encourages young people's role as creators not consumers.

'Creators not Consumers': knowledge practices and everyday activism

In the early 1980s Mark Smith wrote the pamphlet 'Creators not Consumers: Rediscovering Social Education' which was published by the National Association of Youth Clubs (NYAC, now Youth Clubs UK). It served as a 'go to' booklet for me in the early years of my professional youth and community training and practice, often when top-down government and employer directives were deemed to be contrary to the principles of the profession I was committed to upholding (Davies, 2005). Despite its age, the overarching sentiment, that young people can critically contribute to creating their own social and political worlds rather than consuming what is being directed at them with their many ideological agendas, rings true today (De St. Croix, 2011; Davies, 2015). The case study below introduces a young man at a youth club, and his request to go ice-skating. Previously deemed to be somewhat problematic, this young man's request and the unfolding of the trip serves as an example of the focus on processes within social education in youth work, requiring a recognition and development of

knowledge, feelings, and skills through a critical look at the society in which we live and are part of creating:

Personal problems and experiences can only be fully understood and acted upon when they are seen as both private 'troubles' and public issues. This is the task for a critical social education and whilst the problems are formidable, the opportunity for action is always with us. The starting point can be as close as a member's request for you to organise a trip and the readiness on your part to encourage and help them to do the thing for themselves. Neil's request may not have seemed very special, but the fact that he ended up a creator rather than a mere consumer is not without personal and political significance. (1982: 56)

Smith utilises this case study about young people in a youth club (informal education setting) organising a trip to go ice skating. Instigated by one young man Neil, who was known to be a "right bastard" (1982:8) and yet organised a youth club trip. In 1994 bell hooks' *Teaching to Transgress: Education as the Practice of Freedom* was published, and lent a further impetus and celebration of experiential knowledge in the context of more formal learning contexts. Hooks says "if someone else brings a combination of facts and experience, then I humble myself and respectfully learn from those who bring this gift" (1994: 89). Indeed she attests that experiential learning enhances the classroom experience by stating:

If experience is already invoked in the classroom as a way of knowing that coexists in a nonhierarchical way with other ways of knowing, then it lessens the possibility that it can be used to silence. (1994: 84)

The scholarship of hooks and Smith reminds us that young people create their own - collective and individual - versions of what they know. For example, young people engage in knowledge practices online and their accounts of their

experiences help them make sense of what's around them and what they are being offered. Crucially, the role of the youth and community worker and educator can enable opportunities for critical thinking and for creating (different) knowledge.

More directly, within scholarship on youth sexualities there are many critiques of children and young people's access to/levels of (rather than creation of) knowledge regarding sexualities and sexual health (Corteen and Scraton, 1997; Davies and Robinson, 2010; Renold, 2005). There are also many examples of young people's experiences of sexualities and sexual health being researched (Ingham, 2005; Wellings, Nanchahal, Macdowall, McManus, Erens, Mercer, Johnson, Copas, Korovessis, Fenton and Field, 2001; Maxwell and Aggleton, 2011; Holland et al., 2004; Holland and Thomson, 2010). My experiences are that when young women make claims to sexual health professionals regarding their own knowledge or expertise regarding their bodies and their sexualities, they are often confronted with disparaging responses from the sexual health nurses and doctors (Hanbury and Eastham, 2015; Carabine, 2007; Jutte, 2008; Cook 2005; McDaid and Hilton 2014).

Within contemporary society there are many examples of young women creating their own knowledge through zines, online blogs and vlogs, fan fiction (Wailoo et al., 2010; Conis, 2015; www.notjustskin.org/sites/notjustskin.org/files/HPV%20FINAL%20single%20page.pdf accessed 15th July 2014; www.laurie-penny.com accessed 2nd June 2016 and www.girlonthenet.com accessed 2nd June 2016) and indeed through participatory oriented research such as this. I argue that these are examples that show how some young women engage in subversive and transgressive practices that I refer to as everyday activism. Borrowing from the now popular Everyday Sexism project (www.everydaysexism.com accessed 10th May 2015), I use the term 'everyday activism' to describe activities that are sometimes mundane, habitual or indeed so momentary that they may often be overlooked. It is about

recognising or introducing small but impactful behaviours into our everyday lives. Examples of more formalised notions of everyday activism specific to young women's sexualities include the Feminist Webs project; the Young Women's Health project in Manchester, which creates a range of information booklets on various topics including a lesbian and bisexual young women's guide to sex and relationships (www.likt.org.uk accessed 11th June 2014), the Good Sex Project (McGeeney, 2013) and Brook's Sex:Positive campaign (www.brook.org.uk/old/index.php/sex-positive-home accessed 22nd May 2015) that I was involved in creating and contributing to as part of my employment with the charity.

Everyday activism can also be seen in the examples provided in Chapter Two where the young women who were involved in the project constructed new knowledge and shared stories between each other. Beth, who I introduced in Chapter Two, became an everyday activist by declining the vaccine and being known for being 'different' and 'difficult'. Having the information provided to her that was contrary to the knowledge practices that she and Suzanne engaged in resulted in the decision to critique and decline the vaccine. Having access to the HPV vaccination programme and contributing new and different knowledge surrounding it potentially leads to Beth engaging in 'difficult citizenship' (Robinson, 2012). I suggest an extension of the meaning of the term and imbuing it with an unapologetically political slant; one that is positive and generative of different ways of practicing as a sexual and 'difficult' citizen. Thus being a 'difficult citizen' is potentially productive of alternative and embodied ways of knowing and engaging with the HPV vaccination programme.

My role as a professional youth and community worker in a sexual health service was challenged when the HPV vaccination was introduced. I was expected to agree with and promote the vaccination to young women. Through reflecting on the scholarship I have presented here I am reminded of the role of enabling young people to explore, understand and create their own knowledge.

And furthermore, as a feminist youth and community worker it reminds me to remain curious and reflexive about the role I play in the lives of young women, and to value their knowledge.

Young women's knowledge practices in the school nursing team

Knowledge that is born out of embodied experiences is sometimes valued and privileged over official knowledge. This was demonstrated specifically by the school nursing team at Wendy Chicken Shop school. I carried out a paired research conversation with Olwen (school nurse) and Dilys (school nurse support worker) and asked them about the impact on their work when the HPV vaccination programme was introduced in 2008. Dilys and Olwen remembered media reports (noted in the opening excerpt to this chapter) of a high profile case of a young woman in the West Midlands who had died following a HPV vaccination:

I think initially when we started the HPV [vaccination programme] it's like any new vaccine isn't it? Because we didn't have enough information ourselves to reassure parents, it's only what you've been told. Because obviously it's not been trialled here has it, so it's not our evidence is it? So you have parents asking and questioning and so that was the hard bit I think. And then when you have incidents like that happening, so consequently you then had parents who'd given consent, they were withdrawing consent by telephone, and I think we opted in the end to just cancel the [vaccination administration] session because it wasn't worth [it]. Because it had happened the night before, things were in the press and it was difficult. (April, 2014)

Here Olwen makes the distinction between the clinical trial of the vaccine and the local experiential trial of the vaccine in practice by saying 'it's not been trialled here has it, so it's not our evidence is it?' Referring to my early unease detailed in

the Introduction, I asked; what knowledge do various practitioners rely upon when administering and promoting the HPV vaccination? This example shows that despite the media reports not being 'their own' evidence it was viewed as significant enough for parents to withdraw their previously given consent, and as such the vaccination administration session was cancelled. Here, the specific localised practice that occurred was not to 'trust blindly' in the intervention but instead to go against the dominant knowledge of the vaccine being safe and to cancel the session. This demonstrates the tension and difficulties that arise when the HPV vaccination programme, with its many versions of knowledge, is administered in practice. It also provides an example of how the administration of the HPV vaccination can happen differently so to protect more young people from various risks. Olwen goes on to say that once a vaccine has been in use for a little while the nursing team gather their own evidence on what is normal and what to expect following vaccination:

Olwen: For us I think it was a case of 'suck and see' and it was using your knowledge then to [the] next [vaccine administration] sessions about what you'd seen, what had come back to you from pupils saying [...]

Dilys: And uptake was quite poor wasn't it?

Olwen: Initially, initially, so it was using what had been shared by pupils saying, 'I've got a headache, I feel', you know the majority like I say, headache, bit of nausea, dizziness. You can account for numerous things can't you, anxiety, working themselves up. So I think that the complaints that they were telling us were similar. There was a pattern. So I think as we became confident in doing subsequent sessions, you didn't sort of pre-empt the girls and say you might have this, that and the other. If they were coming back and saying 'I feel a bit sick' or 'I've got a tummy ache', you know I think we were then confident in saying, 'that's fine, that's normal, we've had a handful before'. So you just got used to [it]. (April, 2014)

Olwen relies upon the young women's reports of their embodied experiences by stating that they took the approach of 'using what had been shared by pupils' to know what the common affects are that they experienced. They are able to use this knowledge for subsequent vaccination administration sessions and felt more confident in reassuring the young women as to what the nursing team acknowledge as normal and acceptable. These particular school nursing staff showed a preference for their 'own' evidence and trialling of the new vaccine above the official presentations and annual updates from DH that they receive as part of their staff development and training:

It was an update that we have each year; mandatory training. Obviously with any new vaccine, yes we have to sign our - what we call – PGD [Patient Group Directive] which tells us the inclusion or the exclusion criteria for the girls, so that's in fact your new information isn't it? It's to say who can be in the programme, who can't [...] So there was no specific training. (April, 2014)

Throughout this thesis I have shown that the dominant version of the HPV vaccination is that it is safe and efficacious. However, there appears to be an example of everyday activism in some of the knowledge practices of the nurses; Dilys and Olwen do not always trust the dominant presentation. Instead they appear to be in solidarity with the young women they are vaccinating and they do their own research as they collate and evaluate the embodied experiences of the young women and incorporate it in their practices. The nursing team at Wendy Chicken Shop school are integrating and making meaning from several sources e.g. media stories, parental withdrawal of consent and young women's embodied experiences, in order to carry out their daily work of vaccine administration. This process of consolidating different accounts of experiences has had a more significant impact on their practice and is collated with their mandatory training and PGD criteria alone which, as seen in the quote above, simply provided

inclusion or exclusion criteria rather than a more collective account of the effects young women felt post-vaccination.

For me, I argue that this reliance on, and co-option of, the young women's experiences as evidence is indicative of the ways in which people reflect on knowledge and it shapes their practices. The school nurses in their position and relationship to the HPV vaccination and its administration opted for more localised, direct and experiential knowledge. They consolidated the various sources into a coherent set of knowledge upon which to then base their professional practices. If they were scrutinised, they could defend their decision to cancel the vaccination administration session with specific evidence and concerns. Arguably they are also demonstrating momentary resistance or, in the terms of this chapter, everyday activism. However reassuring and heart-warming it was for these momentary instances to occur, the nurses do later vaccinate young women in the strict bureaucratic way in which they have done before. This tension is key to developing my argument that there are multiple ways that the HPV vaccination can be administered. This is just one example of the vaccination not going ahead for one day, but it highlights that things can be done differently. I return to this point in Chapter Five and the Conclusion when I make recommendations for practice.

Conclusion: young women's difficult citizenship as everyday activism

In this chapter I have argued that there are various ways that people engage in knowledge practices regarding the HPV vaccination programme. These are nuanced and specific to the positions they occupy in relation to the HPV vaccination and programme. Each of which can bring new insight and value to the ways in which the HPV vaccination programme can, or should, be administered. Some feminists and other health activists critique the HPV vaccine while demonstrating commitment to the vaccination programme as they campaign for young women to have access to Gardasil not Cervarix and for men

who have sex with men to be offered the vaccine.²⁶ However, by and large, these activist voices are advocates of the HPV vaccine as an additional measure which can help protect people against a common viral sexually transmitted infection which is thought to be associated with life-threatening, but rare cancers (Dubriwny, 2013).

I have presented the cases of a number of women who are involved in the HPV vaccination and its programme. These women administer it, are offered it for their daughters, receive it and some have experienced vaccine-injury. I co-construct different versions of HPV vaccinations and what they can do, to demonstrate that the knowledge that becomes visible varies in different contexts and is hence always limited and packaged in particular ways. As a result of such knowledge different decisions can be made about whether or not to accept or decline the HPV vaccination. And furthermore, what these decisions mean for the femininity and citizenship of the young women and their parents.

I also highlighted some spaces and people that are displaying everyday activism. Examples which highlight this include those from online bloggers in the USA and Dilys and Olwen's nursing practices in the UK. I have critiqued the privileging of certain knowledges that have been further highlighted as disassociated from the administration and experiential knowledge of those most directly affected by the HPV vaccination and programme. Knowledge of the HPV vaccine affects the way in which young women are viewed societally and sexually, particularly if they produce this knowledge from engagement with sex/sexualities that has otherwise been downplayed. Thus information, knowledge practices and decision-making are strongly associated with the dominant (largely biomedical) versions of femininity and of youth sexualities that readily circulate.

