Cervical Screening:

Women's Resistance to the Official Discourse

by

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Glossary of Abbreviations and Terms Used

Abbreviations

GP   General Practitioner

HPV   Human Papilloma Virus (see below)

LBC   Liquid Based Cytology (see below)

NHS   National Health Service

NHSCSP   NHS Cervical Screening Programme

NICE   National Institute for Clinical Excellence

PCT   Primary Care Trust

WHO   World Health Organization

Terms

Abnormal   A smear test which reveals abnormalities in the cervical cells examined.
Smear

Colposcopy   Further examination after the identification of cervical abnormalities to determine whether any further treatment is necessary.

Cervix   A small segment of the uterus located in the upper part of the vagina. It is covered by a thin layer of cells, called the epithelium, and more than 90% of cervical cancers develop in a small area of this called the transformation zone.

HPV   A sexually transmitted virus, particular strains of which have been detected in virtually all cervical cancers.

Inadequate   A test which, for a number of possible reasons, cannot give a result.
Smear/Test

LBC   Alternative means of preserving a sample of cervical cells in fluid.

Smear Test   Test during which a sample of cells are taken from the cervix and 'smeared' onto a slide to be sent to the laboratory for examination.

Key for Respondent Characteristics in Chapters 7-9
Respondent Identification has three elements:

> Pseudonym
> Age Group: 20-34, 35-49 or 50-64 years
> Ethnicity: White British (WB), South Asian (SA) or African Caribbean (AC)
> e.g.   Nisha 20-34 SA

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Abstract

This study is an empirical exploration of Foucault's theoretical ideas on resistance, through a case study of cervical cancer screening and women's responses to the official discourse surrounding it. In England, this form of screening is organised through a national programme and consistently achieves coverage of over 80%. Given this high attendance it may appear that any resistance is negligible. However, this thesis argues that such a focus on attendance, or behaviour, is misguided and that, by focusing attention on the level at which the official discourse on screening is interpreted, understood and made sense of by individual women, it is possible to identify instances of thought and talk based resistance.

Using qualitative interviews with a sample structured to include a range of ethnic backgrounds and ages, the thesis identifies three key forms of resistance. Firstly, women may resist the general subject position suggested within the official discourse and make sense of screening in ways that are meaningful to them as individuals. Secondly, many women resist the general 'at risk' status suggested and negotiate their own position drawing on a range of risk factors that do not always fit well with those medically recognised. Thirdly, in making sense of the information they receive, women frequently attempt to create a rational framework of knowledge and understanding which can lead to them interpreting issues such as risk factors or disease development in different ways.

Based upon these, the thesis argues for conceptualising power and resistance in terms of a complex network of possibilities with multiple points of potential difference or divergence that can lead to individuals adopting very different subject positions. Although the majority of resistance detailed is thought and talk based, this is nevertheless important as it provides the means for challenges to the official discourse and constitutes a necessary prerequisite for further behavioural resistance.

Chapter 1

Introduction

1.1 Origins of the Study

This research stems from an interest in the theoretical ideas underpinning much sociological work which argues that individuals are increasingly being encouraged to act in particular ways in order to maximise their health, therefore behaving as responsible and moral citizens (see for example Armstrong, 1995; Lupton, 1995; Nettleton and Bunton, 1995; Petersen and Lupton, 1995). Much of this work is framed in terms of Foucault's work on discourse, discipline and governmentality in order to explore how individual subjectivities are created and maintained (see for example Foucault, 1980, 1981, 1991b).

I was keen to further explore these kinds of theoretical ideas through the use of a particular example, and identified cervical cancer screening as a useful case study. This area allowed me to combine a range of issues that were of particular interest, including a focus on women, aspects of female sexuality and women's sexual behaviour. Cervical screening also represents an instance with a long degree of duration, individual women are expected to present themselves for screening every three to five years for a substantial portion of their adult lives[1], and is delivered through a national programme receiving strong institutional support. It is therefore also an accessible and practical case study.

Many empirical studies that are framed in Foucauldian theory, including those dealing with cervical screening (see for example Howson, 1998a&b, 1999) tend to focus on his earlier works on techniques of domination (Foucault, 1980, 1981, 1991b) to explore how individuals are constrained and controlled through powerful discourses within society and therefore, through this, are created and behave in particular, desirable, ways. Although work of this kind recognises the more subtle and dispersed ways in which power may operate within society, and its productive rather than merely coercive potential, it nevertheless tends to imply that individuals are ensnared within these

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[1] The current age range invited for screening is routinely 25 to 64 years, therefore meaning that women will be encouraged to attend for almost 40 years of their lives.

powerful discourses and have no means for resistance. Foucault himself has argued that this portrayal of passive and powerless individuals was never his intention and his later works clearly balance the earlier focus on techniques of domination with an exploration of how individuals have the ability to demonstrate resistance to the discourses that attempt to discipline and control them (Foucault, 1984b&c, 1988). Through what he terms 'technologies of the self' Foucault suggests a more flexible relationship between discourse and the individual, therefore arguing that the process need not be one of straightforward imposition, and opening up at least the potential for resistance. However, this later work is often ignored in empirical studies and remains underdeveloped. While Foucault set out his ideas theoretically, a consideration of how these might work in practice is lacking. This study therefore seeks to explore these theoretical ideas of resistance through a case study of cervical screening in order to consider whether and how such resistance may be possible, provide examples of the forms it takes and the resources upon which it draws, and, finally, what this can tell us about the relationship between power and resistance in this context and more widely.

1.2 The Study and its Framework

The study is an exploration and development of theoretical ideas of power and resistance through the example of women and cervical cancer screening. Its primary contribution is therefore to sociological understandings within this theoretical area, and to the large body of work concerned with lay understandings of, and engagement with, health, illness and healthcare. It explores the potential for resistance, the forms this may take, and the potential limitations that may be placed upon it. It is therefore an empirical study that aims to 'speak back' to the theoretical level and develop the theory through an exploration of how it does, or does not, work in everyday life. As I have discussed above, such work is valuable as it addresses this gap and further develops Foucault's ideas on the relationship between discourse and the individual, particularly the potential for resistance within such a relationship.

The specific question driving the research is therefore whether, and in what forms, women demonstrate resistance in the context of cervical screening. The study is framed in terms of individual women and their relationships to, and with, what I have termed the 'official discourse on screening', and which constitutes the state level. This comprises the Department of Health and the National Health Service (NHS), who made

their continued commitment to screening clear in the NHS Cancer Plan (Department of Health, 2000), and the NHS Cervical Screening Programme itself, which is co-ordinated by the National Office of the NHS Cancer Screening Programmes. Framing the research in this way allows an exploration of how individual women respond to, and potentially resist, a state level health promotion discourse that encourages them to think and behave in particular ways.

The analytic focus is on how women interpret, understand and make sense of this discourse and how they respond to it in terms of thought, talk and behaviour. The way(s) in which these can be conceptualised as resistance is pursued and the different forms that this may take are explored. The different resources that are drawn upon in the process of resisting are considered, together with the potential limitations that may be encountered. Finally, the contributions of this particular case study to theoretical understandings of the relationship between power and resistance, and the nature of resistance itself, are set out.

1.3 Structure of the Thesis

The thesis begins with Chapter 2, which gives information on both cervical cancer and the national screening programme operating in England at the time of the research. Current policy and recent changes are detailed in order to ensure a thorough grounding for what follows.

Chapter 3 sets out the theoretical framework for the research. It explores Foucault's work in some detail, and the different ways it has been applied to the specific area of health and illness, before explaining how it is used and developed within this research. Following this, the concept of potential resistance is dealt with, both through Foucault's own work and through feminist work that has engaged with his ideas. Such feminists have explored Foucault's work for its potential to think about the control of women, and have developed this to consider how women may demonstrate resistance. Through this the chapter begins to question what such resistance may look like, and what can or should be regarded as resistance. This debate is returned to in the subsequent chapter and empirical studies employed to move towards a definition of resistance to be adopted. Finally, the chapter highlights the importance of perceptions of the body for this study by setting out sociological ideas on how the female body is constructed as

problematic, societal attempts to regulate bodies, with a particular emphasis on medicine's role, and women's responses to such attempts.

Having established the theoretical context of the research, Chapter 4 places the study in its empirical context. A key concern is to demonstrate the need for research of this kind on cervical screening by setting out existing work and highlighting its shortcomings. Having done so it draws attention to relevant sociological work in the area of health and illness, for example on lay and professional ways of knowing, and finally employs recent empirical studies of resistance to sensitise us to the potential forms that such resistance may take. This develops on from the more theoretical conceptualisations of resistance considered in the previous chapter through the use of empirical examples, and leads me to set out what I will use as the criteria for determining resistance in the course of this research.

With the research framed both theoretically and empirically, Chapter 5 details the methods used to address the specific research questions. It sets out the methods used, why these were chosen, the practicalities of conducting the research and reflects upon how the methods used, and the researcher's personal characteristics, may have impacted upon the material collected.

The initial stage of the research involved a documentary analysis of the written information material produced and sent to women in the course of their contact with the screening programme in order to characterise the official discourse. In Chapter 6, the first of the data chapters, I present this analysis and explore the ways in which power works through this discourse, thereby providing a firm foundation from which to go on and analyse how individual women demonstrate resistance to this.

Chapter 7 is the first of three data chapters dealing with resistance within this thesis. It explores how women demonstrate resistance to the general subject position that is put forward by the official discourse through individualising and personalising screening, and working out their own position in relation to it based on their personal characteristics, experiences and context. This process demonstrates that women are not necessarily willing to accept an abstract 'one size fits all' approach and actively engage in a process of individualisation that involves putting forward particular characteristics

or aspects about themselves that make this negotiation of the official discourse necessary. It is suggested that this frequently involves them holding and putting forward very different conceptualisations of screening, or more commonly, particular aspects of it, that do not fit well with those found within the official discourse. These can culminate in women challenging the official discourse in favour of these alternatives.

Chapter 8 explores how individual women think about and negotiate, their personal risk positions in relation to cervical cancer and the understandings of risk and disease causation that they employ in doing so. It explores these understandings, contrasts them with the risk factors identified in the official discourse, and considers the relative social acceptability of different risk factors. Following this, the consequences of such self-positioning for screening attendance are explored as thought and talk level resistance is translated through into behaviour.

Chapter 9 is the final data chapter exploring resistance and turns its attention to the differences between professional and lay ways of knowing about cervical cancer and screening. The chapter explores how women make sense of issues such as disease causation, and who is invited to attend for screening, when and how often. The underlying theme throughout the chapter is the creative processes through which women make sense of medical ideas and policy decisions, and 'fill in the gaps' in order to create links between established pieces of information. These frequently involve women developing alternative discourses on cancer and screening that do not necessarily fit well with medical perspectives or medical ways of knowing.

Chapter 10 provides the conclusion to the thesis, and draws together the new material put forward in the four data chapters to consider how the initial research questions can be answered. It further expands on the types of resistance that have been identified in the research, how these differ and how they can be limited by context and available resources. Finally, I explore what this research can tell us about the relationship between power and resistance, how we can or should think about resistance and the potential and power that it has.

Chapter 2
Cervical Cancer and Screening

2.1 Introduction

The purpose of this chapter is to set out in some detail information on cervical cancer and the current NHS Cervical Screening Programme (NHSCSP) operating in England[2], and, secondly, to explore debates within medicine around screening. It provides the context for the research and allows the reader to become fully acquainted with not only the cervical screening programme, but also with cervical cancer itself and the wider context within which the programme operates.

This chapter therefore covers a wide variety of material in order to set the scene for what follows. It will be necessary to refer back to some of the information covered here at various points within the thesis in order to refresh the reader's memory and demonstrate how particular types of information are important within the context of individual chapters and the types of resistance being discussed.

The chapter begins with information on cervical cancer itself, providing background on the nature of this disease and its incidence. Mortality rates for cervical cancer are detailed and how these have changed over time. The current orthodox medical knowledge on the causes of cervical cancer and its risk factors are also set out.

Following this, the chapter moves on to detail the current arrangements in the UK for screening for this disease under the NHSCSP. The development of this programme, its aims and objectives, how it works and how it is delivered on the ground will all be set out together with basic information on the numbers of women involved and how the programme is financed.

Finally it is necessary to give some thought to the critiques of screening that exist, both in the case of cervical screening in particular and in the wider context. It is important to be aware of both the claimed benefits and alleged limitations of such interventions. In

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[2] Throughout this thesis I am concerned solely with the English screening programme. This is because, following devolution, Scotland and Wales operate slightly different systems. Therefore to avoid confusion I refer only to the screening programme operating in England.

specific relation to cervical screening, questions concerning the appropriate threshold for further intervention, the best way to manage women with mild abnormalities, uncertainty about the process of transition from abnormalities to cancer, and therefore the potential for false positive and false negative results, will all be discussed.

2.2 Information on Cervical Cancer

Cervical cancer affects the uterine cervix, the neck of the womb, which is a small segment of the uterus located in the upper part of the vagina. It is covered by a thin layer of cells called the epithelium. More than 90% of cervical cancers develop in a small area of this called the transformation zone. This area is the most vulnerable to outside pathogens, such as viruses, which are implicated in the development of cervical cancer. This form of cancer is one that is widely accepted to be preceded by benign pre-malignant lesions, which take the form of abnormalities within the cells of the cervix. These abnormalities are classified in different ways under different systems, but all grade them according to severity ranging from cells with mild abnormalities through to carcinoma *in situ* (Cancer Research UK, 2003a).

These pre-cancerous changes in cervical cells, and also early invasive cervical cancer, are typically asymptomatic and virtually all cases are detected through routine smear tests. If these changes are not detected and treated then cervical cancer may develop. However, it is by no means certain that a cervical abnormality will develop into cervical cancer, or that all cases of cervical cancer will display these pre-malignant lesions. These uncertainties regarding disease progression will be discussed further below when critiques of screening are considered.

In terms of incidence, in 2000 there were 2,424 new cases of invasive cervical cancer registered in England (National Statistics, 2003). A recent report by Cancer Research UK states that cervical cancer is the eleventh most common cancer in UK women, and that it accounts for around 2% of all female cancers (Cancer Research UK, 2003a). There are peaks in the incidence of invasive cervical cancer amongst certain age groups that are taken to represent birth cohort effects (Cancer Research UK, 2003a). These effects are evident when a cohort experiences different patterns of disease to those born either immediately before or after. In the case of cervical cancer, there appear to be peaks in incidence amongst women born at the end of the nineteenth century and around

1920. These peaks are also found in mortality data with these groups having higher cervical cancer mortality throughout their lives than for previous and subsequent birth cohorts, with rates reaching nearly 20 per 100,000 women in both cases (Cancer Research UK, 2003a). It is argued that changes in sexual behaviour are important in explaining this kind of cohort effect. These two groups of women would have become sexually active around the times of World War I and World War II respectively, times of uncertainty during which sex may have been more casual. For birth cohorts after the mid-1920s until the mid-1940s death rates are lower. In addition, an increased risk in women born after the mid-1940s is consistent with the changing attitudes towards sex since the 1960s, therefore indicating a third cohort effect. The importance of changes in sexual behaviour in cervical cancer incidence will be explored more fully below in the context of different risk factors for the disease.

In terms of mortality, in 2003, 953 deaths from cervical cancer were registered in England and Wales (National Statistics, 2004a). Deaths from cervical cancer have declined markedly over the last few decades, with mortality rates in 2000 at 3.3 per 100,000 women, 60% lower than 30 years earlier when they stood at 8.3 per 100,000 women in 1971 (Cancer Research UK, 2003a).

The impact, on both incidence and mortality for cervical cancer, of both screening in general and the national programme in particular is of course of interest. Quinn *et al.* (1999) suggest that, since the introduction of the national programme in 1988 there has been an overall fall of 35% in the incidence of invasive cervical cancer. In addition, they suggest that studies based in regional cancer registries indicate that the distribution of cancer stage at diagnosis has shifted towards the earlier stages. They therefore conclude that the fall in cervical cancer incidence over this period is directly related to the increased coverage of screening brought about by the national programme.

However, they argue that attributing any decline in cervical cancer mortality to screening generally is more problematic. They argue that little, if any, of the observed long-term decline in mortality up until the late 1980s, when the national programme was introduced to standardise existing regional arrangements, can be seen as a direct result of screening. This is because relatively few of those women in the age group for which mortality was highest and the falls largest, those over 55 years old, were being

screened under these arrangements. This is because screening was typically dealt with in contexts such as contraception or pregnancy, areas in which this age group are less likely to participate. Therefore attributing this fall in mortality directly to screening is problematic as few of the women in the group with the biggest decline were being screened.

The exact cause of cervical cancer is not known. However, several risk factors have been identified. The most widely accepted of these is the role played by the human papilloma virus (HPV). Certain types of this virus have been detected in, and linked to, virtually all cervical tumours tested worldwide (Cancer Research UK, 2003). Most HPV infections will not progress to cervical abnormalities, but it is believed that cervical cancer will not develop without the presence of persistent HPV. This has led to HPV being proposed as the first ever identified 'necessary cause' of a human cancer (Cancer Research UK, 2003a). HPV is generally transmitted through sexual activity and is rarely detected in women who have never been sexually active. Risk factors for HPV infection therefore include the number of sexual partners and not using condoms. This focus upon the importance of HPV in cervical cancer development, and its nature of transmission, has led to some branding this a 'sexually transmitted cancer' (Sevin, 1999).

In terms of the risk factors that may cause abnormalities to develop in HPV positive women, a study by Deacon *et al.* (2000) found that the main risk for severe abnormalities amongst these women was early age at first intercourse. They suggest that this is because duration of exposure is the main risk factor. Interestingly, the number of sexual partners does not seem to increase the risk of severe abnormalities amongst HPV positive women. Deacon *et al.* suggest this is because, once a woman is infected, her risk is not increased by re-infection. Meaning that having several sexual partners is only a risk in terms of initial HPV infection.

The role of smoking in cervical cancer development is difficult to establish, but it has been suggested that both the direct carcinogenic effect and the indirect effect on the immune system may contribute to increased cervical cancer risk for smokers. Recent research evidence has shown that smoking predisposes women to the development of a range of cervical abnormalities (Scholes *et al.*, 1999) and confirmed an association between smoking and carcinoma *in situ* (Ylitalo *et al.*, 1999). In addition, the website of

the NHSCSP states quite clearly that those women who smoke are about twice as likely to develop cervical cancer as those who do not, and smoking is explicitly listed as one of five risk factors that make cervical cancer more common in the information leaflet that women receive when invited to attend for screening[3].

Socio-economic status has also been linked to incidence and mortality from cervical cancer, with those in manual classes being at considerably higher risk of developing cervical cancer than those in non-manual classes. In a worldwide study of social inequality and cervical cancer risk, Parikh *et al.* (2003) consistently found a social stratification disparity in cervical cancer rates, but this seemed to be more pronounced in North America and in low/middle income countries rather than in Europe. They argue that a greater socio-economic disparity for cancer rather than simply abnormalities suggests both lifestyle factors influencing exposure to HPV and participation in adequate screening programmes are important in explaining these disparities. Furthermore they suggest that lifestyle factors are the primary cause of social class differences in Western Europe, while access to screening programmes is more important in low/middle income countries.

Other factors have been proposed as being implicated in the development of cervical cancer, although the associations are less clear. For example, a link with oral contraceptive use has been suggested, but this is complicated by a possible confounding with the kinds of sexual behaviour risks highlighted in the previous discussion of HPV. However, a study carried out by the World Health Organisation's International Agency for Research on Cancer (IARC) found that prolonged use of the oral contraceptive pill increased cervical cancer risk up to fourfold, but only amongst those women carrying HPV (Dyer, 2002).

High parity has also been linked to increased cervical cancer risk among HPV positive women. The reduction in cervical cancer in many developed countries could therefore be partly explained by the general decline in parity. There is conflicting research evidence on the effect of parity in cervical cancer development, for example Munoz *et al.* (2002) suggest that high parity increases the risk among HPV-positive women while

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[3] More information about this leaflet can be found in Chapter 6 where it is the subject of a documentary analysis. More detail on this analysis can be found in Chapter 5.

Mogren *et al.* (2001) found that increased parity was protective and argue that this contradicts other research in which multiparity was found to be associated with higher risk.

It is therefore the case that HPV remains the most important risk factor for the development of cervical cancer, and that many of these other potentially important factors only apply to women carrying certain types of HPV. Women with no evidence of HPV infection are very unlikely to develop cervical cancer, and even if they do have an abnormal smear it is unlikely that any abnormalities will progress. However, the mechanisms through which HPV **causes** cervical cancer are not fully understood. In section 2.3.5 below, in which I highlight potential new developments in screening, I consider the possible incorporation of HPV-testing in order to distinguish between those women at high risk of developing cervical cancer and those not.

2.3 The NHS Cervical Screening Programme

Cervical screening as a procedure has been in use in the UK since the mid-1960s, but the national programme was not established until 1988. Up until this time cervical screening had been opportunistic and *adhoc*, with women being recruited when they visited the doctor for other reasons for example during pregnancy or in the context of family planning. Although many women were being regularly screened under these arrangements, and indeed there were notable successes in some areas (McGregor *et al.* , 1986), there was concern that those at greatest risk were not being screened and that those who had positive test results were not being followed up and treated (NHS Cancer Screening Programmes, 2004). Therefore, in 1988, it was decided that a national cervical screening programme would be established in order to absorb the various local programmes that existed and to ensure an equitable level of screening across the country (Patnick, 2000). The NHS Cervical Screening Programme (NHSCSP) aims to reduce both the number of women who develop invasive cervical cancer and the number of women who die from the disease through a co-ordinated programme of regular screening for all women perceived to be at risk in order to identify and treat pre-cancerous abnormalities that may go on to develop into invasive cervical cancer if left untreated.

Cervical screening in England operates in the context of the National Health Service (NHS), which is funded from general taxation and offers health care free at the point of delivery. Funding is given by the Department of Health to Primary Care Trusts (PCTs) who then commission the provision of services to interpret smear tests, report the results and provide further investigation and treatment where necessary. The programme is therefore organised and delivered locally, through PCTs and General Practice, but is nationally co-ordinated by the National Office of the NHS Cancer Screening Programmes based in Sheffield. The National Office is charged with monitoring and improving the overall performance of the programme. It was established in 1994 and has two main priorities:

- Develop systems and guidelines which will assure a high quality of cervical screening throughout the country
- Identify important policy issues and help resolve them, and improve communications within the programme and to women
  (NHS Cancer Screening Programmes, 2004)

As previously stated, cervical screening itself is organised and delivered locally and all PCTs have a nominated individual who is responsible for screening and implementing national guidelines.

2.3.1 The mechanics of the programme

When the national programme was established in 1988 one of the most important changes was the introduction of a system of computerised call and recall for an established target population, 'call' being a woman's first invitation and 'recall' meaning all subsequent invitations (Patnick, 2000). This call and recall system holds lists of all women currently registered in general practices within a particular area. This list is then passed to individual practices so that they can check and amend the lists if necessary. For example, this may include the checking of name and address details and the removal of any women for whom screening would be inappropriate, such as those who are terminally ill or those who have had their cervix removed as part of a full hysterectomy. Once amended, the call and recall system then sends invitation letters to all women on the list and issues reminder letters at designated intervals if screening appointments are not made and attended. It is possible for women who do not wish to attend for cervical screening to have themselves removed from these lists, and therefore

to stop receiving invitations, but this requires negotiation with a practice nurse or General Practitioner (GP) and involves them signing a disclaimer in case they should then go on to develop cervical cancer.