²⁶ Gardasil is a quadrivalent vaccine offering protection from four strains of the virus rather than Cervarix which is a bivalent vaccine offering protection against only two strains.

The knowledge that is available is largely controlled and policed by the triad institutions of the NHS/DH, education and pharmaceutical companies. Sexual citizenship, health citizenship and difficult citizenship inter-relate in this knowledge, and other practices of the HPV vaccination programme. Central to the argument I have presented in this chapter is that bodily experiences and meaning-making can be based on different information that is available, and furthermore, that alternative knowledge can be practiced and applied to everyday activism. I argue that the young women involved in this project are knowledge creators. Conis showed that (some) young women use online spaces where they are media savvy critics who demonstrate engagement and awareness of the power relations that are a part of and demonstrable in the advertising campaigns for the HPV vaccination. Critiquing the HPV vaccine can result in difficult citizenship, which is experienced by women who are practicing femininity in ways which are deemed non-normative and/or challenging.

I have shown that information, knowledge practices and decisions arise from multifaceted and collective endeavours within hierarchical structures. Highlighting the divergence between these is not an attempt to separate and dichotomise 'good' vs 'bad' knowledge or to promote experiential over analytical thought, as my engagement with hooks and Scott have both highlighted. Instead it is a political commitment I have to valuing the engagement, critiques and contributions to constructing knowledge by young women, parents and school nurses. In Chapter Five I consider how women's knowledge is responded to when they highlight the limitations and failings of medicine. I do this through using research materials of vaccine-injury from young women and their parents. Utilising the accounts and narratives of vaccine-injured young women allows me to consider the risks and outcomes that occur when young women practice difficult citizenship through going against the normative trajectory of what is expected when they accept the HPV vaccinations.

Chapter Five: Young women and the pharmaceutical burden of HPV vaccinations

Reporting adverse reaction to vaccination side-effects

Ali: Would the [Health Protection] Unit here investigate adverse reactions following a vaccine?

Iris: The way that works in the UK is through the yellow card system. So every new vaccine that comes in, or a new medicine or any product, gets what they call a black triangle on it, so because they've only recently been introduced they're what they call a 'black triangle product', so any reaction no matter what it is, no matter whether you think it might not be linked to it, has to be reported, and then that goes up to the Medicines and Healthcare Regulatory Authority which is called the MHRA. So that's a national system, that's on a website, and you can go in the website and look at side-effects from vaccines, or any new products. So they coordinate all that information and then they provide regular reports and there's a couple of reports on that website in relation to Cervarix [the first HPV vaccination used in the UK]. And the reasons being that whenever you undertake trials you do them on a limited number of people in the population, even though it may be a couple of thousand, it's not the same as rolling out the programme to millions, so you're gonna get rare reactions that won't be picked up in the trial, so they will come out subsequently. So all the school nurses who give the vaccines are able to report any reaction whatsoever, and you know so, we may get involved, most of it goes nationally up [on the system] coz there's one here, one there but we have had a few cases where somebody has had an allergic reaction or sometimes we get people who are fainting, and once one faints, they all faint don't they? And it's that age group isn't it? So we could be involved in talking with the school nurses giving advice, and I have done that or to the head teacher. But that vast majority, in terms of reactions, goes to the national system and they look at the incidence of the reactions and look at whether it's higher than what they'd expect

Iris, Health Protection Unit Manager, September, 2012

Building on from the materials and arguments presented in Chapter Four, here I draw attention to negative experiences of the HPV vaccination programme through presenting young women's experiences and accounts of vaccine-injury.²⁷ As the final chapter of this thesis, before the conclusion, these stories about the programme as a life-limiting - not life-saving - vaccination are explicated further in these stories of vaccine injury. I argue that truth claims and knowledge practices promote the HPV vaccination as a positive life-saving intervention, but this requires a series of specific compliant behaviours and identity practices carried out by young women and parents. Another version of the HPV vaccination is presented here. I primarily attend to research materials (focus group transcripts and home research conversation transcripts) with families about vaccine-injury to interrogate the effects of the HPV vaccination and programme on the lives of young women, and indeed their parents. I document truth claims of the devastating physical side-effects and in so doing argue that the programme constructs norms around, and subjectification to, appropriate femininity that create multiple risks. Through constructing a normative script of appropriate femininity both the young women and their mothers assume the role of responsible health seekers. What follows are the stories of their difficulties in engaging with the medical establishment following life-limiting side-effects. These case studies extend beyond my original research question of how young women engage with the HPV vaccination programme, and go further so to consider how they, and their parents, engage with various clinicians and health professionals as a result of their engagement with the programme, and subsequent side-effects, of the vaccination.

The way in which the programme is organised assumes that young women need the vaccination but that young men do not. The programme focuses on the long term health of the uterine cervix, a body part often thought of as being an integral part of being female. However, this focus on young women is, in some

²⁷ For vaccine-injury controversies in Columbia see Maldonado Castañeda, 2015 and in Canada see Rail, Molino, and Lippman, 2015 and Tomljenovic, and Shaw, 2012

ways, incongruous. The pharmaceutical drug used in the vaccination programme is effective against a viral STI that affects the genitals and other areas of the body linked to sexual activities e.g. mouth, anus and pharynx. Therefore being female is not essential to receiving the vaccines; young men could be recipients of the vaccine.

The vaccine has been granted approval for administration to both women and men. Indeed the drug is available in the United States of America and Australia to both women and men. However, the policy decision within the UK and many other countries, including Sweden and Columbia, is for a national vaccination programme to be offered to girls and young women only (see Lindén, 2016 and Maldonado Castañeda, 2015). Considering the pharmaceutical burden and social prescriptions of the HPV vaccinations and programme suggests that young women are made responsible for reducing the transmission, incidence and aetiology of the most common viral sexually transmitted infection (Human Papillomavirus) that affects all genders.

The HPV vaccination programme prescribes a particular version of gender, through appropriate femininity, onto the lives of young women. Prior to vaccinating, young women must accept unquestioningly the vaccination and view it as a positive health measure introduced into their lives. The expectations of a successful HPV vaccination programme assume that young women will be compliant with the demands of the programme and that their bodies will accept the pharmaceutical drug – Cervarix or Gardasil - in a way which is unproblematic. In this chapter I present accounts of young women, their families and their bodies rejecting the drug and responding in problematic ways.

The State, choice and the pharmaceutical burden

Public health vaccination programmes are presented as a state intervention to promote the health of its population by lowering or eradicating

communicable diseases (Sarraci, 2010). The HPV vaccination programme is free and participation is voluntary. It is offered to all young women within a certain age range. Thereby the UK government is presented, through the programme, as caring for its citizens; a state that invests its resources and finances into a national, free vaccination programme. However the supposed caring practices of the state are called into question through claims to vaccine-injury. The accounts of vaccine-injury provide a view of the programme as both limited and complex in its administrative practices, as well as being problematically paternalistic in its interventionist approach to young women's lives (Dubriwny, 2012).

Young women (via their parents) have a choice of whether to participate or not, even if this choice is, as I have suggested in the Introduction chapter, an illusion. This 'choice' distributes responsibility for having the vaccine, and by extension, for developing HPV and potentially cervical cancer, to the young women and her parents if they choose not to vaccinate. Hence the practices of the HPV vaccination programme significantly contribute towards placing the pharmaceutical burden onto young women. Despite the Human Papillomavirus being gender-neutral, in that it does not discriminate amongst genders, only young women receive the vaccine as a part of the programme meaning that they are the ones who will be burdened with the potentiality of side-effects and life-limiting ill-health as a result. There is an uptake target of 90% for the vaccine and it is administered through the compulsory schooling setting in order to enroll the majority of young women.

Accepting the HPV vaccination is a way of being recognised as, and recognising oneself as, a rational, informed, healthy woman. When a young woman/her parents do not accept the vaccine she is termed a 'refuser' and is often understood as being uninformed, irrational or 'alternative'. I assert that an extension of these unreasonable and ignorant behaviours includes insisting there are side-effects and the implied challenge to the efficacy of the vaccine and authority of biomedical knowledge.

Young women and their parents described frightening and devastating physical, social and emotional consequences of having the vaccination. They also described feeling ostracised, shame and guilt when they presented with vaccine side-effects to medical professionals. They describe the difficult and demanding fight for diagnosis, treatment and recognition in a collection of knowledge practices I set out below.

Morag, the secretary of Sane Vax, collates information and puts parents and young women in contact with one another in order to create and share collective knowledge and information which may help with diagnoses and treatment. This is done mainly via email and Facebook, after which some parents talk over the telephone or via video calling such as Skype. The cases which follow are summaries of the accounts shared with me during my research. Dates and timescales are not always clear, as some people prioritised the telling of the symptoms and traumas experienced rather than a chronological account. Where possible I have reflected the focus and priority of the people speaking rather than trying to fit these cases into a formulaic order. Presenting these accounts as truth claims affords the narratives the same weight as the other versions presented thus far.

Julie and Marilyn: ill-informed consent and implications for decision-making

Julie was my main contact for the focus group we arranged in the South East of England in February 2013. There were seven adults who attended, representing five vaccine-injured young women (not all of whom are presented here). Following this focus group, I left the church hall where it was carried out, exchanged thanks, expressed my gratitude and walked towards the train station. Before crossing the street I began to cry at the enormity of the stories that had been shared with me. The pain, the dismay and the utter dejection felt by these families led me to experience a four-day episode of “vicarious trauma” (McNamara, 2009), which McNamara cautions is an “occupational hazard” of the

feminist ethnographer who “mines” sensitive issues (2009: 174) with their work. Such traumatic experiences were not part of what I expected to hear. The accounts that follow provide an insight into the experiences that were shared with me.

Julie told her story about the onset of her daughter Marilyn’s symptoms following the vaccination. This incident happened some time prior to the focus group, but after Marilyn had the HPV vaccination. Within this quote Julie tells us of an incident that it reminded her of from Marilyn’s childhood too. Julie said:

Her eyes were twitching, her legs were giving out. Her eyes were twitching, she couldn’t sleep, dizziness. You’ve heard it all before. I even rushed her down to A+E once because she couldn’t feel her leg. She cries out ‘I can’t feel it, I can’t feel it’ and that was how Guillain-Barré’s started when she was three years old, it started in the legs. And back then the doctor’s thought, ‘cause I called the doctor out on it, he tried to make her stand up and she collapsed. She was only three years old. I heard him on the phone: ‘I think this child’s legs are broken.’ And he had her rushed down the hospital. And we found out she had Guillain-Barré syndrome. So when she was doing that on Saturday night I panicked. Sunday morning I got up and brought her down to A+E [...] I mean we wonder if giving her vaccines gave her Guillain-Barré? (February, 2013)

On the Saturday in question, when they attended A+E, Julie’s daughter Marilyn was experiencing an episode of extreme leg pain. This reminded Julie of Marilyn’s childhood diagnosis of Guillain-Barré syndrome some years earlier.²⁸ Once at Accident and Emergency (A+E) the doctors wanted to take blood for testing. Marilyn began to cry and Julie explained that she has Asperger’s

²⁸ Guillain-Barré syndrome is a rare and serious condition of the peripheral nervous system. It occurs when the body's immune system attacks part of the nervous system (<http://www.nhs.uk/conditions/Guillain-Barre-syndrome/Pages/Introduction.aspx>).

syndrome which means she suffers from some anxiety and is scared of needles. Julie explained that the doctor then attributed Marilyn's tingling, twitching and achy limbs to her anxiety as a manifestation of her Asperger's syndrome, despite Julie disagreeing with the doctor about this. Julie said that Marilyn and herself left the hospital in tears, they felt let down by the doctor not attributing Marilyn's Asperger's Syndrome to her current ill-health. At the time of the focus group Marilyn and Julie were still awaiting further tests but were also cautious that Marilyn's diagnosis would concentrate on her Asperger's syndrome as the root cause of her anxiety and bodily symptoms.