When women attend for a screening appointment a cervical smear test is taken. Women can choose where they have this test taken and by whom. They have the choice of attending their surgery, and having either the GP or, more commonly, the practice nurse take their test, or they may attend a community clinic such as a family planning or well-woman clinic (NHS Cancer Screening Programmes, 2004). During this test a sample of cells is taken from the cervix for analysis. To do this the smear taker inserts a tool called a speculum, in order to open up the vagina, and then uses a spatula to sweep around the cervix and collect a sample of cells. Conventionally, the sample of cells is smeared onto a slide, hence the term smear test, and this is then sent to a laboratory for examination. However, a new way of preparing cervical samples, called liquid-based cytology (LBC), has very recently (2003/4) been introduced, following pilots and guidance from the National Institute for Clinical Excellence (NICE), and will be rolled out across the national programme in the future. The guidance (National Institute for Clinical Excellence, 2003) recommended that LBC should be used as the primary means of processing cervical samples in screening programmes in England and Wales. Using LBC, the sample is collected in a similar way to the conventional smear using a speculum device to brush cells from the cervix. Following collection the head of the device is broken off into a container of preservative fluid. This is then sent to the laboratory, where any obscuring material is removed, and a sample of the remaining cells is taken for examination. Women are reassured that there will be no difference to the test itself and in particular that it will not feel any different, but that they might notice a slight difference in procedure after the test has been taken (NHS Cancer Screening Programmes, 2004). A particular attraction of moving to LBC is its potential to reduce the number of tests taken that are inadequate, currently around 1 in 10 (Department of Health, 2003). An inadequate smear means that no result could be determined as the sample did not contain suitable material for analysis. These tests need to be repeated, which inevitably causes inconvenience and anxiety to the women involved and incurs financial costs resulting from the repeat tests.

2.3.2 Who is invited and how often?

A target population of women has been identified and this is the group that is routinely invited for screening using the call and recall programme. Until very recently all women (except those removed from the list) between the ages of 20 to 64 years old were routinely invited to attend for a cervical smear every three to five years, depending upon local policy. However, in the light of new evidence, the NHSCSP will now be implementing a system within which the screening interval (the time between an individual's smear tests) will vary depending on the woman's age. This change is recommended to take place after each woman's next smear test, as this will already have been scheduled.

Given that this change is very recent, and indeed is unlikely to have affected the vast majority of women as yet, and the fact that my doctoral research interviewed women under the previous system, I will take some time to explore both systems in more detail.

Under the previous system women were invited for cervical screening between the ages of 20 to 64 years old, with an interval of between three to five years depending upon local screening arrangements. The national guidance was that all women should be screened at least every five years, and in fact more than half the health authorities in England invited women every three years (Patnick, 2000). Under the new arrangements both the screening interval and the ages between which women are invited to attend has changed.

The interval for cervical screening has been much debated in recent years both within the UK context and more widely (see for example Dickinson, 2002; Grant, 1999; Waugh and Robertson, 1996), and the NHSCSP asked Cancer Research UK to evaluate the interval for this form of screening and to recommend alterations if necessary. The research (Sasieni *et al.*, 2003) analysed the screening histories of 1305 women diagnosed with invasive cervical cancer and 2532 age-matched controls, the results of which called into question the policy of having a uniform screening interval throughout the target age range. The research showed that screening is less effective at preventing invasive cervical cancer in women under 40 years of age than it is in women aged over 40 years. In addition, they suggested that cervical cancer develops more quickly in young women than in older women. Based upon their results, the researchers made

recommendations for changes to the screening interval as they suggested that the programme could provide a more effective service by changing the frequency of screening according to women's age. These were accepted by the Advisory Committee on Cervical Screening (NHS Cancer Screening Programmes, 2004). Under the new system screening starts later and the interval is tailored according to age. This is summarised below:

Age group (years)	Frequency of screening
25	First invitation
25-49	3 yearly
50-64	5 yearly
65+	Only those not screened since 50 or with recent abnormal tests

(NHS Cancer Screening Programmes, 2004)

Under the previous system screening started at age 20 and continued routinely until age 64. However, the new system starts screening later, with women not receiving their first invitation to attend until age 25. The previous starting age was because cervical cancer is rare in women under age 20 and teenagers' bodies, particularly the cervix, are still developing, meaning that young women are more likely to receive abnormal test results when nothing is wrong. This may then lead to unnecessary treatment and so screening may do more harm than good in these cases (NHS Cancer Screening Programmes, 2004). The potentially enormous psychological issues of such unnecessary treatment must also be borne in mind. I discuss this, and the wider problem of false positive tests, later in this chapter. In explaining the decision to start screening later, at age 25, the rarity of cervical cancer and the frequency of cervical changes in women under this age are again stressed. This is in response to the study by Cancer Research UK (Sasieni *et al.*, 2003), which recommends not screening women under age 25.

'Although lesions treated in very young women may prevent cancers from developing many years later, the results of this paper would suggest that it is enough to begin screening around age 25 – lesions that are destined to progress will still be screen-detectable and those that would regress will no longer be a source of anxiety' (Sasieni *et al.*, 2003:92).

In common with the previous system, the new screening arrangements continue to withdraw women from routine screening at age 64, providing they have not had any abnormal smears in the preceding ten years. This means that only those aged 65 and over who have not been screened since they were 50, or have had recent abnormal test results, continue to be routinely invited to attend. This is explained in terms of the natural history and progression of cervical cancer indicating that women who do not fall into these groups are unlikely to go on to develop the disease (NHS Cancer Screening Programmes, 2004). The age at which women are withdrawn from the system has been much debated, with some suggesting that withdrawal could start before age 64, the most commonly suggested age being 50 years. This has been considered in terms of potentially reducing costs and/or more efficiently targeting resources (Ogilvie, 2001; Sherlaw-Johnson *et al.*, 1999), and the relative value, ease and accuracy of screening in these women (Cruickshank, 2001). However, other research has suggested that early withdrawal scenarios are clinically less effective and therefore offer little economic benefit (Philips and Whynes, 2001), and some even suggest extending routine screening to age 69, if not further (Law *et al.*, 1999). Aside from these clinical and economic considerations, it is likely that any potential move to reduce the age at which women are withdrawn from the programme would meet with resistance from service-users as research has shown that cervical smear tests are highly valued. A willingness-to-pay study carried out by Wordsworth *et al.* (2001) found that the monetary value women placed on having a smear test was higher than the cost to the NHS of providing them. Therefore any move to reduce the age group entitled to free cervical screening on economic grounds is likely to encounter public resistance.

In the context of exploring how women think about and understand cervical cancer and screening, the impact of these changes to target age range and screening interval may prove interesting. In particular, their potential to influence how women think about both their own personal cancer risk and that of other women may be significant.

2.3.3 Numbers of women involved and costs

The number of women screened varies slightly from year to year, but is constant at just over three million. During the most recent year for which figures are available, 2002/3,

the number of women aged between 25 and 64[4] years screened was 3,130,274 (NHS Cancer Screening Programmes, 2003). In terms of coverage of the eligible population[5] this means that 81.2% had been screened at least once in the last five years. This is a slight decrease on previous years (NHS Cancer Screening Programmes, 2003) and, although overall coverage has remained fairly constant since 1997, analysis by age shows an ongoing very slow but steady decline in coverage amongst women under 50 years and an increasing coverage of women aged 50-64[6]. Nevertheless, coverage of over 80% is extremely high, perhaps higher than might have been expected given the intimate and personal nature of the smear test[7].

In addition to age variations, coverage rates also differ by region with the East Midlands having the highest reported coverage at 84.6% and London the lowest at 75.7%. In all, 0.2% of women had attended but never had an adequate test, while 6.5% had been called but had never attended for screening[8] (Department of Health, 2003). Research into coverage and non-attendance is plentiful, with studies looking at reasons for variations in coverage in the NHSCSP (McGahan *et al.*, 2001), the impact on screening attendance of a cervical cancer story line in a popular soap opera (Howe *et al.*, 2002) and, most notably, reasons for non-attendance (Bentham *et al.*, 1995; Eaker *et al.*, 2001a; Elkind *et al.*, 1988; Neilson and Jones 1998). These studies looking at non-attendance for cervical screening will be examined more closely in Chapter 4.

In terms of costs, cervical screening is estimated to cost around £150 million per year in England, including the costs of treating abnormalities. This works out at about £37.50 per woman screened. At the time this research was carried out, approximately half the costs of the programme took the form of target payments to GPs for smear taking (Patnick, 2000). These target payments were introduced in 1990 to encourage GPs to

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[4] Only the target age range is covered in these figures. 25 years is the starting point as, under a system in which screening started at 20 years and interval was at least every five years, women should have had their first smear by 25.

[5] The term 'eligible population' excludes those women who have been removed from the list by a practice as screening has been deemed inappropriate for them.

[6] It would be interesting to know more about why these trends are occurring, but no detail is given.

[7] Later in the thesis I suggest that this high level of coverage is partly attributable to the nature of the programme, which is opt-out in nature and therefore assumes attendance.

[8] This figure is considerably less than the approximate 15-20% that coverage figures indicate have not been screened at least once in the last 5 years. Making the point that there is movement across the attender/non-attender divide with only a relatively small minority having never been screened.

ensure their female patients participated within the programme[9]. There were different levels of payment depending on the level of coverage attained. No payment was made for coverage below 50%, a low payment is received for between 50-79% and a higher payment is received for 80%+. The actual payment received depended on the number of eligible patients, in comparison to those on the list of an average GP, and the number of tests taken as part of general medical services as opposed to those taken in health authority or private clinics (Ellis and Chisholm, 1997). Under this system there was therefore a strong financial incentive for GPs to reach the 80% coverage target.

2.3.4 Test examination and results

When the tests have been taken they are passed to the laboratory where they are screened by a bio-medical scientist or a cytology screener. Those smears thought to be abnormal are screened again by senior laboratory staff and are given a result based on the degree of abnormality seen. These results are then sent to the PCT, the GP and the smear taker (if this is not the GP). If a woman receives an abnormal test result then her GP will refer her for any necessary further treatment.

In 2002/3 the breakdown of test results show that, of the women who received a result, i.e. not an inadequate test, 92.6% were negative, 4.0% showed borderline changes, 2.1% showed mild abnormalities, 0.7% showed moderate abnormalities, 0.6% severe abnormalities and 0.1% suspected invasive carcinoma or glandular neoplasia (Department of Health, 2003).

A woman's status within the call and recall system varies depending on past test results. Normal status, meaning routine recall, may only be used where a test result is negative. Repeat recall status requires a repeat test earlier than is routine, typically within six months of the previous test. This status may be used where a test is negative, inadequate, borderline or mild abnormality. Suspended recall indicates the suspension due to referral for further investigation and treatment. This is the only allowable status following a result showing moderate abnormality or worse.

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[9] The new General Medical Services contract may impact on these arrangements.

If women are referred for further investigation, known as colposcopy, then this is performed by a specially trained clinician at an outpatient appointment. The cervix is examined using a microscope to assess the extent or severity of the abnormality and to determine if further treatment is needed. If needed a sample of tissue can be taken from the cervix, and/or the cervix may be treated. Alternatively, women may be asked to have a repeat smear test. If treatment is deemed necessary then this may take two forms. The abnormal cells may be destroyed using laser ablation or may be cut away using loop diathermy or laser excision. Loop diathermy, in which a thin wire loop cuts through and removes the abnormal area, is the most common (NHS Cancer Screening Programmes, 2004).

2.3.5 Potential future developments

There is currently a seven year, multi-centre (Dundee, Aberdeen and Nottingham) trial being carried out that explores the best way to manage women with borderline and mildly abnormal smear tests. The MRC-funded Trial of Management of Borderline and other Low grade Abnormal smears (TOMBOLA) has three main aims.

1. Determine whether cytological surveillance or colposcopy is the best way to manage mild or borderline abnormalities.
2. Determine the most efficient and effective mode of treatment following colposcopy.
3. Evaluate the contribution of HPV testing to the effectiveness and efficiency of existing management of mild or borderline abnormalities.
   (NHS Cancer Screening Programmes, 2004)

However, perhaps the most interesting potential development in cervical screening centres on HPV testing. There are over 80 subtypes of this virus and most do not cause significant disease in humans. However, some types, most notably 16, 18, 30 and 33, have been confirmed as agents that cause cervical cancer (see section 2.2 above for more details). Research has indicated that mild or borderline abnormalities in women with no presence of high-risk HPV are very unlikely to develop into cervical cancer and, therefore, HPV testing has been proposed as a means of distinguishing between those women at high risk and those not. The use of HPV testing needs further research, although its potential is clear (Herrington, 2001; NHS Cancer Screening Programmes, 2004) and pilot schemes are under way to explore this. However, a more radical employment of HPV testing is also possible, with this being used as the primary screen

and cervical screening only for those women testing positive. Professor Peter Sasieni, of Cancer Research UK, has called for a large-scale study to explore this possibility (NHS Cancer Screening Programme, 2003:14). The impact that such a move away from universal, population-wide screening, in favour of a more targeted approach, may have on lay perceptions of cervical cancer, the relative social acceptability of being 'at risk' of this disease and attendance for HPV testing and subsequent screening are potentially very interesting.

2.4 Critiques of Screening

In this section I briefly set out some of the background to debates around screening. The proposed criteria that screening programmes should meet and the ways in which screening has been criticised are set out. I then move on to look at cervical screening in particular and detail some of the critiques suggested in this particular case. In some instances steps have been taken that effectively deal with some of these criticisms, such as the introduction of the national programme. However, others are still pertinent and raise important questions.

2.4.1 Screening in general

In discussing medical screening, Wald (1994a) acknowledges that, whilst there is no universally accepted definition, there is general agreement on the principles involved and, as a result of this, he puts forward the following definition.

> Screening is the systematic application of a test or inquiry, to identify individuals at sufficient risk of a specific disorder to benefit from further investigation or direct preventive action, among persons who have not sought medical attention on account of symptoms of that disorder (Wald, 1994a:76).

Writing many years earlier, McKeown (1968) particularly drew attention to how screening puts the doctor and patient in a very different relationship from that which is normally observed. In the traditional medical encounter it is the patient who seeks the help of the doctor, however, in this context the roles are reversed and it is the doctor who seeks out the patient who is deemed to need help. It is therefore essential that the doctor can then offer some form of effective intervention, '…no one should be expected

to submit to the inconvenience of investigation or the anxieties of case-finding without the prospect of medical benefit' (McKeown, 1968:2).

These concerns led to the establishment of general principles of screening; criteria that a screening programme should meet before being implemented. Calman (1994) cites the principles proposed by Wilson and Junger in 1968 as a series of general principles that have been widely supported. These are listed below:

- The condition for which screening is undertaken should be an important health problem
- There should be an acceptable treatment for the cases identified
- Facilities for diagnosis and treatment should be available
- There should be a recognised latent or early symptomatic stage
- There should be a suitable test or examination
- The test should be acceptable to the population
- The natural history of the condition should be understood
- There should be an agreed policy on whom to treat as patients
- The cost of case findings should be non-wastefully balanced in relationship to expenditure on medical care as a whole
- Case finding should be a continuing process and not a once and for all event (Wilson and Junger, cited in Calman, 1994:101).

In addition, Wald has argued that a screening test should be judged '…by how well it identifies individuals who actually have the disease or who, in the absence of preventive action, would develop it' (Wald, 1994b:205). He argues that screening programmes run the risk of being judged in terms of how many positive results they find. Apart from being misleading and making screening appear more effective than it really is, this can '…create the impression that having a positive screening result is itself a disease' (Wald, 1994b:205).

More recently, the World Health Organization (2004) has listed a number of factors which should be taken into account when considering screening programmes. These are:

- Sensitivity: the effectiveness of a test in detecting a cancer in those who have the disease;
- Specificity: the extent to which a test gives negative results in those that are free of the disease;
- Positive predictive value: the extent to which subjects have the disease in those that give a positive test result;

- Negative predictive value: the extent to which subjects are free of the disease in those that give a negative test result;
- Acceptability: the extent to which those for whom the test is designed agree to be tested.

(World Health Organization, 2004)

It is generally accepted that cervical screening is a good fit with these criteria, and given the high coverage rates achieved by the NHSCSP the acceptability criterion appears to have been clearly met.

The issues surrounding screening create much debate among medical professionals, and Holland and Stewart (1990) have discussed these. Proponents of screening argue for the potential to reduce morbidity and mortality, while opponents draw attention to the possible misuse of limited resources, the danger of over treatment and causing unnecessary anxiety. The issues surrounding anxiety are an important consequence of screening programmes and have been much discussed in the literature. Shickle and Chadwick (1994) draw attention to the way in which the offer of a screening test implies that we may not be as healthy as we thought, and that something could be happening in our bodies that we have no awareness of or control over. This may well cause anxiety and create what Shickle and Chadwick term the 'worried well'. Stoate (1989) has argued that the debates about screening should be widened to take more account of its effect on a person's mental state and subsequent behaviour. He concludes his article by stating that 'we must also address the possibility, previously largely ignored, that for some people at least, screening can do more harm than good' (Stoate, 1989:195).

In discussing the possible psychological aspects of cancer screening, Ellman (1996) has discussed three possible ways in which screening may lead to psychological morbidity.

Firstly, the process of being encouraged to accept screening may increase anxiety by raising awareness about vulnerability to the cancer concerned. Secondly, anxiety is inevitably caused when an asymptomatic person has a positive screening test, and, for those who turn out to be false positives, this may be a serious unwanted side effect of the screening programme.

Thirdly, in patients with screen-detected cancer, anxiety may be greater than in other cancer patients because of their previous asymptomatic state (Ellman, 1996:159).

The possible anxiety caused, together with the reversed doctor/patient role, means that screening therefore carries considerable ethical responsibilities as it has the potential to move an individual from the state of supposing themselves to be healthy to the state of having some disorder or potential disorder (Holland and Stewart, 1990). Dubos (1960) has argued that being completely free from disease is almost incompatible with being alive, and therefore we must be careful that screening is not detecting conditions that are either untreatable or insignificant.

A further risk associated with screening is the potential for false positive and false negative results. As McKeown (1968) argues:

On the one hand, failure to recognize abnormalities when they are present may lead to unjustified reassurance which delays diagnosis and treatment. On the other hand, erroneous identification of disease may result in unnecessary treatment which may be costly, unpleasant or even harmful (McKeown, 1968:4).

It is not always possible to make an absolute distinction between those people that have the condition being screened for and those that do not. This is particularly the case where screening is used to identify the potential future development of some disease, especially if the biology of transition is not fully understood[10]. In some cases there may be a continuous distribution of variables with people at one end being considered healthy and those at the other diseased, or in other cases the extremes may be found at either end of the scale. This leads Shickle and Chadwick to argue that there must be a threshold to trigger further intervention or treatment. 'The position of this cut-off in the distribution should be based on the associated risk of morbidity or mortality that warrants further intervention. The choice of threshold may therefore be arbitrary or depend on the resources available' (Shickle and Chadwick, 1994:13).

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[10] This is arguably the case with cervical screening, in which it is not fully understood which abnormalities will progress into cancer and which will not, nor on what basis.

2.4.2 Cervical screening

Many of the critiques of screening set out above, such as the possibility of false positive and false negative results and the subjective element in reading and interpreting tests, can be seen as relevant to the particular case of cervical screening. Some of the more specific critiques of cervical screening, in particular those concerning organisation, can be seen to have been addressed. For example, Day (1989) criticised cervical screening provision for being disorganised and having no clear focus of responsibility. Since then the national programme established in 1988 has done much to ensure that screening provision is organised and equitable across the country, and the setting up of the National Office in 1994 to have overall responsibility for the programme has further emphasised this. However, other critiques have not been so easily dealt with and remain relevant to this day. Indeed, recognition of these problems is clear within the kinds of research being carried out, for example the best way to manage women with mild or borderline abnormalities, in order to suggest improvements and 'fine tuning' to the programme.

The idea of a threshold for further intervention is particularly important in the case of cervical cancer. Moss (1996) discusses the recent debates around the best way to manage women with mildly abnormal smears. She states that, although there is widespread agreement that women with moderate or severe abnormalities should be referred for treatment, the management of women with mild or borderline abnormalities remains the subject of debate, and the TOMBOLA trial discussed above explores this. In 1986, a UK Intercollegiate Working Party recommended that women with mild abnormalities should be referred for immediate colposcopy. However, many argue that this policy is too aggressive. In their 1991 study, van Oortmarssen and Habbema found that a significant proportion of cervical abnormalities would regress on their own.

> Between age 18 and 34, the incidence of pre-invasive lesions is high, and the estimated proportion of regression among these lesions is 84%. The proportion regression over age 34 is 40%. From all lesions developing before age 65, an average of 62% is regressive (van Oortmarssen and Habbema, 1991:561).

They argue that their study provides clear evidence that a considerable proportion of cervical abnormalities will regress, especially at young ages. Coppleson and Brown (1975)[11] also found that most mild abnormalities would regress to normal in a short period of time. They argue that, in addition to the problems associated with unnecessary treatment and anxiety, the issue of regression also raises important questions about cervical cancer screening as a whole. 'Two things are certain, namely, that we do not properly understand the biology of the transition between dysplasia and carcinoma *in situ* and its proper categorization and that this problem needs immediate careful experimental elucidation' (Coppleson and Brown, 1975:134). Knox (1968) states that '…it is fairly clear that carcinoma *in situ* may progress to invasive cancer but it is not known how often this happens nor after what interval it is likely to happen, nor how often the *in situ* lesion regresses' (Knox, 1968:46).

In discussing cervical cancer screening, Narod *et al.* (1991) draw attention to the way in which it is based on the premise of a natural progression from normal to carcinoma *in situ* to invasive cancer. Screening assumes that if a woman can be identified and treated early in this progression then invasive cancer can be prevented. However, Narod *et al.* (1991) argue against this natural progression and regard cervical abnormalities only as a risk factor for subsequent invasive cancer, with severe abnormality conferring the greatest risk.

The unnecessary treatment of abnormalities that may regress spontaneously is counted by Ellman (1991) as a cost of screening. Ellman explores the costs both to the health service and to the patient. For the health service there are the implications of increased financial costs, the diversion of gynaecologists from other activities and a reduced cost/benefit ratio. The patient may experience costs such as increased time and travel, greater anxiety, unnecessary treatment and false reassurance from negative findings. Ellman argues it is crucial to bear in mind that a referral for colposcopy is not a trivial matter and can be very upsetting. There may be physical distress such as vaginal discharge after treatment and also a strong possibility of severe anxiety, which may

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[11] I am conscious that some of the studies cited in this section may appear somewhat dated. However, despite their age they raise issues which are still not resolved. For example, the process of transition from cervical abnormalities to cancer is still not fully understood hence the continued research into the role of HPV and studies exploring the best may to manage women with mild or borderline test results.

include changes in body image and have a strong negative effect on sexual feelings and behaviour (Posner and Vessey, 1988).

Perhaps the strongest criticism of cervical screening as a whole comes from Hann (1999) who questions whether it should be seen as preventive medicine or as an expensive mistake. She suggests it may be time to rethink the whole policy of screening for cervical cancer. The subjective nature of the way test results are arrived at and the scandals of mis-reporting that occur with 'monotonous regularity' are used by Hann to question the usefulness of screening. She is critical of the costs incurred by screening, particularly the opportunity cost (the amount of alternatives that must be sacrificed) and the broad costs of over-diagnosis,

> …cervical screening has the potential to generate excessive spending when patients who will never go on to develop cancer are repeatedly screened and treated…new technologies have the potential to increase costs by increasing the identification of even more minor abnormalities (Hann, 1999:252).

This view that screening as it currently stands is not cost-effective, and that too many women are being referred for further treatment when this is often unnecessary, is relatively widespread. For example Raffle *et al.* (1985) call for a more discriminating assessment of screening results in order to reduce the number of women referred. Again the NHSCSP can be seen as addressing these critiques through research into the potential of HPV testing to identify those women at high risk. So it is clear that the NHSCSP has dealt with many of its shortcomings, for example in relation to its organisation, and is engaged in research to identify possible new developments that can improve the way in which cervical screening is delivered and implemented in England.