Following self-directed research into symptoms and possible vaccination side-effects Julie felt annoyed with herself that she had not looked more deeply into the new HPV vaccine. She told the focus group:

I could kick myself cos I never let my kids have the MMR [vaccine] because of all the controversy over it. Because this [HPV vaccine] was quite new, obviously I hadn't heard of any of this [vaccine injury]. If I'd have done my research there's no way she would have had it because I wouldn't give my children the MMR [vaccine]. (February, 2013)

Julie reflected further upon the information and consent practices that play out during the vaccination programme's administration:

We got one letter [Appendix 4] [...] it didn't really explain much at all. You signed the consent form and [after the first injection] Marilyn was given, she didn't bring it home unfortunately, but she would have been given a leaflet out of the box [Patient Information Leaflet] after the vaccine about all the side-effects [...] You can't give a child an injection and then give the information afterwards. (February, 2013)

Julie reported a full list of Marilyn's symptoms using the yellow card system described in the opening quote to this chapter from Iris, stating her belief that they are side-effects from the HPV vaccination. The reply she received stated that the Patient Information Leaflet (PIL) recognised and listed that the side-effects experienced by Marilyn were a possibility. Julie was clear that had she seen the PIL prior to giving consent, she would not have allowed Marilyn to have the HPV vaccination because Guillain-Barré syndrome was listed and Marilyn had experienced this as a child. How to incorporate a list of possible side-effects in decision-making is itself an important issue. However, more important for Julie is a concern that the information regarding side-effects should be given prior to the decision being made about whether or not to accept the vaccination. Julie feels that she had not provided informed consent, rather it was ill-informed consent that was given. In the PIL it states that you should inform your doctor if you/your child has a weakened immune system *prior* to vaccinating. Yet the PIL was not received prior to giving consent for vaccinating, hence my use of the term ill-informed consent. Many parents have subsequently informed clinicians about the contraindicators listed within the PIL, yet many clinicians have nonetheless given responses that doubt the vaccine's causal role. The PIL states under Section 4. Possible Side Effects:

As with other vaccines, side effects that have been reported during general use include: swollen glands (neck, armpit, or groin), Guillain-Barré Syndrome (muscle weakness, abnormal sensations, tingling in the arms, legs and upper body), dizziness, vomiting, joint pain, aching muscles, unusual tiredness or weakness, chills, generally feeling unwell, bleeding or bruising more easily than normal, and skin infection. (Sanofi Pasteur MSD, 2011)

Julie said that she would not have consented for Marilyn to receive the vaccines had she seen this leaflet prior to making the decision on whether to vaccinate. It is such issues that highlight the fallacy of informed consent and form the starting

point for some basic recommendations for change and improvements in the administration practices of the HPV vaccinations that will be included in the Conclusion chapter.

Vicky and Pollyanna: stigma of mental health and erasure of illness as vaccine side-effects

One of the over-arching themes in the young women's and parent's accounts of their experiences of seeking medical advice for symptoms is that professionals have reportedly offered psychological diagnoses to explain the symptoms. During the focus group in South East England Vicky waited patiently for her turn to speak. She would interject when the other parents spoke of their daughters' symptoms and experiences, often nodding and providing verbal cues that indicated the similarities with Pollyanna's case. Vicky brought with her a folder crammed with letters, health records and photographs of Pollyanna's bodily symptoms. Pollyanna was 12 when she had the HPV vaccinations, Cervarix, starting in December 2009. Following her first vaccine, Pollyanna felt achy and had flu-like symptoms. Following her second vaccine in January 2010 Pollyanna was feeling increasingly worse with general fatigue and ill-health which carried on for some weeks. In April, she returned from school with skin welts as described by Vicky:

It looked like an insect bite quite honestly, it was red around the outside, white in the middle and it looked like lots of little bumps inside. It was like a, I don't know, some kind of bite or something, and we watched it turn into tiny tiny tiny little blisters and then you watched it, it was like watching mercury. We watched the tiny blisters all sort of join up and make one huge big blister, then it popped and all this yellow liquid sort of came out, and then it just started ulcerating and then within a couple of hours she had another one on her other arm, so I took her to A+E cos the doctor was shut at that point. I said 'look, I don't really know what this is', I said but,

and it smelt really bad, it smelt like sort of rotting chicken really, it just didn't smell very nice at all. (February, 2013)

Pollyanna was diagnosed with impetigo and told to remain off school as it is a highly contagious bacterial infection. During this absence Pollyanna missed the third HPV vaccination but Vicky had told her daughter that she didn't want her to have it as:

My mum had sort of said to me, 'do you think it could be anything to do with the vaccination?' and I went 'ooh I don't know, maybe I'll have to have a look into it'. (February, 2013)

When the welts continued to develop, further diagnostic tests ruled out any bacterial cause and thus it could not have been impetigo. Following months of ill-health and various doctor appointments, in November 2010 Pollyanna rang Vicky:

[...] in tears and said that they'd forced her to have it [third vaccine] even though she'd said 'mummy had said' she wasn't allowed to have it. And they said, 'it's too late because, you know, your mum's signed the consent form', so I'd signed the consent form [previously] so she had it done. And then it just got worse and worse and worse. (February, 2013)

As quoted in Chapter Four, Vicky also challenged a dermatologist who diagnosed that Pollyanna's symptoms were the result of self-harm and suggested that Pollyanna be referred to the Child and Adolescent Mental Health Service (CAMHS).²⁹ Vicky rejected this diagnosis of self-harm and was unhappy with this suggestion, stating too, that Pollyanna denied that she was self-harming:

²⁹ A specialist team of mental health services that focus on the needs of children and young people. They are multidisciplinary teams that often consist of: psychiatrists, psychologists, social workers, nurses, support workers, occupational therapists, psychological therapists, primary

Pollyanna wouldn't [harm herself]. She's a wimp, she's a wimp when it comes to pain, you know, and she gets a paper-cut and she thinks she needs stitches and reconstructive surgery, she's awful. (February, 2013)

Based upon these disappointing experiences, Vicky asserts the authority of her own knowledge of her daughter in rejecting the medical diagnosis and dominant version of the vaccine's effects. Vicky sees her knowledge of Pollyanna as being superior to that of the dermatologist who has assessed her symptoms once. She also explained during the focus group that she no longer trusts the doctor. According to Vicky both the 'diagnosis' of self-harm and the refusal of a CAMHS referral were noted on Pollyanna's medical records and she feared that this would influence further assessments i.e. there would be a stigma attached to mental health diagnosis and the parental refusal of a referral to CAMHS. Despite this fear, one subsequent medical appointment suggested an auto-immune disorder, rather than self-harm, as the cause of Pollyanna's symptoms. Yet, the fear of stigma and potential erasure is a powerful one which still affects the cautionary ways of many of these parents in their dealings with medical professionals.

Vicky said that tests, diagnoses and assertions by various health professionals differ and create the illnesses and symptoms as difficult to understand and to fit into a neat category for intervention or cure. Despite receiving numerous and contradictory diagnoses Vicky remains concerned that the suggestion of self-harm will have a lasting impact on how Pollyanna's health is viewed by any new health professionals. She told us:

mental health link workers, specialist substance misuse workers
(<http://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/about-childrens-mental-health-services.aspx> accessed 13th June 2016).

It's [self-harm] there on her records, everywhere and every letter of referral, it's you know, it's wedged in there somewhere, you know, I'm deluded, I'm a trouble maker, I'm deluded because my daughter is effectively pulling the wool over my eyes. (February, 2013)

Vicky feels that the psychiatric assessment and the refusal of the CAMHS assessment will negatively affect the way in which she is viewed by medical professionals and it will also impact on how her daughter is treated. The risks involved in the process of gaining recognition of and support for Pollyanna's symptoms are multiple. Vicky is at risk of being seen as ignorant about her daughter's mental health. She is also at risk of being seen as a resistant to medical knowledge. Furthermore she is at risk of being seen as difficult through her challenge to the medical establishment through her advocacy and campaigning regarding vaccine side-effects. As a result of learning about Pollyanna's suggested referral for mental health assessment and then Vicky's account of the consequences of resisting this referral, several parents are now being more strategic in their interactions with health professionals, cautious about the stigma and erasure that a psychiatric diagnosis could bring and suspicions about their parenting practices that they may be risking.

Mark and Stephanie: the fear and frustration of medical disbelief of side-effects

Mark and his wife first heard about the vaccine through school, after which they asked a good friend of theirs who is a nurse about her thoughts on it. She stated that she couldn't see any problems with it as it was not a live vaccine, which are thought to be less concerning, as live vaccines may actually cause the disease trying to be prevented in immune-suppressed people. Here Stephanie's parents were drawing on a personal connection with someone deemed to have expert knowledge. Unlike the material regarding Dilys and Olwen's assertions of collating their own evidence (in Chapter Four), their nurse-friend ostensibly reassured them to accept the new HPV vaccination, after which they signed the

consent form and Stephanie received her first vaccine in 2008. Mark spoke as part of the focus group in South East England also and told us that Stephanie's side-effects started within one week of her first vaccine, with pain in her hands which soon began "shooting" around her body. Mark described taking Stephanie to the GP who asked:

'Is there anything different that she's been having?' We said, 'the only thing is the vaccination' to which the GP reportedly replied 'oh the vaccination's safe, it's not that, and subsequently Stephanie received both her second and third HPV vaccine. (February, 2013)

Mark reported that Stephanie's pains became progressively worse following each vaccine and the joints in her knees and hips became extremely painful, so much so that she needed crutches to aid her walking and was receiving physiotherapy. Mark told me how he and his wife Kim (not present at the focus group) had continued to highlight the potential relevance of the vaccine when asked by doctors, but received reassurances of its safety. During an appointment with a rheumatologist Mark stated:

He just took one look [at Stephanie], he said 'what's she been doing?' [I replied] 'Vaccination', 'What Cervarix?', 'Yeah' and he went 'Why on earth did you let her have the third injection?' [and I said] 'Because everyone said the vaccination is safe'. (February, 2013)

Of gravest concern to many of the parents with vaccine-injured daughters is the fear of, what they see as, unnecessary psychiatric intervention. Despite this rheumatologist's insight into the possible side-effects of the HPV vaccination, Mark told me how the family spent months being referred to different clinicians to try to treat Stephanie. He claims that misdiagnosis and mistreatment has exacerbated her symptoms and because none of them improved or cured her it resulted in the medical professionals suspecting the parents.

Following the action of Stephanie's parents to try to receive a diagnosis, treatment and recognition of causality, Stephanie was sectioned to a psychiatric unit and subsequently spent almost two years at this facility diagnosed with pervasive or persistent refusal syndrome.³⁰ Mark told me during the focus group that Stephanie had used crutches and a wheelchair at times but, despite high doses of pain killers, still experiences excruciating pain which means she does not like her legs and joints being touched and refuses palpation during clinical consultations. Mark stated that he believes this led to him and his wife being suspected of physical abuse and Stephanie's brother questioned about potential familial abuse.

Mark believes that Stephanie received incorrect medical advice throughout the duration of her interactions with various medical professionals. Such advice was to "push and push" so that Stephanie remained active. Mark now believes this advice to have had a detrimental impact upon his daughter's health. Following five years of ongoing ill-health Mark states that Stephanie also believes that she has been treated unkindly and unfairly by many physicians. After tens of times repeating her story to numerous medical professionals and cataloguing her symptoms, Mark told me that:

She got fed up of telling the same people the same things over and over and over again. She said, 'I'm not talking to you any more, you don't listen to me, why on earth should I talk to you?' (February, 2013)

This, along with a lack of improvement that was expected following the prescription of strong medication led to Stephanie's diagnosis of, and institutionalisation for, pervasive or persistent refusal syndrome.

³⁰ A rare psychiatric disorder characterised by refusal to eat, drink or engage in self-care and a resistance to treatment first documented in 1991. Since 2011 it no longer appears in the psychiatric diagnostic manual.

Jackie and Milly: Jackie's investment in her daughter's ill-health

At their home, around the kitchen table, with plates of sandwiches, salad, cakes and coffee, and with a grumpy old Labrador growling gently at the stranger at their table, Milly and Jackie shared their stories. Here Jackie talks about Milly's symptoms in relation to other young women whose parents she has had contact with or knowledge of:

Jackie: And they were very similar, seemed similar people, similar types of people, and I spoke to her [Karen] a few times when Milly was first starting to be diagnosed, and her daughter's [Rosie] gone through exactly the same pattern as Milly. She goes to an ME clinic and the rest of it, but she's two years ahead of Milly and I can remember having a conversation with her mum and her mum said, 'oh and Rosie suffers with this and her joints' and I was going 'oh yes, Milly has problems with her joints' and so on. She says, 'does Milly have problems with her ribs? It drives her mad, her ribs just hurt'. I went 'oh no, she's never complained of that', and I made a point of not telling Milly because I thought, I don't want to plant information in her head, so all these things I kept to myself. And then lo and behold the week after, 'oh my ribs'. And this happens so often where...

Milly: lump in my throat...

Jackie: Yes, Karen would say, 'oh Rosie has problems with her lymph glands and things', you know I'd think, 'oh no Milly hasn't, we're not suffering with that'. And then lo and behold she'd have this big lymph, oh it was under your arm wasn't it, big lymph.

Milly: And I couldn't lift my arm up. (February, 2013)

Many parents play a significant part of their daughters' experiences of ill-health. They provide care, they advocate for their healthcare and treatment, undertake time-consuming research and they may also be involved in campaigning and increasing the visibility of the side-effects of the vaccine through media stories. Many parents spoke about having a responsibility not only to their own daughters but also to the wider community of vaccine-injured young women.

During the interview I asked Milly how many doctors she had been to during the past two years and what their responses had been. She told me that she'd been to "countless. I've been like a pin cushion the amount of blood tests and things I've had" and that from those responses they have been "75% bad". An example of a 'bad' clinical response was following the sabbatical of her paediatrician. She was then referred to another one, Dr Jones:

Jackie: And we transferred to Dr Jones, the other paediatrician, who won't talk about the vaccine, he doesn't want to know.