2.5 Conclusion

This chapter has set out information on cervical cancer, the NHSCSP and has highlighted the debates within medicine around screening in general and cervical screening in particular. Its aim has been to provide vital background information and to set the scene so that the rest of the thesis can be put into context.

A great detail of information has been provided but, in the context of the forthcoming chapters, the following are perhaps the most important things to take forward. Cervical cancer is widely accepted to be preceded by benign, pre-malignant lesions, although the degree to which this transition is fully understood is questioned. These pre-malignant changes are typically asymptomatic and the majority are therefore detected through routine screening. The exact cause of cervical cancer is unknown but the role of high risk types of sexually-transmitted HPV is acknowledged, meaning certain forms of sexual behaviour, such as becoming active at a young age, having several partners and not using condoms, are regarded as risky. The possible influence of smoking, socio-economic group, oral contraceptive use and high parity have all also been explored.

Cervical cancer is therefore, given its benign, pre-malignant stage, a disease amenable to screening. A national screening programme was developed and the chapter detailed how this is managed and delivered. We saw that the programme achieves consistently high coverage of its target population, with over 80% of women being screened within the recommended interval. Both the target population for screening and the interval between smear tests have very recently changed and the potentially interesting ways in which this may influence women's understandings of cancer and screening, and their ideas on who is at risk and why, were highlighted. The chapter also gave some thought to potential new developments in screening, most notably the use of HPV testing to identify those women at most risk. The consequences of this in terms of women's understandings, their preparedness to attend for screening and the potential impact on the social acceptability of the disease were highlighted.

Critiques of screening were considered both generally and in specific relation to cervical screening. In particular, the appropriate threshold for further intervention, whether the biology of transition from abnormality to cancer is fully understood and the amount of unnecessary treatment that is possible are important. However, it was also noted that many of the problems highlighted are being addressed by the National Office of the NHSCSP through research into how the programme can be further improved and 'fine tuned'.

The areas covered here, and the kinds of material employed, to a degree represent the very clinical side of screening. It must be remembered that this is not the kind of

material or information that women typically encounter in the course of their contact with the programme. Instead, in Chapter 6, I explore the way in which screening is presented to those invited to participate and therefore characterise the official[12] discourse on cervical screening and how it is presented to women.

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[12] I explain what I mean by this term, and what I take to represent it, in both Chapters 5 and 6.

Chapter 3

Framing the Research Theoretically

3.1 Introduction

This research explores the ways in which women may demonstrate resistance to the official discourse that surrounds cervical cancer screening, and the purpose of this chapter is to frame this within relevant sociological theory. This is predominantly achieved in relation to Foucauldian theory, although more recent interpretations and developments of these ideas are also used.

The chapter begins with a focus on Foucault's earlier work on the disciplines and techniques of domination, exploring how individuals are controlled and constructed through discourse. This apparently deterministic perspective may initially seem to be at odds with the overall aim of the research and its focus upon the possibility for resistance. The emphasis may appear misplaced as it is his later works on 'technologies of the self' that are most relevant. However, these later works have developed from the perceived shortcomings and critiques of his earlier works and so it is appropriate, and indeed necessary, to become acquainted with these before moving on to explore how his later works balance them. An examination of these earlier works also allows a recognition of what it is that is being resisted.

Foucault's ideas on governmentality and the normalising discourse are employed as a means of characterising the official discourse surrounding cervical screening. Following this, Foucault's later works on the technologies of the self are considered as a way of opening up the space for lay women to demonstrate resistance to this. In order to ground the discussion more firmly in the sociology of health and illness, the New Public Health perspective within the discipline is explored and the ways it has taken Foucauldian ideas and applied them to this specific area are considered.

The chapter then moves on to consider the issues associated with resistance. This is pursued largely through feminist work that employs and develops Foucault's thinking in this area. As I discuss, some feminists have been highly critical of Foucault and reject his work as overly deterministic and as reducing women to nothing more than passive

victims. However, other feminist thinkers have been more willing to engage with it and this is a particularly fertile area in which to explore the issues associated with defining, representing and researching resistance.

Finally, the chapter develops the importance of perceptions of the body for the research. It details debates surrounding the nature of bodies, feminist arguments that the female body is constructed as 'problematic' within society, attempts to regulate bodies, with a particular focus on the role played by medicine in this respect, and finally women's responses to such strategies.

This coverage allows the chapter to conclude with a clear demonstration of how the research is framed in sociological theory and the perceived gap that it aims to fill.

3.2 Foucauldian Thought

To summarise his work very basically, Foucault is concerned with attempting to contextualize and historicize the notions of truth, knowledge, rationality and reason that are found within society at different times and to show how these relate to the construction of individual identities (Danaher *et al.*, 2000). For Foucault, what people could know was always limited by the particular context in which they were located and that which constituted truth and rationality was not inevitable, but rather liable to change across different cultures and different historical periods, therefore emphasising that things could always have been other. An important idea for Foucault is that people in another time and place may have understood things in a very different way to us, and may have made sense of the world in ways that we can hardly begin to imagine. In his 1973 work *The Order of Things*, Foucault explores the history of ideas in Western Europe and argues that it represents a series of 'epistemes', or sets of conceptions, that were each organised around a specific view of the world and how it was ordered (Gutting, 1989). This leads Foucault to argue that the episteme in which we live, or what is considered to be the 'order of things', determines how we make sense of things at that particular time and in that particular context. This position inevitably results in Foucault questioning the idea of the self-governing subject, as he argues that context comes between ourselves and how we understand and interpret our experiences. He is critical of the view of the individual as being fully self-reflexive, unified and rational

and instead sees the individual as being, to some degree, regulated and controlled by the structure and discourses within which they exist.

As a result of these arguments, Foucault is keen to explore the historical origins of the powerful institutions and discourses that are found within societies. An important method employed in this exploration is the 'archaeology of knowledge' (Foucault, 1972). Archaeology is the term used by Foucault to describe the process of uncovering the discursive formations and events that have produced the 'knowledge' of a particular historical period. He argues that knowledge and truth are the results of struggles between different institutions and disciplines, but are then presented as being inevitable and universal. Foucault uses this approach to try and make sense of the relationship between the individual and the society in which they find themselves. In his view, the subject is not 'natural' and has no pre-existing form outside the particular society. Instead, the subject takes on different forms both between and within societies and is constituted by the dominant rules of each society. In his later works Foucault balances this exploration of the technologies of domination with an exploration of the ways in which individuals may be involved in the construction of their own subjectivity through what he terms the technologies of the self. I return to this below.

In the course of these explorations of the complicated relationship between the individual and society, Foucault is continually concerned with the nature of power relations. He is concerned with how power works within societies and how it can be used in the creation of particular subject positions. As a result the continual development and reformulation of a concept of power is a constant preoccupation throughout his work (McNay, 1994). Foucault conceives of power as an essentially positive and enabling force, and is keen to explore the ways in which power operates at the micro level of society. Foucault sees this focus on the everyday nature of power relations as a microphysics of power. Instead of being seen as centralised and used by one group against another, power is conceptualised as much more diffuse and dispersed, and contained within all social relationships. Foucault argues that power,

…must not be sought in the primary existence of a central point, in a unique

source of sovereignty…it is the moving substrate of force relations which,

by virtue of their inequality, constantly engender states of power, but the

latter are always local and unstable (Foucault, 1981:93).

This formulation of power relations does not deny the possibility of a repressive form of power, but it does relegate it to one in a multiplicity of the potential effects of power (McNay, 1994). Therefore, although coercive and repressive relations of power do operate, Foucault is more concerned to explore the ways in which power works as a positive and enabling force through the creation of particular identities and subjectivities.

However, although this is his intention, McNay (1994) argues that Foucault has a tendency to slip back into a negative view of power and regard it as merely engaged in the production of docile and passive bodies. According to McNay, Foucault's reconceptualization of power as an essentially positive force attracted a great deal of criticism that drew attention to,

…a central tension in his work manifested in a slippage from the central

insight of power as a positive force to a negative and monolithic notion of

power as a dominatory force (McNay, 1994:85).

Foucault's later work on his ideas around the concept of governmentality (for example Foucault, 1991b) attempts to overcome some of the limitations of his previous idea of bio-power, and it is this concept of governmentality that will be of particular importance to this research.

3.3 Governmentality

The concept of governmentality attempts to overcome some of the problems of Foucault's previous conceptualisations of power through a broadening of the notion to include several forms. However, before there can be a discussion of this new concept of governmentality it is necessary to give a brief overview of Foucault's previous notion of bio-power.

Foucault argues that the notion of bio-power began to emerge with the concept of population as a potential economic and political problem in the eighteenth century. At this time governments began to become aware that they were no longer simply dealing with individual subjects, but with a population that had its own specific phenomena and peculiar variables, for example birth and death rates, frequency of illnesses, and patterns of diet and habitation (Foucault, 1991a). The population therefore came to be seen as possessing its own peculiar characteristics and variables that are, inevitably, linked to the prosperity of the nation. It was under these conditions that a new form of power began to develop and emerge: a form of power that was concerned with the administration of bodies and the calculated management of life.

> Hence there was an explosion of numerous and diverse techniques for achieving the subjugation of bodies and the control of populations, marking the beginning of an era of 'bio-power' (Foucault, 1981:140).

The exercise of this new form of power, Foucault argues, played an indispensable role in the development of capitalism, which greatly benefited from a means through which bodies could be inserted into the machinery of production. This new form of power allowed the optimisation of forces and life in general without making individuals more difficult to govern (Foucault, 1981).

The slippage from a view of power as a positive and enabling force back towards a view of power as a uni-directional and dominating force engaged in the production of docile and passive bodies is evident within this description of power. However, as McNay argues, Foucault's development of the concept of governmentality overcomes some of these problems as it broadens the category of power. The concept of governmentality moves the discussion of power from discipline and on to government. The notion of discipline is not replaced (Barry *et al.*, 1996). As previously discussed there is still the possibility for repressive forms of power, but the category is widened in order to include within it an analysis at the level of individuals and their conduct in everyday life. The concept of governmentality therefore represents an extension towards more diffuse forms of social control. The notion of government has a fairly wide sense and can be understood to refer to numerous different forms of the 'conduct of conduct' (Burchell, 1996; Dean, 1990). Burchell (1996) argues that the objects, methods and scale of

government will vary, and that there may well be interconnections and continuities between different forms of government. This will particularly be the case between localised and more centralised forms of government,

> …or between forms of government existing within micro-settings like the family or the school and the macropolitical activities of government directed towards individuals as members of a population, society or nation (Burchell, 1996:19).

In terms of these more diffuse forms of social control, the concept of normalisation plays an important role. Through the surveillance and analysis of populations, attention to their specific phenomena and peculiar variables, different sets of knowledges can be built up and the categories of what is considered to be normal and what is considered to be deviant can be established. The category of the deviant therefore establishes a set of divisions between the normal and the abnormal within society, and this implicates the subject within a set of normalizing assumptions. These assumptions can therefore be used to divide the population into subgroups: those that contribute to the welfare of society and those that retard it (Dean, 1990; Rose, 1996). This enables society and its members to

> …specify subjects in terms of certain norms of civilization, and effect a division between the civilized member of society and those lacking the capacities to exercise their citizenship responsibly… (Rose, 1996:45).

Foucault therefore argues that, in the modern disciplinary society, individuals are controlled through the power of the norm and that this power is effective precisely because it is relatively invisible. The behaviour of the individual is not simply regulated through overt repression, instead a set of standards and values associated with so-called normality is employed. This movement away from direct forms of social control and towards the use of more diffuse methods has been seen as a form of politics 'beyond the state' and as constituting a method of 'governing at a distance' (Rose, 1996; Barry *et al.*, 1996).

3.3.1 'Government at a distance'

Contemporary liberal societies are seen as constructing a particular relationship between government and those governed, which increasingly depends on individuals to fashion themselves as certain kinds of subjects (Barry *et al.*, 1996; Burchell, 1996; Dean, 1996; Rose, 1996, 1998). In this vein, Rose has argued that advanced neo-liberalism represents far more than a phenomenon at the level of political philosophy, instead it,

> …constitutes a mentality of government, a conception of how authorities should use their powers in order to improve national well-being, the ends they should seek, the evils they should avoid, the means they should use, and, crucially, the nature of the persons upon whom they must act (Rose, 1998:153).

The principle of this form of government requires that those who are governed freely conduct themselves in a certain rational fashion. In this way, those governed are identified as both the object of governmental action and, at the same time, a necessary and voluntary partner of such government (Burchell, 1996). The principle of such a form of government therefore requires that individuals exercise the 'proper use of liberty' (Burchell, 1996:24).

Rose (1996) has suggested that such liberal forms of rule represent the possibility to govern without governing society as such. Instead, they govern through the,

> …regulated and accountable choices of autonomous agents – citizens, consumers, parents, employees, managers, investors – and to govern through intensifying and acting upon their allegiance to particular 'communities' (Rose, 1996:61)

In this way, the reference above to the individual as constituting both the object and necessary partner of government can be refined to construct more specifically the **autonomy** of that individual as both the objective and the instrument of such forms of government.

The autonomy of individuals, and particularly ensuring its proper exercise, is therefore crucial and, to this end, various techniques are employed that interweave and link up to form a mutually reinforcing series that impacts upon the ways in which individuals conduct themselves. Liberal strategies of government depend upon such devices that create individuals who will govern themselves. In this way Rose (1998) draws upon the ideas of Foucault to explore how power works **through** and not **against** subjectivity. He stresses that Foucault saw power not as negating the capacities of individuals but as a force involved in the creation and shaping of human beings as subjects. The relationship between power and the self is therefore not a matter of autonomy being suppressed but of investigating the ways in which subjectivity is an essential object, target and resource.

> The autonomy of the self is thus not the eternal antithesis of political power, but one of the objectives and instruments of modern mentalities and strategies for the conduct of conduct. (Rose, 1998:155)

Burchell (1996) argues these techniques of government frequently involve governed individuals adopting particular practical relations to themselves in the exercise of their freedom in appropriate ways, therefore ensuring,

> …the promotion in the governed population of specific techniques of the self around such questions as…saving and providentialism, the acquisition of ways of performing roles like father or mother, the development of habits of cleanliness, sobriety, fidelity, self-improvement, responsibility and so on (Burchell, 1996:26).

Similarly, Rose has argued that such government is dependent upon the 'proliferation of little regulatory instances across a territory' (Rose, 1996:61) and their multiplication through our everyday practice and experience. Liberal strategies of government therefore require devices, such as schools and the family, that can produce individuals who do not need to be governed as such, '…but will govern themselves, master themselves, care for themselves.' (Rose, 1996:45)

Expertise, taken to refer to the authority arising from a claim to knowledge, neutrality and efficacy, is seen as central here and as providing a solution to the apparent opposition of liberalism. This tension is between the need to govern on the one hand, in the interests of morality and order, and the need to limit such government on the other in the interests of liberty and economy (Rose, 1992, 1996, 1998). For Rose, expertise is important in three main respects, which distinguish it from past regimes of government. Firstly, the authority of expertise is grounded in claims to scientificity and objectivity and, therefore, creates a necessary distance from the state. Secondly, expertise can be mobilised in distinctive ways so as to produce a new relationship between knowledge and government. Thirdly, expertise is seen as operating through the particular relation it has with the self-regulating capacities of individuals. Rose argues that, through this, subjects are bound to experts in new and potent ways and that experts and expertise become central to the process of self-formation. In the context of cervical screening, the expertise of medical experts and policy makers encourages women to act in a particular way and construct themselves as a particular kind of citizen: a responsible individual who attends for screening.

Through the deployment of such techniques and 'little regulatory instances', individuals learn how to exercise their freedom in appropriate ways and therefore come to govern themselves. Certain norms of civilization are established and, therefore, divisions can be drawn between those individuals that are considered civilized and those that lack the capacity to act responsibly (Burchell, 1996; Rose, 1996). Individuals in contemporary liberal societies are encouraged to regard themselves as a project to be continually worked on and improved (Rose, 1992). They must continually develop and refine themselves with the ultimate aim of developing a 'style' of living that '…will maximize the worth of their existence to themselves' (Rose, 1998:157). In his discussions of this transformation, Rose (1998) identifies health as an exemplar and argues that, while healthy bodies and hygienic homes are still publicly valued and a political objective, the state no longer encourages these through compulsory inspection. Instead, individuals themselves now **want** to be healthy, and experts will instruct them on how to achieve this through identifying certain practices as healthy and others as unhealthy. Therefore, through the creation of individuals who will govern themselves, and the development of expertise to help them do so, liberal strategies of government remove the need for the governing of society as such. The practices of modern freedom are therefore built on

strategies of government and techniques of regulation, but Rose does not conclude that this means such freedom is a sham. Rather,

> …the agonistic relation between liberty and government is an intrinsic part of what we have come to know as freedom. (Rose, 1996:62)

3.3.2 The role of discourse

One important way in which this new form of government operates is through discourse, and Foucault sees a 'discursive explosion' as having taken place over the last few centuries (Foucault, 1991a). Of particular interest to Foucault were the discourses that began to emerge around sexuality. These discourses began to appear with the emergence of the concept of population, as previously discussed. This focus upon sex is of critical importance to Foucault as it represents the first time a society began to understand that its future prosperity was tied to the number and, more importantly, the behaviour of its citizens. It also raises the important question of how society could or would have been different without such a focus. The political value of mobilising and shaping the capacities and conduct of individuals was being recognised (Barry *et al.*, 1996). It is commonly assumed that sexuality was controlled through a system of repression in which it was carefully confined and hidden away behind closed doors, not to be spoken of. However, Foucault (1981) expresses serious doubts about what he has termed this 'repressive hypothesis'. He questions whether sexual repression is really an established historical fact, whether the power operating within society was really repressive in nature and, finally, whether the critical discourse addressed to repression acted as a block to these power mechanisms or whether it was part of the same historical network. Foucault argues that this 'repressive hypothesis' was not the method through which the sexual behaviour of individuals was controlled and managed within society, instead he argues for the role of discourse as the means through which power came to be exercised and sexuality controlled.

In contrast to the idea of the 'repressive hypothesis', in which sex is hidden away and not spoken of, Foucault argues there was a proliferation of discourses concerned with sex. It was in this way that '…sex was taken charge of, tracked down as it were, by a discourse that aimed to allow it no obscurity, no respite' (Foucault, 1991a:303). Sexuality came to be controlled by, and through, discourse.

The most powerful discourses within society are argued to be those that have a firm institutional base, for example in the law or in medicine, social welfare or education (Weedon, 1987). Discourses look to institutionally legitimised forms of knowledge for their justification, the most common of these being science, god and common sense. The social interests that these discourses represent will depend upon the particular social conditions under which they are produced (Weedon, 1987). The saturation of bodies through discourse has the effect that the individual begins to internalise the discourses and eventually become a self-policing subject. The concept of government is therefore extended right down to the way in which individuals come to govern themselves (Burchell, 1996; Dean, 1990; Rose, 1996, 1998). The individual comes to question their own conduct so that they may be better able to govern themselves.

> Control in modern societies is achieved, therefore, not through direct repression but through more invisible strategies of normalization. Individuals regulate themselves through a constant introspective search for their hidden 'truth', held to lie in their innermost identity (McNay, 1994:97).

3.4 Technologies of the Self

As has been discussed above, Foucault is often criticised for the unresolved tension between his proclamation of power as a positive and enabling force, and the tendency for him to slip back into a negative, uni-directional form of power. McNay (1994) argues that this slippage is exacerbated by Foucault's one-dimensional analysis of institutional power. It is argued that power relations are only examined from the perspective of how they are installed within institutions and little attention is paid to the ways in which the potential subjects view this power. Dews (1989) uses the penal system as a case in point and argues Foucault's analysis concentrates too heavily on the official representations of these institutions at the expense of those being controlled. This can lead Foucault to significantly overestimate the effectiveness of disciplinary forms of control as he paid little attention to the other 'knowledges' that may emerge, for example a prison subculture.

McNay (1994) suggests Foucault conceded that the emphasis he placed on the effects of power on the body led to a one-dimensional account of social agents and a monolithic account of power and that,

> …to obtain a fuller understanding of the modern subject, an analysis of *techniques of domination* must be counterbalanced with an analysis of *techniques of the self* (McNay, 1994:134, emphasis in original).

Foucault addresses this apparent imbalance in his later writings and argues against his conceptualisation of power as implying a system of domination that denies the possibility for individual freedom. He states,

> The idea that power is a system of domination that controls everything and leaves no room for freedom cannot be attributed to me (Foucault 1984c:442).

He argues that his views on the nature of power have always implied the possibility of resistance, because without this possibility there can be no relations of power (Dumm, 1996). In order for power relations to come into existence there must be a certain degree of freedom on both sides. If there were no possibility for resistance then there would be no power relations.

Foucault's later works balance his previous focus on technologies of domination with an exploration of what he terms the 'technologies of the self' (Foucault, 1988). This idea complements Foucault's earlier work on the ways in which the subject is constituted as an object of knowledge with an analysis of the ways in which individuals come to understand themselves as subjects (McNay, 1994). It is through this concept that a theory of possible resistance is developed.

In his studies of Ancient Greek and Roman morality, Foucault perceives a difference between these classical moral systems and those of the Christian tradition (Foucault, 1984a&b). An important distinction between morality and ethics is discerned. Morality is seen as a set of imposed rules and prohibitions, ethics as the actual behaviour of individuals in relation to the advocated morality. Foucault is therefore able to argue that

the possibilities for resistance are located at the level of ethical behaviour, that is, at the level of individuals' daily lives. The dominant discourse with which an individual is presented (likened to morality) need not be perfectly reflected in the individual's subject position (likened to ethics). The individual's thoughts, accounts or actions may differ from those advocated by the discourse. Foucault is therefore able to introduce the possibility of autonomous action on the part of the individual. The individual can now be seen as having the opportunity to influence the way in which their subjectivity is constructed. A more flexible relationship between the dominant discourse and the individual is suggested and emphasis is placed on the formation of a relationship with the self and on the methods and techniques used to work out this relationship (McNay, 1994). Burchell (1996) argues the introduction of technologies or techniques of the self implies a loosening of the connection between subjectification and subjection. A greater element of freedom is allowed within individual behaviour in relation to the normal rules of conduct within a society. Individuals have the potential to interpret the norms of behaviour in their own ways rather than simply conform to them exactly.

Foucault can therefore argue that the process through which large-scale cultural patterns come to be demonstrated at the individual level need not be one of straightforward imposition, cultural patterns need not be perfectly reflected in individual behaviour. Individuals may engage in 'practices of the self' and therefore have the potential for some display of resistance. McNay (1994) discusses this in terms of an 'ethical moment' in the process of mediation between large-scale patterns and individual identity. During this moment practices of the self achieve a level of 'critical self-awareness or reflexivity' (McNay, 1994:155) and forms of identity can be questioned opening up the space for an exploration of new forms of experience.

However, neither is the individual free to act in any way they wish,

> …I would say that if I am now interested in how the subject constitutes
> itself in an active fashion through practices of the self, these practices are
> nevertheless not something invented by the individual himself (sic). They
> are models that he finds in his culture and that are proposed, suggested,
> imposed upon him by his culture, his society and his social group (Foucault,
> 1984c:441-2).

The relationship is not uni-directional in terms of society merely producing docile bodies, but equally, neither can it be seen as a voluntarist process of self-construction. Instead the process represents a point of contact at which techniques of domination and techniques of the self interact to produce individual subject positions (Burchell, 1996). The process is complex as particular discourses suggest more than one subject position because, while there exists a preferred form of subjectivity, its very existence implies others and the possibility for reversal (Weedon, 1987). In order to be effective, discourses need to be activated through the agency of individuals and this works best when the subject position assumed within a particular discourse is identified by the individual as compatible with their interests. Where this is not the case then the space for resistance is opened up. As Weedon argues,

> Where there is a space between the position of subject offered by a discourse and individual interest, a resistance to that subject position is produced…The discursive constitution of subjects, both compliant and resistant, is part of a wider social play for power (Weedon, 1987:112-3).