Milly: He won't entertain it.

Jackie: He doesn't want to know about it, he refuses to...

Milly: He thinks you're just grasping at straws. (February, 2013)

This assessment of Dr Jones was made following an appointment that Milly and Jackie attended where Jackie was excluded from the consultation. They recounted the story in tandem during our research conversation. They told me that Dr Jones made Jackie sit at the back of the consultation room and he sat with his back towards her whilst he asked Milly to tell him about her symptoms. When Jackie attempted to move her chair closer to her daughter, initially

surmising that the chair had been placed at the back of the room as it was seldom needed, Dr Jones reportedly said:

Milly: 'No, no, that's your seat over there Mrs R, I want Milly to sit here' and then like, I wouldn't know what to say or I'd forget because my memory's so bad and I look at my mum at the other side of the room and he'll go, 'no, no, look at me, I want you to tell me, not your mum'.

Jackie: Yes he completely cut me out. Milly thought it was hilarious.
[BOTH LAUGHING]

Milly: [You were] trying to butt in and he's going 'no, no no'.

Jackie: He really put me in my place. (February, 2013)

Throughout the process of accessing medical advice Jackie and Milly have felt excluded and not taken seriously. Despite laughing, they are visibly upset and demonstrate frustration with the lack of recognition they, and their version of truth about the vaccine, have experienced. Milly feels that she needs Jackie's support during her interactions with medical professionals, in part due to her symptoms of 'brain fog' and memory loss. However, Jackie's support was deemed by this paediatrician to be an unwanted interference. However, it is important to consider what could have been motivating Dr Jones to act in such a way to exclude Jackie from the consultation with her daughter. Milly and Jackie have their own theory as to why this is:

Milly: I think he thinks that you're an over anxious mother.

Jackie: Yes, from a lot of the parents that I've spoken to, not just the vaccine related ones but the ME; girls with ME that's unrelated to the vaccine. If you push and question doctors too much, you get labelled with

either being over anxious or in the extreme case Munchausen's by proxy.^{31 32} (February, 2013)

Being labelled and suspected of harming your child (as in the risk of being assessed for Fabricated or Induced Illness (FII) or Munchausen's by proxy) is an experience a number of parents described. This experience, of attributing blame, promoted feelings of shame and also fear for many parents. It goes beyond the rudeness of the paediatrician placing the parent's chair at the back of the room because it is a dismissal of the side-effects and a refusal to acknowledge or accept that the HPV vaccine has harmed the young women.

Andrew, Linda and Gemma: moderating self-identity after vaccine-injury

In April 2013 Andrew and Linda invited me to their home to interview them about their daughter's vaccine-injury. They had originally decided against the HPV vaccination for Gemma as she had suffered side-effects following the MMR vaccination as a small child. However, according to Andrew "the school nurse convinced mum [Linda] that this vaccine wasn't like MMR that it was quite safe and persuaded mum to sign the consent form". Gemma received the vaccines between October 2010 and May 2011 and when Andrew and Linda looked back at her medical records they saw that her symptoms had started in December 2010 but they had attributed them to flu. They now believe this was the onset of her vaccine-related illnesses. What followed was months of ill-health, uncertain diagnoses and inconclusive tests:

³¹ Myalgic Encephalopathy; it can involve severe fatigue, painful muscles and joints, sleep disturbance, gastric problems, poor memory and poor concentration. This acronym is often used interchangeably with CFS or Chronic Fatigue Syndrome.

³² Fabricated or induced illness (FII) is a rare form of child abuse. It occurs when someone who is caring for a child, usually the child's biological mother, fakes or deliberately causes symptoms of illness in the child. FII is also known as Munchausen syndrome by proxy (www.nhs.uk).

[Gemma had] extreme exhaustion, feeling very cold, tired, abdominal pains, severe headaches. The GP thought that Gemma had glandular fever but all tests were negative, did lots of tests. She was admitted to hospital and attended hospital on several occasions. Gemma had a huge number of blood tests, scans, x-rays etcetera, but all tests were negative. On August 10th, Gemma collapsed and was unable to walk without support. She was admitted to hospital again with suspect[ed] brain tumour. (April, 2013)

According to Andrew, following brain scans, a brain tumour was ruled out and the consultant they saw first agreed “in writing to the GP that ‘it is quite likely it’ll turn out to be the HPV vaccine’”. Despite this, subsequent consultants at further hospital visits disagreed when Linda proposed the vaccine as a possible causal factor. During July and August 2011 Gemma was sleeping for between 20 and 23 hours per day. Gemma missed school for the entirety of academic year 9 (third year of high school, age 13-14 years old) as:

[In] September Gemma couldn’t open her eyes and lost her voice and for the next 13 weeks slept constantly. She stirred to press a bell for medication for the constant pain, we spoon fed her liquidised food but she was never fully conscious. (April, 2013)

Andrew and Linda became aware that they had been investigated for FII or Munchausen’s by proxy after an unsuccessful claim was made to the Government’s Vaccine Damage Payment Unit. Following this outcome they requested the information upon which the decision was based, and the private provider (ATOS Healthcare) carrying out the assessment on behalf of the Government’s Department for Work and Pensions (DWP) released the medical records to the family which included details of the investigation. Linda felt clear that the reason for her and Andrew being investigated in this way was as a result of the healthcare professionals’ refusal to accept a more negative view of the

HPV vaccine and that the HPV vaccine has caused Gemma's ill-health. Here Linda focuses on the role of supporting the claims or suspicions of the medical professionals:

Once somebody mentions FII or Munchausen's by proxy, it takes a whole different new route. But that should never have gone on for as long as it did, never ever, because, you know, where's their evidence? They haven't got any, the only evidence they have is, they don't want to believe it's the vaccine, so if it's not the vaccine, what else could it be? And they don't have an answer, so the obvious answer is to point the finger at the parents. (April, 2013)

Towards the end of the research conversation with Andrew and Linda, Gemma came into the room. I had noticed her in the adjoining room sat sleepily wrapped in a blanket, with a small dog nestled into her. Gemma was visibly very tired and her body seemed frail and sickly. I had been shown a photograph of Gemma taken a few months prior to her receiving the vaccines and becoming ill, and I noticed how much lighter and sligher her body was meeting her in person. Her voice was low and she spoke slowly and without many specific details or much clarity, which was in contrast to the detail I received from her healthy and well parents. I saw this as a manifestation of her fatigue and ill-health. Gemma told me that she doesn't remember the three months when she was sleeping for most of the days. Linda recalled how Gemma was surprised to wake up in mid-December to see the Christmas tree had been put up and decorated. Since starting to wake more, Gemma now receives Skype consultations from a homeopath. I asked her what she thinks of the vaccine, to which she replied:

I don't even think of vaccines as being harmful, it's just it wasn't right for me and I don't have any problem with medication, but if I can get it through [the homeopath] it doesn't have any side-effects, I'd rather go that route. (April, 2013)

Gemma is invested in a story of moderated self-identity. She still has faith in vaccinations, accepting and trusting the dominant version of HPV vaccine knowledge, but is aware of the harmful effects they have had on her and other young women. These families are challenging the medical professionals and pharmaceutical companies as a result of side-effects, they are not anti-vaccination campaigners who have prior anti-vaccinationist sentiments, and hold no opposition to vaccines and other prescribed drugs. This position adds to their disbelief and the incredulity they feel when they seek recognition of vaccine injury. They have previously had faith in and have invested in medicine and they are now disappointed that the system they believed in is failing them.

Meaning-making through narrating one's own and others' illness

Diagnosing is something that these parents felt the clinicians prioritise. According to many of the parents, once the clinicians provide a diagnosis they don't then look into other avenues or take any other things into account. For example, Mark said "they fit you into a box and once you've got in that box, you're there and that is it". The parents were frustrated by what they see as the main aim of the clinician as being to make a diagnosis, and once this has been achieved the clinician (and other health professionals) find it difficult to look or act beyond that diagnosis despite changing symptoms or conflicting evidence. Through sharing their stories with me, by engaging with the media and lobbying local MPs etc., these families are engaged in meaning making through what Pia Bülow describes as "narrating one's illness" (2008:131). Bülow carried out research with individuals suffering ill-health regarding their communication with health care representatives. She uses audio-recordings of conversations between sufferers of Chronic Fatigue Syndrome (CFS) as part of a 'patient school' in a hospital in Sweden, where Bülow was an ethnographic observer. Using narrative analysis of story-telling and co-production she highlights that narrating contested illnesses is often a collectivised endeavour whereby:

The active sharing of experience bestows a mutual confirmation of suffering irrespective of whether the individual's experiences correspond or deviate from the common picture. Two parallel transitions seemed to occur: the transformation of personal experience into shared collectivised experiences and the transition when the individual sufferer perceives his/her private suffering through sharing experiences with co-sufferers. (2004: 33)

These vaccine-injured young women and their parents are narrating their illnesses as a necessary characteristic of striving for diagnoses; they are becoming embodied health experts creating their own knowledge, which is a version that runs contrary to the life-saving potential so readily promoted. Many of the young women have suspected contested illnesses such as Chronic Fatigue Syndrome (CFS) where their symptoms are “invisible [and] impossible to confirm by traditional medical procedures” (Bülow, 2008: 131). I argue that it is not only the symptoms and narratives of illness which are invisible and impossible to confirm, but so too is the cause of the illness, whether it be the HPV vaccine or otherwise.

Whilst Bülow's work is useful and similar to the cases of vaccine-injury there are also some significant differences. The contestation of Bülow's cases is with their illness; i.e. CFS/ME. However, the contestation of the vaccine-injury cases is the very existence of illness and the 'fact' that they are side-effects of a prescribed pharmaceutical drug. Furthermore, Bülow's cases are of the patients themselves who have embodied experiences of contested illnesses. Yet, the vaccine-injury cases are shared versions of experience through narration rather than direct embodiment. These accounts of vaccine-injury are co-constructed collaborative accounts between the young women and their parents.

Vaccine critical groups and the practices of (indirect) embodied health experts

Much research exists in relation to health activism, patients groups and anti-vaccination movements. Such work critiques the limited involvement of the people various health interventions affect, the political influences in supposed value-neutral developments and the benefits that can arise as a result of user involvement from patients (Battles, 2008; Rabeharisoa, Moreira, and Akrich, 2013; Epstein, 1995; Allsop, Jones, and Baggott, 2004; Bell, 2009). Following Hobson-West's (2003; 2007) empirical research about organised resistance to the combined (MMR) vaccine introduced in Chapter Four, I use her term 'vaccine critical group' as it is useful in describing Sane Vax's work. During the period of the combined MMR vaccine controversy she classified them as either Reformist or Radical groups as follows:

The Reformist groups are led by parents who have personal experience with children believed to have been seriously injured following a recommended vaccine. Not surprisingly, these groups have a keen interest in issues around compensation and treatment, and campaign for better recognition of the dangers of vaccination. They are more likely to be supportive of vaccination in general: This is one reason why the phrase 'Vaccine Critical groups' is preferable to 'anti-vaccination movement'. In contrast to the Reformists, the Radical groups do not necessarily have personal experience of vaccine damage and exhibit less direct concern with compensation. During the interviews, these leaders described a pre-existing interest in issues such as alternative health, animal testing and 'big pharma' that was then applied to the vaccination case. (2007: 204)

The parents I have spoken with are critical of the HPV vaccination following the symptoms that their daughters have experienced after having the vaccine. These parents and young women have become embodied health experts in that they describe ways in which they have practiced a number of conducive behaviours i.e. being passive, accepting consumers of the vaccination

programme through the appropriate femininity and responsabilised parents it helps to construct. The accounts of the parents and young women express similar concerns to those that motivated the women's health movements of the 1970s onwards and are constructed and motivated by an attempt to affect particular change. The various movements' key concern was that women's bodies are the site of unnecessary medical intervention governed by masculine institutions and often performed by male clinicians (Ehrenreich and English, 2005). Furthermore women's bodies are often subjected to pharmaceutical experimentation and governmental surveillance as a result of a patriarchal idea that that women's' bodies are weaker and more susceptible to ill-health (Padamsee, 2011; Bunkle, 1993; Hanmer and Becker, 1998; Showalter, 1997; Barker, 2011).