However, McNay argues that, despite having developed such a complex theory of this process, and the possibilities opened up for resistance, Foucault fails to sustain an analysis of this. Such an analysis is crucial for distinguishing between those practices of the self that simply reproduce conventional patterns and those that have a radical force. She argues,

> By failing to contextualize the notion of an aesthetics of existence with regard to the social relations in which it is embedded, Foucault finishes by merely juxtaposing rather than relating the micro level of practices of the self against the macro level of the determining social horizon (McNay, 1994:155).

I explore these kinds of criticisms further in relation to the feminist interpretations and uses of Foucault's work and their perspectives on resistance in section 3.6 below. Before this though, I explore how these ideas around governmentality and the potential for resistance have been applied to the specific context of health.

3.5 The New Public Health

The New Public Health (NPH) perspective within sociology takes the ideas of Foucault and applies them to the specific area of health and health promotion. This approach draws attention to the ways in which health status and the means for achieving good health have come to be amongst the predominant concerns of modern society (Petersen and Lupton, 1996). While health has always been of some concern in nearly all societies there has, since the mid 1970s, been a growth of new knowledges and activities related to health status, and in particular to the health status of populations. Of particular interest to this research is the well-documented shift in the focus of health care policy towards the need to promote good health and to encourage populations to monitor their own health. Chronic conditions such as cancer and heart disease are now the central focus of public health practitioners, especially in terms of their prevention.

Public health's reliance upon the themes of science and the statistical calculation of risk reinforces its claims and evokes a progressionist view, as well as clearly tying in with Rose's arguments on the significance of expertise and Foucault's work on bio-power. However, Petersen and Lupton (1996) argue that this view obscures its profound moral, political and social implications. In contrast to this progressionist view, they argue the NPH can be seen as the most recent example of the regimes of power and knowledge employed in the regulation and surveillance of individuals and populations, and that this aspect has been largely unexplored. Sociological work on the NPH therefore clearly draws on the work of Foucault to explore the interconnections between specific techniques of governance and particular forms of knowledge and expertise (Rose, 1996). These ideas are used to examine the ways in which discourses such as public health help to shape individual identity. Emphasis is placed upon an examination of the power of knowledge to define and therefore govern subjects (Petersen and Lupton, 1996). Expert knowledge[13] plays an important role within this function, and the professional, scientific view of what causes ill health, and therefore what should be done to prevent it, is privileged over lay explanations. Expert knowledge is used to shape the thoughts and understandings of individuals. Therefore, rather than fulfilling a constraining and regulatory role, the power exercised within NPH discourses works

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[13] Although it should be acknowledged that experts' views do not always converge.

through the production of individuals who are capable of some form of autonomy and will therefore regulate themselves (Lupton, 1995). Through the production of norms of healthy behaviour, such as practising safe sex, eating sensibly and attending for medical screening, by which they are monitored and classified, individuals are persuaded to conform voluntarily. Indeed, public health largely employs a model of (apparently) voluntary individual action with a much smaller role for legislation. As Lupton argues,

> Individuals are rarely incarcerated or fined for their failure to conform: however they are punished through the mechanisms of self-surveillance, evoking feelings of guilt, anxiety and repulsion towards the self, as well as the admonitions of their nearest and dearest for 'letting themselves go' or inviting illness (Lupton, 1995:10-11).

The concept of citizenship is central within the NPH (Petersen and Lupton, 1996) and this emphasises both the rights and the duties of individuals to take on board and conform to the imperatives of public health knowledges as defined and constructed by the 'expert'. The achievement and maintenance of good health is necessary for an individual to be regarded as a 'good citizen', because illness removes individuals from the workforce and prevents them from fulfilling their other social obligations. Good health is therefore regarded as each citizen's duty. This 'duties' discourse places the emphasis upon social obligations and personal responsibilities in the context of health.

One of the most important objectives in terms of preventative health is to track down, calculate and eliminate risk. Indeed, Castel (1991) has argued that the notion of an individual is increasingly being lost and replaced with simply a combination of risk factors. Within public health discourses, the individual is encouraged to monitor their relationship to risk, and therefore to manage their own 'risk profile'. This has resulted in the ability of the individual to manage their health risks being linked to their ability to manage themselves and to exercise self-control (Ogden, 1995). The body effectively becomes a project that must be worked on and forms part of the individual's self-identity. The healthy body becomes an important signifier of moral worth.

> 'Healthiness' has replaced 'Godliness' as a yardstick of accomplishment and proper living. Public health and health promotion, then, may be viewed as contributing to the moral regulation of society, focusing as they do upon ethical and moral practices of the self (Lupton, 1995:4).

Public health and health promotion therefore privileges a certain type of subject, one who is self-regulating and health-conscious, and a particular type of body, one that is under the control of the individual's will. These strategies are engaged in the production of such subjects and bodies.

However, while public health discourses do have success in changing individual behaviour, they do not succeed with all individuals and not all of the time (Lupton, 1995, 1997). While these discourses may succeed with particular types of individuals, for others their messages will be ignored or will be transformed or contested. Lupton argues that if the individual does not recognise her or himself within the discourse, or has no investment within it, they will not respond accordingly. In particular, attention is drawn to the level of everyday life where these norms of healthy behaviour may be negotiated and reconstructed. Foucault's idea of the technologies of the self is employed to explore how individuals interact with, and make sense of, the public health discourses with which they are presented,

> …people may not conform to public health or health promotional advice because of a conscious sense of frustration, resentment or anger, or because they derive greater pleasure and satisfaction from other practices of the self, or because they experience an unconscious imperative that directs them to take up alternative subject positions and bodily practices (Lupton, 1995:133).

It is not only the health promotion discourse that will have an effect on the individual's behaviour, the media, members of their social network and their personal experiences will also have an impact. The many discourses that impact on the construction of the subject are therefore too numerous to ensure full compliance with particular public health messages. However, as Foucault emphasised, the ways in which individuals can exercise resistance to these dominant discourses are still limited by the social context.

'It is accepted that this dialectic can never be fully resolved; subjects are neither wholly governed by discourse nor fully capable of stepping out of discourse' (Lupton, 1995:137).

3.6 The Nature of Resistance

As I have taken care to stress throughout this chapter, the potential for resistance is acknowledged within Foucault's work as, for him, there must be at least the possibility of freedom for power relations to come into being (Dumm, 1996). However, despite his complex theories of the relationship between techniques of domination and practices of the self he is criticised for not producing a sustained analysis of this and ending up merely juxtaposing the two (McNay, 1994).

Many criticisms of this kind have come from feminist writers who have argued that Foucault did not go far enough in exploring this relationship and that this remains problematic (see for example Grimshaw, 1993; Ramazanoglu, 1993; Ransom, 1993). Indeed Ransom in particular argues that Foucault has systematically refused to address this issue.

> But what is the relationship between discourse and the human subject implied here? Is it one in which human agent exists in some sort of tension with discourse, as Foucault's theory of power and resistance might imply? The question is one which Foucault systematically refuses. (Ransom, 1993:133)

Some feminists have been highly critical of Foucault on this basis and have argued that his ideas on power and discourse have stripped women of the possibility for resistance. However, others have been more willing to engage with Foucault's work and to explore the new ways in which it enables them to look at the control of women (Ramazanoglu, 1993). This has led to attempts to explore the possible ways in which women may be able to exercise resistance.

In this section I deal with important issues around what I have termed the 'nature of resistance' largely through such feminist work. I consider what we can legitimately take to constitute resistance and explore studies that provide examples of what such

resistance can look like. Firstly though, I set out why it is important to study such power/resistance relationships.

3.6.1 Importance of power/resistance relationship

There is a longstanding assumption in feminist scholarship that there is a relationship between power and resistance, and this has raised questions about how to combine the idea that women can construct their own lives with that which holds that they do so within determinant conditions (Davis and Fisher, 1993). The importance of finding a way to combine these two ideas is clear, as there are inherent problems associated with focusing analysis on either structure or agency. Davis and Fisher (1993) have argued that a focus on structure can neglect how women resist and undermine such structures and risks portraying them as passive victims, while a focus on agency can fail to consider context and runs the risk of blaming the individual if resistance is unsuccessful. The concern is therefore with how to 'conceptualize and investigate power and resistance in women's everyday social practices' (Davis and Fisher, 1993:4).

Following Foucault's conceptualization of power as no longer centralized and repressive, but as widely dispersed and localised and occurring in all social interactions, feminists have argued that this means such power relies on there being a multiplicity of points of resistance. Therefore, resistance cannot be reduced to a single locus and attention is focused on how women can be 'negotiating at the margins of power' (Davis and Fisher, 1993:6). Kielmann (1998) is clear that the focus of such an analysis needs to be at the level at which individual women interact with discourse. As such she advocates,

> …shifting attention from the sites of biopower, that is the institutions that develop and sustain discourses on the regulation of the social body, to the sites at which these discourses are internalized, transformed, or resisted by the women who are affected by them (Kielmann, 1998:135).

For Kielmann, it is clear that women can develop different, and potentially opposing, meanings and conduct on the margins of dominant discourses that attempt to regulate them. It is this which allows them to 'mediate between social orders and to invent new forms of knowledge' (Kielmann, 1998:138).

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In a similar vein, Sawicki (1999) has used the example of new reproductive technologies to argue that, whilst it is important to identify how these can threaten to erode women's power over reproduction, it is equally important to locate the potential for resistance to this. To achieve this she focuses not just on the discourses of those men who develop such technologies, but also on those of the women affected and their experiences. This reinforces Sawicki's earlier writings on Foucault in which she argues that resistance must be carried out in local struggles and stresses the existence of the critical subject.

> This subject does not control the overall direction of history, but it is able to choose among the discourses and practices available to it and use them creatively…this subject can suspend adherence to certain principles and assumptions, or to specific interpretations of them, in efforts to invent new ones. Foucault's subject is neither entirely autonomous nor enslaved, neither the originator of the discourses and practices that constitute its experiences nor determined by them (Sawicki, 1991:103-4).

The task of exploring this relationship between power and resistance is therefore a central concern for such feminists who are keen to engage with Foucault's work and develop the potential for women's resistance.

3.6.2 What do we mean by resistance?

Attempting to define what we mean by resistance, and regarding particular practices or behaviours as such, can be fraught with problems. Grimshaw (1993) has discussed the difficulties, including on what grounds we can identify something as resistance, how we can distinguish between effective and ineffective resistance and, perhaps most importantly, how we are to determine when a particular behaviour or practice represents the mere reproduction of conventional norms and when it becomes resistance. Lewin (1998) has echoed this point and suggests that particular difficulties are encountered when attempting to cast everyday behaviours as resistance. She suggests the various forms that resistance may take in order to demonstrate the complexity of the problem.

Resistance…can be either conscious or unconscious, either carefully crafted or serendipitous, either direct and efficient in its impact or stymied by powerful forces beyond the control of the actors. Resistance can be physical and observable or may be imputed even to those who accede to the demands of the powerful while perhaps secretly harboring what seem to be subversive thoughts. (Lewin, 1998:164)

We must also be aware of the need not to 'romanticize' women's resistance and ascribe it a quality that was never intended. Abel and Browner (1998) have suggested that much of the recent emphasis upon women's resistance is the result of a desire to describe dominatory patterns but without portraying women as nothing more than passive victims. They argue that 'our desire to restore agency to such groups may encourage us to find instances of resistance where none exists' (Abel and Browner, 1998:322). Abu-Lughod (1990) has also warned against this and raised further 'analytic dilemmas' about how to deal with such resistance through a case study of Bedouin women. These centre around, firstly, how to deal with such practices without misattributing elements to them that are not part of the experience, while also not devaluing them. Secondly, how to deal with the fact that such women both resisted and supported the existing system of power. Finally, how we can acknowledge that, whilst forms of resistance such as folktales and poetry can be culturally provided, they can still be seen as resistance. Abu-Lughod's proposed solution to such 'analytic dilemmas' is a shift in perspective that is concerned not so much with the status of resistance itself as what forms of resistance can tell us about the forms of power that they are competing with. This, of course, feeds back into the need to explore the power/resistance relationship as a whole, rather then simply one side of it, in order to avoid the inherent problems (Davis and Fisher, 1993).