Of specific interest is the work of Our Bodies Ourselves (OBOS) which is a landmark collection of literature initiated by the Boston Women's Health Book Collective during the 1970s (www.ourbodiesourselves.org) and I found what they call their key ideas to be pertinent to my research concerns. On their website they provide the following:

OBOS introduced these key ideas into the public discourse on women's health:

- That women, as informed health consumers, are catalysts for social change
- That women can become their own health experts, particularly through discussing issues of health and sexuality with each other
- That health consumers have a right to know about controversies surrounding medical practices and about where consensus among medical experts may be forming
- That women comprise the largest segment of health workers, health consumers, and health decision-makers for their families and

communities, but are underrepresented in positions of influence and policy making

- That a pathology/disease approach to normal life events (birthing, menopause, aging, death) is not an effective way in which to consider health or structure a health system. (www.ourbodiesourselves.org/history/womens-health-movement accessed June 20th 2013)

The second and third ideas are most useful in considering the role of the Sane Vax group; 'can become their own health experts' and having the 'right to know about controversies surrounding medical practices'. In the case of the Sane Vax group, parents themselves are not only becoming their own experts prompted by their daughters' experiences and through their own research, but they are also bringing the controversies surrounding the HPV vaccine to the attention of others such as their families, school, local members of parliament (MP) and wider public through engaging with the media.

We can also understand parents as occupying the role of being a 'catalyst for social change'. These families often referred to the extensive research they had conducted and the hours spent online trying to access knowledge that would shed light on their daughters' illnesses. Often, they shared their exasperation at the difficulties they had finding the alternative and embodied knowledge of those affected by vaccine-injury. An explicit example of this is when Jackie told me of the wart that appeared on Milly's face:

You [Milly] actually saw a plastic surgeon. After her jab she got a big wart just there [points to cheek], which is obviously HPV but it's not the same strain, but you just got this huge, in fact you've still got a bit of a mark, where she picked it off. (February, 2013)

Jackie's assertion that the wart is part of the HPV 'family' of viruses suggests that she has researched Human Papillomavirus and has an understanding that the virus is thought to be made up of over 100 types; two prevalent types are reported as often resulting in genital warts which can also infect other parts of the body. Using the dominant medical knowledge Jackie is trying to merge various truth claims to make sense of Milly's facial wart. Jackie shows that she has been trying to research and diagnose her daughter herself following disappointing responses from the doctors. A paediatrician that Milly was later referred to said that he would do his own research into the possibility of the vaccine being the cause of Milly's ill-health. Jackie takes up the story:

He listened to us and he did say, 'I will look into it, I will do my own research into it', and at the next appointment he says, 'well I've been on the Department of Health website' and duh de duh de da and you know, I just said, 'well what is that going to tell you?' So we sort of lost confidence with him. And then he went on a sabbatical last summer. (February, 2013)

Jackie cuts off the quote from the paediatrician with "duh de duh de da" as a way of expressing the 'standard' response of the Department of Health, which promotes and finances the vaccine and does not support the views of Jackie and others that the HPV vaccine can cause ill-health.

This is just one further specific example of how these families are engaged in practices that constitute them as indirect embodied health experts. Many more than seen in the cases presented above. They are drawing on resources that extend beyond the sources that are legitimised and relied upon by the health and medical institutions.

The risks of practicing as an embodied health expert

These cases highlight how the parents are deemed to be responsible for their daughter's health by medical professionals and by the HPV vaccination programme and yet when they become advocates for their daughter's ill-health and for the recognition of vaccine-injury they are deemed to be irresponsible, ignorant or causing ill-health.

In order to take on the role of advocate, parents have to be in good enough health to fight on behalf of their daughters. These parents are fully involved and embroiled in the experiences of their daughters as indirect embodied health experts. Their fight is not only for the recognition that their daughters are ill but for doctors to believe that the HPV vaccine has caused this ill-health. This would require clinicians and the health professions as institutions, to accept that their industry and intervention could cause significant life-limiting illnesses. When this has been the case, as with health activist successes in the past, positive changes have been made when healthcare and activist groups work together. For example, in "embodied health movements concerning for example HIV/AIDS, breast cancer, childhood asthma, and DES" (Bell, 2009: 4).³³ However, I argue that with the cases of vaccine-injury, rather than positive changes in HPV vaccination delivery, the embodied knowledge and expertise of these parents and young women appears to be in conflict, rather than complementary, to the 'expert' knowledge of the clinicians.

Feeling outside of the mainstream experiences of vaccination has been difficult for Milly and Jackie; Julie and Marilyn; Vicky and Pollyanna; Mark and Stephanie and Andrew, Linda and Gemma and other vaccine-injured young women and their families. I suggest that to counter the authoritative claims of the UK and Europe's largest and most powerful medical organisations, committees

³³ DES, or diethylstilbestrol, is a synthetic estrogen given to pregnant women as a prophylactic treatment between the 1940s and 1960s thought to prevent miscarriage. In the 1970s an association was found between women who had pre-natal exposure to DES and a rare form of vaginal cancer (Bell, 2009).

and pharmaceutical companies and to challenge their authoritative knowledge runs the risk of being labelled deviant or mad.³⁴

Jackie relayed to me her worries that she would be deemed to be 'mad' as a result of her attempts to fight for Milly to be diagnosed and believed, and for challenging the doctors' diagnosis and treatment for Milly:

And in January [2012] I said to Mum, 'they're going to end up, I'm going to end up being carted off to the funny farm', because it was driving me mad that she was so poorly and nobody would do anything. (February, 2013)

Taking this quote alongside another of Jackie's quote where she states "If you push and question doctors too much, you get labelled with either being over anxious or in the extreme case Munchausen's by proxy", we can see that not only the process of not being believed but also the continued challenging of the medical profession can result in being labelled as 'mad' as in the case of some parents being assessed for FII or Munchausen's by proxy and the embodied experience Jackie has of feeling mad.

Many of these families are not anti-vaccination in their view or political positioning, rather they have found themselves questioning and critiquing the vaccination programme as a result of side-effects, "in fact, many embodied health movement activists become involved in response to a direct experience of illness" (Bell, 2009: 5). Despite challenging the medical professionals and the vaccination, these parents and young women are looking to the medical profession for a response and a subsequent 'cure' or treatment of the illnesses presented. However these parents are clear that some of the practices of the HPV vaccination programme are to be questioned and should be changed. For example, Vicky signed the consent form in December 2009 for Pollyanna to

³⁴ See Maines, 1999 and Showalter, 1997 for a history or 'histories' of women as hysterical.

receive three HPV vaccinations. Following her ill-health into 2010, Vicky had told the school to hold off giving her the third injection in the following November. However, almost a full year later, the nurses used the same signed consent form in order to vaccinate Pollyanna despite her verbal indication that her mother did not want her to have it.

Dubriwny's (2012) notion of the activist feminist approach to healthcare suggests that those engaged with healthcare decisions as patients or consumers of medicine are invested and engaged in their own lives and experiences of health and illness; as such they play an active part in the prescriptive requirements of particular medicines. The young women have to play the role required of them in order for the vaccine to work. That role includes accepting the vaccine without issue and involves the body responding in specific ways. Attending to the experiences of the vaccine-injured young women exposes the 'work' that is necessary to ensure a successful vaccination and programme through the bodily reactions that are expected in the common version of the programme. Without the successful practices of appropriate femininity the success of the HPV vaccination programme cannot too become a success.

Risks to appropriate femininity

In Chapter Four I presented some specific examples of the ways in which small acts of everyday activism and agential practices can place young women in risky and marginalised positions. These examples included when one young woman showed an interest in the possible effects the HPV vaccine has on a foetus, and another of Beth and her parents declining the vaccine thus being labelled a 'refuser' and having to re-join her empty class. These examples may now seem somewhat pedestrian given the severity of the examples narrated above in the cases of vaccine-injury. The practices that are required in order for young women to be deemed appropriately feminine, or at the very least, in the pursuit of such an identity position, are vast, labour-intensive and require control

over one's body. I suggest that young women and their parents break from these expectations when they challenge the authority and success of the HPV vaccination. By having side-effects and campaigning to gain recognition and treatment, they no longer conform to the passive and docile expectations of appropriate femininity. They should not be causing a fuss and disagreeing with the health professionals. They should not be calling into the question the safety and necessity of the HPV vaccination.

In contrast to what is expected and assumed of the young women, an inappropriate and unfeminine young woman is one who is ill, disabled and challenging to the postfeminist norms. Through their challenging - both in terms of being difficult and as they offer critiques - these young women are bolshie and chaotic, with unpredictable symptoms and uncontrollable bodies. As such they are "erupting into men's space" (Holland et al., 2004:7) and threatening the overall success of the HPV vaccination and programme. Taking control of such an extremely negative situation warrants a significant response and has been something these young women have carried out by practicing femininity and feminism in other ways.

Risks to self-identity

It is difficult to narrate notions of health, sexuality and self in ways that do not include pharmaceuticals. Such is the dominance of pharmaceutical products on many areas of living. Drawing on Louisa Allen's work with young people in secondary schools in New Zealand, I suggest that young vaccine-injured women's identities are effected by pharmaceutical products in powerful and far reaching ways that could be described as a "paradoxical state of simultaneous mastery and submission" (Allen, 2008: 567). That is, the young women have been accepting and compliant with the HPV vaccination but following their experience of what they consider to be side-effects are now active in critiquing and challenging its status as being life-saving. The submission to the life-limiting

side-effects is something that cannot be fought against in a physical sense; these young women are sick and embody such sickness. Through both bodily and identity submission these young women are now having to articulate a self-identity that is contrary to the powerful and dominant messages promoted within the HPV vaccination programme. I argue that they are mastering the identity of being an embodied health expert and everyday activist. Gemma, for example, is storying a version of a moderated self-identity. She does so through making active decisions about her health to ensure her treatments cannot have iatrogenic side-effects i.e. through seeking homeopathy. The young women who have experienced vaccine-injury find themselves in a minority position in relation to their friends and peer group. Not only are they seen to be unwell through visual indicators such as skin welts, the use of crutches, facial warts and other bodily signifiers of ill-health, they are also often absent from school, missing social gatherings and, as is the case with some of these young women, featured in local and national media stories.

Risks to sexualities

Sick women aren't beautiful! Or so it often seems given the depictions of conventional beauty in everyday life and imagery. British society has difficulty enough recognising and celebrating women's active sexuality even when they adhere to the many limited options of practicing an appropriate aesthetic femininity. Sick and disabled women in particular therefore lack sex appeal; they aren't sexy and neither are they expected to be sexual beings (Gill, 2012). Bringing forth my key question; how are young women's sexualities constructed and practiced through the HPV vaccination programme, the vaccine-injured young women have their sexualities constructed in very different ways post-vaccination and thus when they are seen as unwell or disabled. The bodies of the young women whose stories are narrated in this chapter are marginalised and erased through a sexual and sexy social aesthetic. Vicky's description of Pollyanna's blisters that started to appear on her arms describes the scene

where these blisters merged, ulcerated and smelt like “rotting chicken”. This description serves as an example of the ways in which bodies can erupt into the social space around them, sometimes causing feelings of repulsion and distress. Michael Gill, who is a researcher and educator in the areas of Disability Studies, Women’s Studies and Sexualities Studies in the USA, highlights how problematised populations are deemed to be sexual deviants and thus the “sexuality of certain groups such as prisoners, people in group homes, and institutions fall under regulation and restriction of everyday life” (2012: 472). His article *Sex can wait, masturbate: The politics of masturbation training* attends to the ways in which those with intellectual disabilities are encouraged to express their sexualities in non-partnered, private/individual and non-reproductive ways as a way of practicing an ‘appropriate sexuality’. Gill also suggests that:

The binaries of good and bad, appropriate and inappropriate, private and public point to the contested terrains in which many individuals with intellectual disabilities negotiate their sexuality. (2012: 476)

Applying this assertion to the vaccine-injured, sickly young women, I argue that their current/future sexualities are now at risk through the regulations highlighted here by Gill. The masquerade of active choices lauded by post-feminism are rendered a clear fallacy through the experiences of ill-health and disability. Bringing forth the arguments of Bastleer (2013) and Holland et al. (2004) about the materiality of women’s bodies, this provides us with a very real example of the ways in which young women are at risk not just of the side-effects of vaccinations but also of social exclusion and the disgust that others may feel in response to the symptoms of vaccine-injury. Furthermore, more generally, this compromises these young women’s ability to be sexually desirable in normative feminine ways.

Conclusion: pharmaceutical burden and precarity

There are several burdens placed upon young women, as the accounts above show. Young women's bodies are taking on the addition of yet another pharmaceutical product as part of a new prescriptive vaccination programme in which they are encouraged to participate. As of September 2014 the vaccination programme was reduced from three injections to two; thus for those young women vaccinated between 2008 and 2014 they received a higher dosage of unknown impact. Young women are also socially, physically and emotionally encouraged to assume their gendered identities in engagement with feminine health practices of which the HPV vaccination programme is one example. There is an unequal expectation on young women to protect the health of future generations, further loading them with pressure, responsibility and engagement with a patronising paternalistic medicine. The programme sets up young women as being sexually responsible individuals who should engage in advised health interventions. Their engagement is deemed to be not only the rational and reasonable choice but also the appropriate female choice in that it safeguards the potential 'consequences' of inappropriate sexual practices by herself or her future partners.

However, it is the mothers (and fathers) of the young vaccine-injured women who have shouldered the burden of the ill-effects of the vaccine. They have taken on an additional caring role and have sacrificed their careers and businesses to be available for their daughters. Although it is speculative, I question with some insight whether the responses from clinicians would be different if this programme had had such grave consequences on the lives and health of young men and their fathers. Yet, I suggest that if young men were included in the UK's programme the ability for young women (and young men) to decline based upon previous adverse reactions, contraindications, anti-vaccination concerns and commitments or underlying health issues would be absorbed and herd immunity (and fewer side-effects) could still be achieved. This possible recommendation would reduce the gendered inequalities of the vaccine's prescribed social and health realities. However, without other practice

amendments being made i.e. parents receiving the PIL prior to consenting, school nursing teams respecting the wishes of parents to discontinue the vaccination and a greater willingness by medical professionals to recognise vaccine-injury and side-effects, the pharmaceutical burden of the HPV vaccine on young women will not be reduced.

The assumption that young women should participate willingly and compliantly in the HPV vaccination programme is therefore a clear indication that the practices surrounding the HPV vaccination programme 'gender' the participants and submit them to pharmaceutical subjectification. The young women's bodies are configured in the programme as accepting and responding well to the pharmaceutical product and the young women and their parents are, it seems from the accounts above, expected to react with passive acceptance when side-effects occur. The assumption underpinning the HPV vaccination programme is that young women's bodies will respond in a particular positive way to receiving vaccines; they should not experience adverse reactions. They are compliant and unproblematic. This is all part of what it means to be and behave as an appropriately feminine young woman. Looking back at Milly, Marilyn, Pollyanna, Stephanie and Gemma's stories it is not difficult to see them as occupying a problematic position. These young women and their bodies did not respond in the expected way to the HPV vaccinations. They are no longer young women on the anticipated trajectory into future healthy adult women. When the young women and their parents deviate from this trajectory and make challenges and claims of iatrogenic illness, the system and the state responds in ways which, according to the priorities of the young women's experiences, are unacceptable and/or extremely damaging.

I argue that young women are responsabilised for ensuring the efficacy of the vaccine through the notion of being postfeminist healthy citizens; appropriately feminine in their health practices. It is therefore not difficult to see how knowledge about the HPV virus and vaccine is contestable, with varying

accounts and stories from experiences being presented in this chapter. Most notably the experiences and truth claims of vaccine-injured young women and their parents are clearly in competition with the truth claims of the powerful medical and pharmaceutical industries. This has resulted in a precarious state of being for these young women, and as well as the life-limiting side-effects, this also renders the project of appropriate femininity impossible for them too.

Conclusion: From Gardasil girls to Gardasil grrrls: HPV vaccination as a contemporary feminist concern

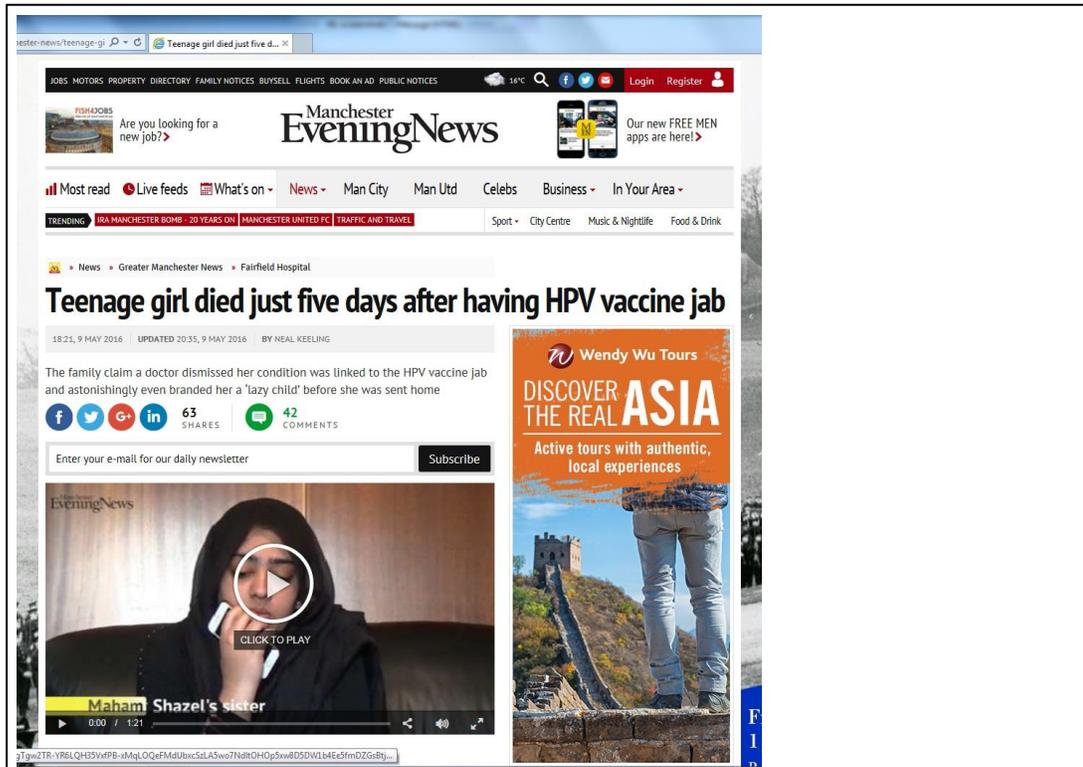


Figure 41 www.manchestereveningnews.co.uk/news/greater-manchester-news/teenage-girls-dies-hpv-vaccine-11308240 accessed 20th May 2016

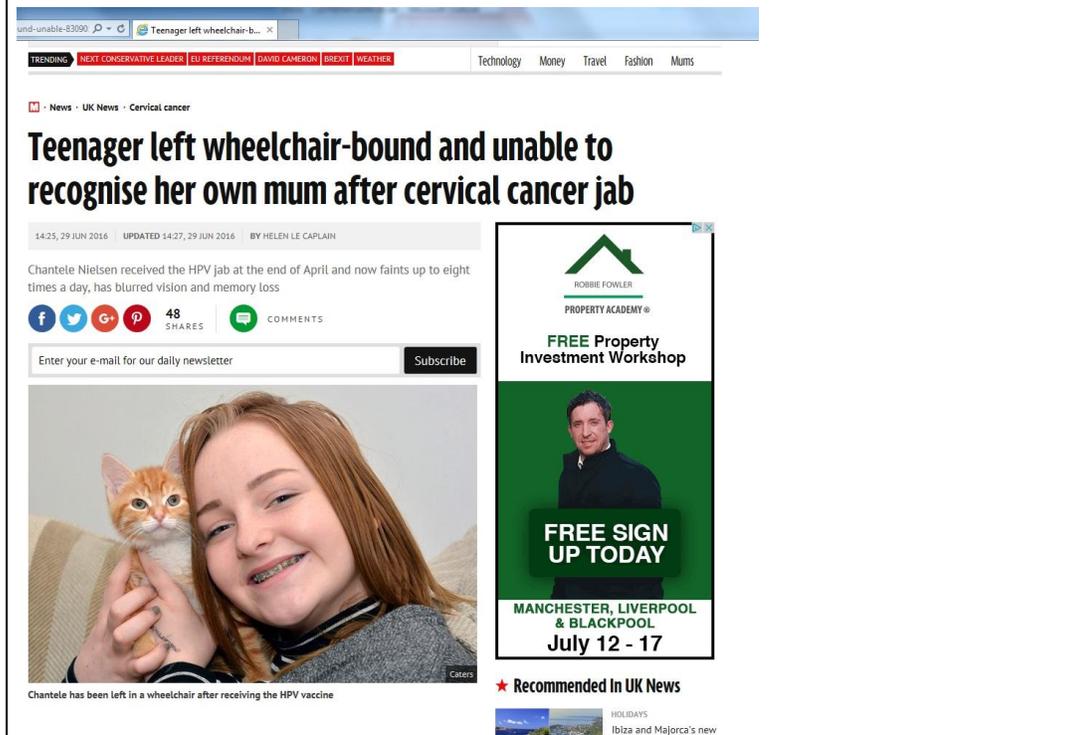


Figure 42 www.mirror.co.uk/news/uk-news/teenager-left-wheelchair-bound-unable-8309055 accessed 30th June 2016

During the time I was writing-up my thesis three significant events occurred. Two of these are indicated in the images above. The first is the case of 13 year old Shazel Zaman from Bury, Greater Manchester who, on April 17th 2016, died five days after receiving the HPV vaccine. She had been taken to hospital where she was reportedly called a 'lazy child' and sent home where she was later found unconscious and subsequently died. The second is the case of 13 year old Chantele Nielsen who received the HPV vaccination at the end of April 2016. The news article states: "Since being vaccinated, Chantele faints up to eight times a day, suffers uncontrollable sleep episodes, painful headaches, blurred vision and memory loss." (www.mirror.co.uk/news/uk-news/teenager-left-wheelchair-bound-unable-8309055 accessed 30th June 2016).³⁵ These cases highlight the fact that the concerns about the safety of the vaccine raised during the research I have carried out are not isolated cases. But, most importantly the knowledge and media interest that these minority cases are creating is not having an impact on administration practices or being believed and supported outwith the existing networks of vaccine-injury. These cases focus on the tension I have highlighted in the thesis title regarding HPV vaccination being life-saving or life-limiting. Arguably they are both. It is with urgency that these life-limiting vaccination experiences need to be shared with other parents and practitioners who could help to prevent some of these tragic life-changing consequences.

This leads me to the third event that happened during the writing-up period. I was contacted by Professor Geneviève Rail, who has worked extensively on women's health issues and is carrying out research into the HPV vaccination at a Canadian university.³⁶ We had previously met at a Society for the Social Studies of Science (4S) conference on a panel entitled 'Anticipation, Anxiety and HPV Vaccine Politics. Global Tensions and Local Enactments' in 2014 and she had remembered the paper I gave on vaccine-injury. She was in the UK in March and

³⁵ Both cases were also reported in other local and national newspapers, for example, Telegraph, Daily Mail and Sun.

³⁶ I sought consent from Geneviève who agreed to me recounting her experiences in my thesis

April 2016 and asked if we could meet. We arranged a place to meet for dinner and she told me about her recent experiences of being dis-credited having sent an open letter calling for a moratorium on the use of the HPV vaccine to a national newspaper (Rail, Molino and Lippman, 2015; Petherick, Norman, and Rail in Dagkas and Burrows, 2016). As justification for a moratorium, she drew on evidence she had gathered through her research. Her professionalism was called into question, her words misquoted, her suitability for research funding brought under scrutiny, her recent promotion – that she was encouraged to apply for by senior colleagues – declined and her work was brought into disrepute. And what were her reasons for her wanting to meet me, an unknown PhD student engaged in feminist activist research? To caution me about the possible consequences of speaking out and rocking the boat; to tell me that pharmaceutical companies have key opinion leaders in lots of areas of academia, to offer to be my examiner for my PhD *viva voce* in order to ensure that there was no pharmaceutical company-funded academic as part of the process who might discredit or fail my work. She gave me a very clear account of what had happened to her and that she did not want my career to be jeopardised by my challenging the programme and advocating for the vaccine-injured young women and their parents. Despite support from families, selected colleagues and vaccine-critical groups, as a result of speaking out against the dominant discourses that celebrate the HPV vaccine, Rail has been lambasted for her criticisms and medical experts have reacted forcefully against her claims (Dyer, 2015).

These three events remind me of the importance of the research I have carried out. Indeed they are real, persistent and traumatic lives being felt and lived by the young women, their parents, families and wider circles. Having asked what knowledge do various practitioners rely upon when administering and promoting the HPV vaccination, I argue that these cases should also inform practitioners. Based upon these events and my reflections on them, I will hold these in mind as I write my final conclusions of the research project.

Some reflections on politics, feminism and pharmaceutical subjectification

Despite these compelling stories of vaccine-injury and death, it remains a difficult task to critique the overall necessity of the HPV vaccine or indeed to highlight its negative impact on some young women and their families. This is in part due to the fact that some vaccinations do indeed have a positive impact on infection rates and life-threatening diseases, but they also construct definitions of illness and create lucrative responses to these too. My argument is one which highlights the political factors at play, the assumptions that are made and the burden of these pressures on the lives of (young) women and indeed on the lives of those, such as Genevieve Rail, who have brought the HPV vaccination programme into scrutiny. I argue that young women experience pharmaceutical subjectification by the HPV vaccination and through the practices of the vaccination programme.

I continue to use the term successful femininity (Holland, Ramazanoğlu, Sharpe and Thomson, 2004) and feel that this accurately encapsulates the ways in which young women are coached into accepting the HPV vaccination and behaving in ways that support and uphold the HPV vaccination programme. Furthermore I have explored the neoliberal framing of choice and argue that its relationships with post-feminism results in a pervasive precarity for young women. I contribute to this debate by arguing that young women must behave in ways that are deemed to be 'for their own good', but also in ways that see them as responsible for the sexual health of young men. As Gill and Scharff compellingly argue, young women are "constructed as [neoliberalism's] ideal subjects" (2013: 7) and are expected to behave in ways that do not attend to or critique the burden of the social and political powers of the DH, education system and pharmaceutical companies. There have been many instances during my research, at conferences, in the pub, with friends-of-friends and colleagues where a sentiment similar to 'so you want women to get cancer and die', has been levelled following my critiques. My journey through the research and thesis

writing has been a difficult one as a result of such sentiments and quick responses. Rather than the numerous downhearted sinking feelings, I instead would choose to remember my motivations for undertaking the research.

My research question: what are the diverse ways in which feminists can support, engage with, and critique, the HPV vaccination programme, has now become more of a commitment, and I find myself arguing that there are indeed many diverse ways that feminists can and do support, engage with, and critique, the HPV vaccination programme. In Chapter Three I presented a field note where I observed a young woman asking a school health advisor: “does it kill the baby?” This interaction is one such way in which I feel there could be numerous diverse feminist responses to such a simple and momentary question. I argue that practitioners could promote this young woman’s question as a youth-led opportunity for engaging in a learning opportunity. What could follow would be an exploration of topics such as underage sex, teenage pregnancy and vaccine safety. Such opportunities could be used to enhance the limited focus that is afforded to sex and relationship/s education in schools in the UK. It also piques the interest of the professional youth and community worker in me, and demonstrates the fact that there are more opportunities for political education to be embraced. Indeed, I am often lamenting the missed opportunities and the keenness I have to continue to work alongside the young women and parents involved in this project, despite the ‘data collection’ period having come to an end.

I argue that my research speaks to scholars, youth and health practitioners, and activists alike. My obvious affiliation is with professional youth and community workers and sexual health practitioners. It is with them that I see the greatest potential for making changes to the ways in which messages about the HPV vaccination programme are circulated and delivered. Feminist activists will also find this research of interest, particularly those who wish to fight for social justice in relation to women’s health. The HPV vaccination programme has

been presented by some as a success story of feminist campaigning, and as I demonstrated in the Introduction, many feminists and women's rights advocates and activists actively campaigned for its introduction as a positive intervention and offering (Valenti, 2014; www.womens.cusu.cam.ac.uk/campaigns/hpv/HPVpamphlet.pdf, accessed online September 10th 2014). My critique of this position has come from the research materials presented, and my argument that the programme responsabilises young women and mothers, as well as the pharmaceutical burden being unevenly distributed onto young women for an STI that affects all genders. My research materials and arguments may also be of interest to feminist scholars with a focus on health and youth studies.

Methodologically I used a participatory orientation (Eubanks, 2009) and methods which have been termed as 'creative' within academic circles. My commitment to young women choosing their own methods has generated compelling evidence that shows how the practices of the HPV vaccination programme coach young women's compliance and encourage acceptance and obedience in a new health-seeking intervention. Without such compliance, the HPV vaccination programme, which has been absorbed into the workloads of school health advisors and their staffing resource and capacity, would not be possible. I therefore suggest that if too many young women refused the vaccination the efficacy of the HPV vaccine itself, the chances of the 'herd' being protected, would be reduced.

The HPV vaccination programme as a (post)feminist intervention

My thesis opened with a set of materials produced during my research, and I have continued to foreground the key arguments and academic journey based upon a considered and emotionally-engaged investment in the lives and experiences of the people I have researched alongside. It perhaps goes without saying that the engagement and arguments of this thesis began their journey

many years before; both through my professional and activist history. These research materials are presented as empirical facts; this is a political exercise and one which makes attempts at recalibrating the ways in which we consider experience and knowledge i.e. that the sources of information and knowledge can be otherwise. From my years of professional youth and community work I have several specific examples of advocating for young people against or alongside dominant competing agendas of what is deemed best for them, without necessarily asking or finding out from them. This reminded me of the often-used disability activism slogan 'Nothing about us without us'. Such agendas and resultant policies are often based upon large-scale data sets of current trends in risks or problems in adolescence. But working directly with individuals and small groups often garners quite different perspectives on particular issues.

It is within this vein that the research was carried out. I wanted to extend my professional youth and community work practice in a direction that allowed me to settle the unease that I felt when compelled to advocate and promote certain (sexual) health initiatives that didn't sit easily with me. In the Introduction I asked whether it was possible to critique and disagree with an organisation's (Brook) stance on the HPV vaccination and still deliver sex and relationships education that promotes positive sexual health? Firstly, during my research I left the organisation and found employment elsewhere. This decision was based upon many reasons but also it settled my unease at feeling the tension between my critiques and the position of my employer. The process of engaging in a sustained, substantive piece of research has allowed me to go beyond the emotional unease and my activist responses, and introduce a more thoughtful process to engaging with information and knowledge to enable me to strengthen my critical thought. In turn this is allowing me to practice in new ways and to be able to highlight the concerns that have been solidified through the research, and advocate for social justice and political education in new ways and with access to new audiences.

I argue that the persistence of neoliberalism, discussed in the Introduction, has a powerful influence on the ways in which young women are able to self-identify and practice their femininity. Indeed responding to my research question: how are young women's sexualities constructed and practiced through the HPV vaccination programme, one of my key arguments is that the success of both the young women's femininity and of the HPV vaccination programme is intimately intertwined; the latter depends on the former. Evidence supporting this argument was presented in Chapter Two, which shows that although the young women from Wendy Chicken Shop school exhibit momentary practices of challenging the HPV vaccination programme, they also accept the vaccine and do not experience side-effects that challenge its success. Their challenges are within the realms of how it is possible to practice femininity whilst also critiquing the vaccine. As a result of the young women's fear and questioning, the possibilities of practicing citizenship and self-identity in ways which are contrary to the rigid normative scripts of the HPV vaccination programme are limited, discouraged and deemed to be problematic and 'difficult'. This comes about as a result of a postfeminist intervention being introduced under the guise of a feminist one. In Chapter Four I expanded on Robinson's term 'difficult citizenship' (2012) by identifying that it can be used as a double entendre. The young women in this research project are practicing their sexual citizenship in ways that are seen as 'difficult'. Examples of this have included them asking questions about vaccine-safety to the school nurses, feeling faint, getting sick and having declined/refused the vaccine. Thus they have practiced their sexual citizenship in ways which are both often hard to do and can be contrary to the strict norms of successful femininity.

Whilst I feel pleased with the materials I was able to generate with those involved in my project, it was not without its difficulties. They include responding to, in my view, sometimes unjustified requirements of the ethics committee and related University demands. For example, having to gain consent from the youth projects to access and recruit young women rather than gain consent from them or their parents was a surprise to me. Although I satisfied the bureaucracy of the

ethics committee, I carried out the research in a way that allowed the participatory orientation to challenge the research ethics norms. This was largely due to my arguments that opportunities for outward expression are often limited for young women. And I wanted to continue to practice to change that. The facilitated elicitation of the young women's dairies that were presented in Chapter Two provide a specific way that the young women were able to create and narrate their worlds, starting with the HPV vaccination but moving beyond this to include more individual expressions of identity and interests in a collective, social space. Both Chapter Two and the research materials in Chapter Five directly relate to my key research question: how do young women engage with the HPV vaccination programme? Following from Woodiwiss (2014) these young women practiced their identities in ways that relied upon a narrative template of youthful femininity provided for them specifically in relation to information available through the HPV vaccination programme. The use of dairies was a way of enabling them to narrate and make sense of their worlds. Despite various differences in their accounts and meaning-making, their challenges to the HPV vaccination and programme did not put the success of the programme into jeopardy. The young women's dairies indicated a private world of a 'life worth recording' (Crowther, 1999). The glimpses into the private individual worlds of these young women reflect elements of postfeminism in neoliberal times. Yet, the opportunities to create and display the dairies in the social space of the small group discussion at Wendy Chicken Shop school were different. They were momentary examples of a more collective feminist practice.

In Chapter Three, I included the timeline of the childhood immunisation schedule in the UK, which provided an insightful chronology for highlighting the pharmaceutical input and burden into young women's lives. Both prophylactically, and in response to expected developmental markers, pharmaceutical products are an accepted and celebrated part of modern life in the UK and, I suggest, are revered as having benefits beyond what is comprehensible to the public. Attending to this pharmaceutical framing, I argue that young women are deemed

to be at-risk and in need of intervention. This is, for me, a further example of the fallacy of choice that characterises the postfeminist times we are currently encountering. Pro-active choices are not being sought out by the young women and parents, instead they are being presented with an opportunity to make a decision based upon a limited number of options, limited information and a heavy burden of expectation.

It is a key argument that the diagnoses that the vaccine-injured young women have received appear to be lazy and usual rather than in light of changing symptoms and emerging evidence. As highlighted in Chapters Four and Five, the parents have highlighted that to diagnose is a clinical priority; once something has been diagnosed or labelled, no further work appears required i.e. the medical professionals do not question the vaccine as causal and instead focus on treatment of a diagnosed illness. I argue that this practice of prioritising a diagnosis shifts attention away from the acceptance that the vaccine has a causal role in ill-health, and focuses instead on what practices can be done within the limits and boundaries of the clinical encounter. Furthermore, the research materials in Chapter Five showed; 1) the iatrogenic effects of the HPV vaccinations; 2) the subsequent accusations from health professionals; and 3) the fear of psychiatric labelling. This resulted in the young women and their parents feeling ostracised from the programme in which they had previously had faith and optimism. These parents believed that their daughters would benefit from the HPV vaccination. The injustice and impossibility of the parents' position has led me to feel solidarity with these families and their testimonies. Such findings and controversies have also been highlighted in Chapter Five from countries such as Columbia where Maldonado Castañeda (2015) has explored the government's response to side-effects, and from Canada where Rail, Molino and Lippman (2015) called for a moratorium of the vaccination.

All of the information, knowledge and public health materials that are constructed and provided through the 'official' channels are written to accomplish

two things. First, to promote vaccine acceptance and to stave off any potential refusers and, second, to construct an account of the HPV vaccination that is positive. By not accepting a more nuanced and experiential account of the infection, vaccine health practitioners are not recognising that young women and their parents can make rational decisions. Instead they are seen as unstable and hysterical. The HPV vaccination programme is geared towards meeting a high acceptance target thus consent is coached and the choice that these young women and their parents have is limited. The choice is one which appears to be made under the burdensome risk of being seen as an irrational or unreasonably emotionally cautious mother if they hesitate, decline or attempt to retract consent.

Ill-informed consent and decision-making: further questions to be explored

The writing-up of a PhD thesis necessarily involves many exclusions. I have had to refine arguments through cutting research materials and concepts. In so doing I have not attended to various research materials that are worthy of attention and academic analysis. Those issues being excluded centre around a greater focus on consent and decision-making. These issues would also have highlighted recommendations for practice and could affect positive change with beneficial outcomes. In Chapter Two the young women from Wendy Chicken Shop school and Bazinga school noted that there were many people involved in the HPV vaccination. Their responses demonstrated a clear gap between themselves and who they deemed to be experts and important within the process. I contend that this distancing from the supposed expertise of an issue renders the engagement with pro-active decision-making difficult, if not an impossibility, and raises the further question: what is it to be informed?

As presented in Chapter Five, Julie and Marilyn's case highlighted the issue of ill-informed consent. The term 'informed consent' is one which widely circulates and is celebrated as being a necessary prerequisite to many things, not least, to medical procedures and sexual activity (Coy, Kelly, Elvines, Garner, and

Kanyeredzi, 2013); both of which are central aspects and concerns of the HPV vaccine, the infection and its routes of transmission. A further question to explore would therefore be: how are decisions made whether to accept or decline the HPV vaccination? The parents presented in Chapter Five, and those captured but not included in the thesis, expressed varying accounts as to whether they would have accepted vaccination for their daughters based upon the information they viewed in the PIL which was received post-vaccination. Indeed, Mark stated that hypothetically and with hindsight he and his wife would probably have taken the risks of side-effects and still accepted it for Stephanie. So the issues of ill/informed-consent and decision-making go beyond simply knowing the side-effects in advance. Indeed they stretch across time and experiences, taking in issues of clinical responses and disappointment. Another question to explore is the relationship between consent and sexualities, specifically with regard to the HPV vaccination. As I interrogated in Chapter Three, sexualities are a central defining feature in the lives of these young women. How can youth and health professionals practice in ways that distinguish between the autonomy of sexual consent, medical consent and that of parents and other adults? Indeed, I have witnessed in practice the contradictory messages that sexual health professionals provide. Specifically, when they encourage young women to actively consent to relationships and sex with partners, but then utilise their power and expertise over them when prescribing hormonal contraception and insisting on sexual health screening. As well as highlighting research questions for further studies, the findings of this study have generated several practical recommendations.

Recommendations for practice

The materials gathered and the experiences I have learnt from allow me to amplify the recommendations for practice that have come out of the research. I split these recommendations into two categories: the first is a broad category of approaches to working with young women for political education and the second

is a specific category of practices regarding the administration of the HPV vaccination.

Approaches to working with young women for political education

My position is a feminist one. I describe myself as a critical feminist youth and community worker working in neoliberal, postfeminist times. My five-year foray into academic research has strengthened my commitment and passion for informal education with young women. There were several opportunities for political education that were present during my research, however I felt restricted by many factors, and thus unable to intervene as I would have done under different circumstances. Indeed, part of this was down to being a researcher not a professional youth and community worker, and as such I felt it wasn't my place to get involved and open up a dialogue with young women. Similarly when the young women asked direct questions to me, I did not respond in the same way as I would have done in a youth club setting, instead I acted in a way that was governed by a self-imposed methodological policing.

My recommendations are born from my self-reflection on these frustrations and my daydreaming of 'if I was to do it all again'. And quite simply, I would recommend utilising the HPV vaccination programme as an opportunity to deliver sex and relationship/s education. Mary told me that the school health advisors will hold an information assembly prior to the vaccine being given. This could be used as a great way to streamline and make consistent the messages and links between HPV as an STI and broader related sexual health messages. Furthermore, collective political education could be introduced as a way of including discussions and exploration of issues to do with sex and consent within relationships.

Secondly, I argue that scholars, youth and health practitioners and activists should utilise the accounts and experiences of young women to produce more critical, varied and experiential information about the HPV vaccination and

programme. Further, I suggest that the clinical privileging and hierarchical nature of knowledge is unhelpful to a significant minority of young women who are offered the vaccination. Attending to the young women's concerns and experiences – i.e. of their embodied fear – as valid has the potential to make the programme more sustainable and positive for a greater number of young women. As seen in Chapter Four there are many versions of knowledge that exist in relation to the HPV vaccination, including online vlogs, blogs and health zines. Using the experiences of young women to create knowledge that is accessible, engaging and relevant to other young women could enable them to feel greater involvement in the programme and be able to self-advocate when they need too. For example, when Beth's friend was forced to telephone her father and when Pollyanna's school nurse forced her to have the HPV vaccination despite her mother withdrawing consent following side-effects. This highlights that the pressures of the HPV vaccination programme affects the practices of administering it, which have significant consequences on the lives of young women.

Practices regarding the administration of the HPV vaccination

These recommendations have come as a result of the devastation of vaccine side-effects and the feelings of alienation experienced by vaccine-injured young women, their parents, as well as vaccine 'refusers'. The process of giving consent is one which has been highlighted as a significant cause for concern and review by these parents. Having asked: can the administration of the HPV vaccination happen differently so to protect more young people from various risks, I detail ways in which this can be done. The first practical recommendation is that the PIL is received prior to consent being given. This recommendation has the potential to reduce the number of young women with contraindicators receiving the HPV vaccination, and subsequently, experiencing life-limiting side-effects. And furthermore, I argue that should this change be introduced, then the cumulative pharmaceutical burden on young women would be reduced.

I am yet to fully decide and commit to whether I advocate the HPV vaccination. I certainly do not support its practices of administration that have such gendered expectations and inequalities at its core. However, I cautiously propose the recommendation that young men be included in the programme if the amendments to administering it were taken on-board. Many of the parents in the research suggested that if they were provided with a full list of side-effects from the PIL, as well as a broader range of youth-led information about HPV as the most common but largely asymptomatic and unproblematic STI, they would be able to better decide whether to vaccinate their children. Indeed, if young men were included in the programme, herd immunity would be more easily achieved as a greater number of the population would be eligible thus the reduction in those declining the vaccination on grounds of contraindications or other concerns would be absorbed.

Related to this is the third recommendation. This also takes up the general recommendation above regarding information that is available about the HPV virus and vaccine. I argue that the vaccine needs to stop being marketed and promoted as reducing cervical cancer, but rather a clearer distinction made and information given about HPV as a family of infections. This association is cleverly used in the carnival of fights against cancer which essentially plays on frightening people. Indeed, Jackie told me that to her and her family cancer is a 'red flag' due to the many cancers her relatives have had to deal with. The close association of HPV with cervical cancer that is circulated in the health materials, is not in fact, an accurate description of the infection and vaccine, and adds to the social panic around cancer. The vaccine is purported to protect against an STI not an end-point cervical disease. The specifics of the four types of HPV that Gardasil protects against should be made clearer.

And finally: a new version of Gardasil Grrrrl?

Chapter Four explicitly explored the issue around information, knowledge and decisions. Women's contributions to knowledge have previously, and continue to, elicit positive changes and political, social and health advancement (Dubriwny, 2013; hooks, 1994; Scott, 1991). I continue to argue and fight for the inclusion of young women's experiences and interpretations of information as sources of legitimate knowledge. As we saw with Dilys and Olwen in Chapter Four, there are localised examples of how 'evidence' is seen in particular located ways and based upon the specific collective experiences that are observed in their own practices of HPV vaccination administration. Such practices of cancelling the vaccination administration following a media story of a vaccine-related death, is part of the social justice and political project that I see as part of the potential of the HPV vaccination programme.

The key question for consideration here is whether the political commitments that I advocate for are seen as too risky or too radical to be practiced. How, in practice, does this knowledge get out there? And how can practices be amended in order to bring these changes about? Indeed, if the core practices of the HPV vaccination programme were to be changed, would these changes damage or risk the young women's successful femininity? If they were able to challenge, to decline, to be 'difficult' and radical and to disengage with the HPV vaccination programme, what consequences or risks would they run to their practices of sexuality, their self-identity and their sexual health? As with my reflections in Chapter Three about young women being the source of their own sexual knowledge, the very thing I am promoting is inherently risky to the young women. How then, do I see this playing out in reality and limiting the negative effects experienced by young women? By creating spaces and opportunities for feminist collectivity and through embracing the Riot Grrrl movement's attitude to encouraging alternative views and expressions of femininity, a new version of Gardasil Grrrls could emerge (Walker, 2012). By changing the ways that we view women's contributions to knowledge, by advocating, accepting and encouraging more complex and nuanced accounts of young women's experiences, by

recognising the role of embodied as well as 'analytical' (hooks, 1994) ways of knowing, feminists and others with an interest in women's health can construct versions of femininity and a HPV vaccination programme that are more inclusive and positive. These changes could signal alternative engagement with health care and pharmaceutical products. Feminists campaigning for adequate and necessary healthcare practices should not be utilised as a way of fast-tracking loosely regulated and profit-driven pharmaceutical products.

Appendices

Appendix 1: parent's consent form



PARENT CONSENT FOR YOUNG PERSON

Please indicate that you agree to each of the comments below FOR YOUR DAUGHTER/S by placing your initials in each box.	
I agree that I have read and understood the Parent Information Sheet on behalf of my daughter/s and we have had an opportunity to ask questions	<input type="checkbox"/>
I understand that me or my daughter/s can end the sessions at any time and may choose not to answer any question by simply telling the interviewer that I/we don't wish to answer	<input type="checkbox"/>
I agree to the sessions involving my daughter/s being audio recorded and (where necessary) transcribed (typed up)	<input type="checkbox"/>
I agree to my daughter's writing (inc. drawings, note book) being kept and used	<input type="checkbox"/>
I agree to my daughter's photograph being taken and used for the purposes of the data collection process only (e.g. photo diary)	<input type="checkbox"/>
I understand that the material collected will be made anonymous. My daughter/s name/s will not be stored with this material and will never be used in publication or in oral presentations of the study's findings	<input type="checkbox"/>
I understand that I/we can request a copy of any audio and any transcripts if my daughter/s are interviewed and can make adjustments to the transcriptions if they wish	<input type="checkbox"/>
I agree to my daughter/s participating in the sessions	<input type="checkbox"/>
I agree to my daughter/s consenting on their own behalf	<input type="checkbox"/>
Name of daughter/s:	

Parent's signature:

Date:

Witness signature:

Date:

Appendix 2: year 8s HPV survey



The HPV vaccine and you

This survey is part of my PhD project at Lancaster University. I hope to find out what young women your age feel and think about the vaccine.

Please complete as many of the questions as possible. Your answers are anonymous and I will not tell anyone what you have said. Thank you.

Question 1: How old are you?

.....

Question 2: What year are you in at school?

.....

Question 3: When did you first hear about the HPV vaccine?

.....

Question 4: Who first told you about it?

.....

Question 5: Can you tell me what is the HPV vaccine for?

.....

.....

Question 6: Please describe how you feel about the HPV vaccine

.....

.....

.....

Question 7: Who has decided that you have the HPV vaccine?

.....

Question 8: Do you know if you have had vaccines in the past?

.....

Would you like to tell me more about your thoughts and experiences of the HPV vaccine after today (if your parents agree)?

I am looking for some year 8 young women to be involved after this survey by keeping a diary, emailing me, taking photos or being interviewed. YOU get to decide how you want to do this! You can even do it with friends.

If you are interested and would like me to contact you please write your name and number/email address here:

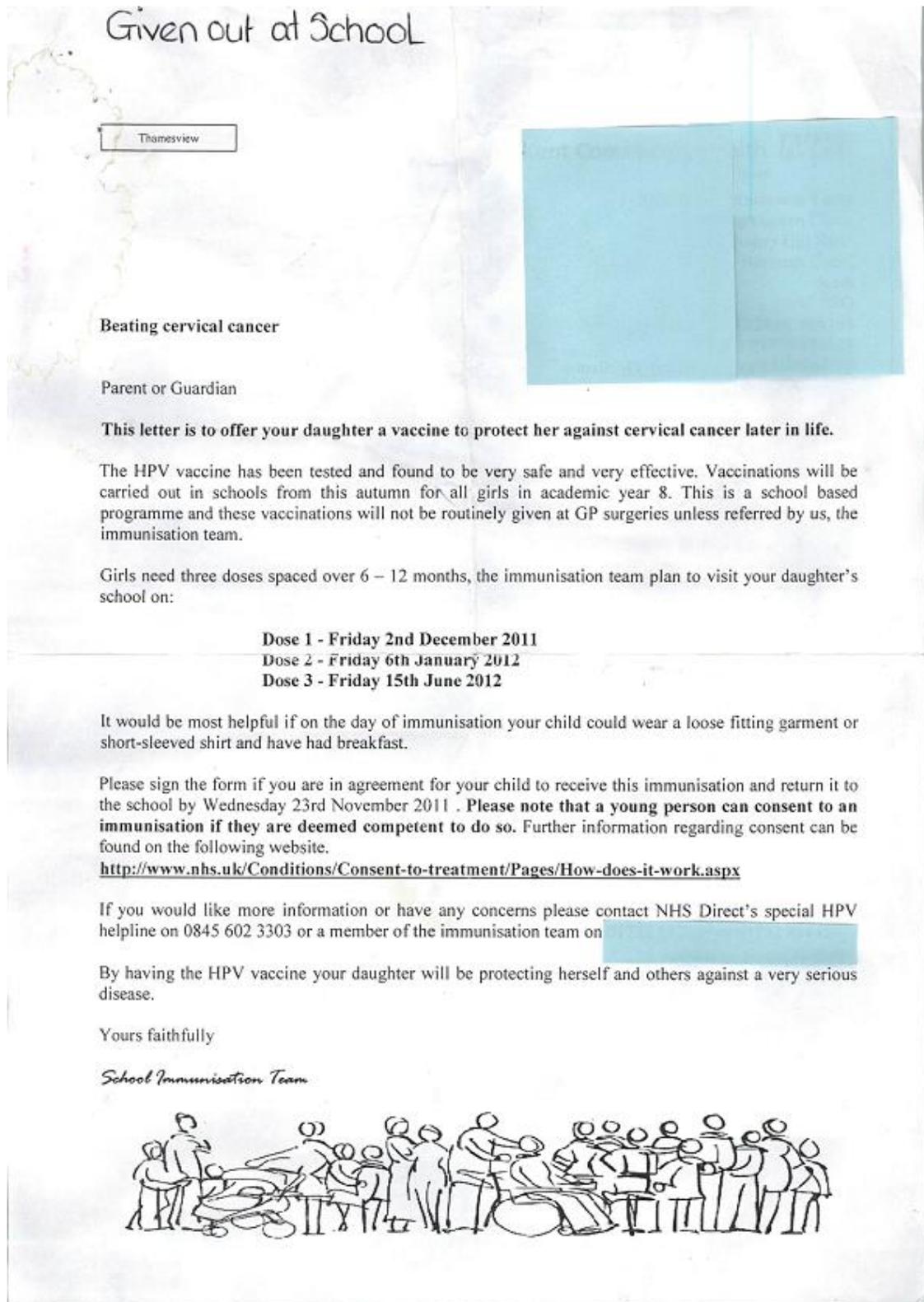
Name.....

Number.....

Email.....

All those who get involved after today will receive a voucher of your choice as a thank you!

Appendix 3: letter from the Immunisation Team



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