However, this does not completely remove the problem of arriving at some form of definition of what can be taken to represent resistance. Appeals to think carefully about what kinds of behaviours or practices should be regarded as such, although sensitising us to the issues and potential consequences, leave us no nearer a conclusion.

Perhaps the most important issue in determining what should be regarded as resistance is whether intention is vital. In considering women's responses to the process of

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medicalization, Lock and Kaufert (1998) explore the complexity of these which, they argue, can range from selective resistance to selective compliance. In specific relation to new medical technologies, they argue that women's relationships to these are usually grounded in existing habits of pragmatism and that in this way women's resistance may be for pragmatic rather than ideological reasons. However, despite this it is still in direct response to a form of power. This leads us to question whether intentionality is vital for a behaviour or practice to be regarded legitimately as resistance.

Kielmann (1998), in the context of exploring women's resistance to the stigma of infertility, adopts the position that intentionality is necessary and argues that,

> …we can only start to attribute meanings of resistance when women themselves envisage and express the possibility of options diverging from orthodox frameworks of meanings (Kielmann, 1998:136).

This may at first appear a relatively extreme position, but Kielmann offers this in the context of discussing the problematic nature of regarding particular bodily practices, such as gestures and habits, as resistance.

In relation to her study of childless women in South India, Riessman (2000) employs a rather less stringent criteria and argues that the women's responses to the stigma of being childless are complex and contradictory. Women collaborate in the reproduction of gender hierarchy in marriage at the same time as challenging those in-laws who blame them for infertility. Riessman argues that a feminist language of resistance is better able to capture the complexity of such resistance than theories of stigma. With particular reference to what can or should be regarded as resistance she argues that,

> Efforts do not have to be public, organized, formal, or *unambivalently intentional* to qualify as resistance (Riessman, 2000:122, my emphasis).

Rather than focus on intention, Riessman uses the concept of 'transformative effects' when considering whether thoughts or actions represented resistance. She argues that studies of resistance need to be contextual and to take the possibilities for resistance into account. However, this does not mean that resistance can or should be ascribed to

practices of simple coping or adaptation in the case of adversity. There must still be an element of agency present. For Riessman, resistance includes 'transformative actions in which women press their own claims vis-à-vis others who stigmatize them' (Riessman, 2000:131).

I regard this conceptualisation as more useful than that put forward by Kielmann (1998). By regarding resistance as the transformative thoughts and/or actions of individuals in order to press their claims in relation to others', Riessman maintains the need for 'palpable agency' without the restrictive criteria of intentionality. Having taken the first steps towards defining what I take to constitute resistance within this research, I now turn, both in this chapter and the next, to exploring how such resistance may manifest itself before ultimately setting out my position.

So how does this resistance manifest itself? In her research Riessman (2000) identifies three patterns of resistance, the first two consist of transformative thoughts and actions in everyday life, including resistant thinking and strategic avoidance and speaking out against stigma, while the third involves rejecting motherhood by being voluntarily childless.

In her research on women and breast cancer, Kaufert (1998) also explores the complex nature of resistance, particularly in terms of resistance from within the system. This stems from Kaufert's argument that withdrawal from such a system for a woman with breast cancer would be difficult to maintain. She therefore explores the various forms of resistance developed from within the system. Kaufert argues that women with breast cancer have put together an oppositional discourse on the disease that challenges existing stereotypes of how women with cancer should see themselves and how they should behave. While this resistance was initially manifested at the micro level of individual encounters with health professionals,

> …resistance subsequently turned into a demand for the reformulation of the
> relationship between women and the medical and scientific research
> establishment (Kaufert, 1998:288).

In terms of the resistance demonstrated at the individual level, Kaufert details how women prepared lists of questions for their oncologists, consulted other women, phoned information lines and did their own literature searches. She asserts that asking questions, querying treatment or changing doctors all counts as resistance, albeit confined to the micro-political level.

It is at precisely this level of everyday life and interactions that Foucault's conceptualisation of power leads us to look for resistance. To reiterate, Foucault did not see power as being centrally located in the hands of the powerful within society. Instead, power is seen as more widely dispersed and localised, present within all social interactions. It is for this reason that traditional views of how to seize power are seen as misguided.

> Revolutions in the sense of traditional political oppression are ruled out as
> ineffective resistance because they are based on the assumption that power
> is an external force possessed by some ruling group and exercised through
> laws and prohibitions (Bailey, 1993:117).

As power is seen as being much more dispersed and as taking a multiplicity of forms, no longer simply repressive or coercive, resistance to these specific power relations must be equally dispersed and diverse. Bordo (1993) has argued that modern power relations are increasingly seen as being unstable and transitory and so resistance to these must also be perpetual and ever-changing. The importance of focusing resistance at the local, individual level is stressed within many feminist accounts. It is therefore important to recognise that the situations of individual women can vary enormously and that the potential for resistance, and the available strategies and resources for this, may be very different. Writers such as hooks (1981, 1989), for example, have long argued that the position of black women can be very different to that of white women, and that mainstream feminism has failed to take sufficient account of this. Difference of course extends beyond race or ethnicity though and there exist a range of other factors that may impact upon the potential for women to resist, such as social class or sexuality. In her study on the ways in which South Indian women resist the stigma of childlessness, Riessman (2000) argues that women in different social class positions can mobilize different resistance strategies. She also draws attention to how such stigma operates

differently over the life course, as the value of motherhood varies. As such the availability, and effectiveness, of particular resistance strategies may also vary. There are therefore a plurality of factors that may influence whether and how different women can demonstrate resistance.

In her introduction to the edited collection *Up Against Foucault*, Ramazanoglu (1993) explores some of the possible forms that resistance may take. She argues that resistance to power,

> …comes through new discourses producing new truths. These may be 'counter discourses' which oppose dominant truths, or 'reverse discourses' (Ramazanoglu, 1993:20).

While a 'counter discourse' exists in opposition and may potentially relate to the original in a variety of ways, a 'reverse discourse' is more closely tied to what is being resisted. This concept can be explored through Foucualt's own example of homosexuality. Foucault (1981) argued that the discourses produced around sexuality served to normalise heterosexuality that was practiced within the marriage relationship and that produced children. In turn, other forms of sexuality, those that did not fit within this discourse, were problematized and came to be seen as deviant. However, it is inevitable that the very act of constructing a particular form of sexuality as normal and desirable will have the effect of creating other forms of sexuality and sexual behaviour that are counter to that desired. Those who occupy these alternative positions will gain some form of identity, however undesirable and abnormal this identity is deemed to be by that which is dominant. Sexual heterogeneity was initiated in which the dominant discourse around 'normal' sexual behaviour was contrasted with '…a multiple implantation of 'perversions'.' (Foucault, 1981:37). While this had the inevitable effect of making the advance of social controls into these areas of perversion possible, Foucault argues that it also had the effect of making possible the formation of a reverse discourse.

Homosexuality began to speak in its own behalf, to demand that its legitimacy or 'naturality' be acknowledged, often in the same vocabulary, using the same categories by which it was medically disqualified (Foucault, 1981:101).

Ransom (1993) has contrasted this production of counter or reverse discourses with the more traditional view of what constitutes effective resistance.

Radical movements are not best understood as seeking to seize power or take power, but rather as producing alternative power-saturated knowledges (Ransom, 1993:129).

In further developing her argument, Ransom uses the work of Weedon (1987) in discussing the various discourses that have emerged around motherhood. As discussed previously, Weedon resists the critique that some feminists level at Foucault, namely that his notion of discourse dissolves the agency of the subject, reducing it to a docile body. Instead, she argues that, although the subject is constructed through discourse, she still exists as a thinking, feeling social agent who is capable of some display of resistance and innovation. This potential emerges from the clash between alternative subject positions suggested to the individual, and how these fit with the individual's interests. Ransom (1993) uses the idea of motherhood to show that, while a discursive construction of the perfect mother may exist, this may be challenged by competing feminist conceptions of what women can be or the differing ways in which they can be mothers.

However, as Bartky (1988) has pointed out, individuals may be unwilling to relinquish the secure self-identity that a particular discipline offers. This is because, regardless of its ultimate effect, discipline has the potential to provide the individual upon whom it is imposed with a secure sense of identity. There may therefore be a reluctance to part with the 'rewards of compliance'.

Putting this possibility to one side, the development of alternative discourses increases the potential for individual agency and resistance. This is because if competing discourses exist then the individual must interact with them and ultimately choose

between them. Feminist writers sympathetic to Foucault have argued that, far from the passive subject that critics accuse him of portraying, this active individual is compatible with Foucault's work. Sawicki (1991) in particular has argued that this kind of critical individual is precisely what Foucault envisaged.

3.7 Sociology of the Body

While the chapter thus far has alluded to the importance of the body and the way in which it is subject to regulation, most notably through the use of Foucault's concept of bio-power, it is now necessary to explore this area in more detail and relate my research more explicitly to issues surrounding the regulation of bodies in general and the regulation of the female body and feminine sexuality more specifically.

3.7.1 The nature of bodies

Foucauldian theory regards the body as merely a fabrication that has no 'real form' outside particular discursive formations. The body is continually constructed and reconstructed in different forms through discourse and various conceptions of the body become privileged over others within different societies and at different times. However, these privileged conceptions are rarely regarded as such and instead are taken to constitute a particular reality, which is used to justify and perpetuate particular claims to truth (Shildrick, 1997). Shildrick is particularly concerned to explore the truths that are attributed to the female body within a male social order. She argues that, although bodies themselves are discursive formations, the results that follow from the adoption of these 'truths' can, and indeed do, have very real material effects on the lives of women (Shildrick, 1997). These material effects on women are also discussed by Lawler (1991) in her discussion of the interdependent relationship that exists between biology and culture, and the way this impacts on the body and is expressed bodily. Lawler cites the work of Kern (1975) who argues that the body, and what are taken to be the truths about that body, are crucial determinants of how our social lives are conducted (Lawler, 1991:71). It can therefore be argued that privileged conceptions of the female body are used to determine the role of the female within a male social order.

> The female body is a problem for women in patriarchal society because it
> forms a nexus with reproduction and sexuality through which female roles
> are constructed and reinforced (Lawler, 1991:100).

The ways in which power can be exercised through the discursive production of the body have been detailed in Armstrong's *Political Anatomy of the Body* (1983). In this work, Armstrong argues that the various ways in which the body has been described and constructed throughout history are not simply the results of random events or a progressive enlightenment. Instead they are based on,

> …certain mechanisms of power which, since the eighteenth century, have pervaded the body and continue to hold it in their grasp. From that time the body has been the point on which and from which power has been exercised (Armstrong, 1983:2).

In particular, Armstrong (1983) has explored the ways in which particular constructions of the body have impacted upon the development of medical knowledge and medical education. The problematic nature of the medical model of the body has been discussed at length within medical sociology and, more recently, in the emergent sociology of the body. Shildrick (1997) has argued that the medical model of the body is problematic, especially for feminist theorists, as it represents the body as some kind of stable and unchanging given,

> …differentiated simply by its variable manifestation of the signs and symptoms of health or disease, ability or disability, normality or abnormality (Shildrick, 1997:15).

This approach, it is argued, ultimately results in the human body being reduced to the level of a machine, the occurrence of illness being seen as merely the malfunctioning of that machine. This reductionist approach, focusing as it does on the pathology of the body, is essentially dehumanising. The medical model of the body, Shildrick argues, relies heavily on a reading of the dualistic conception of mind and body developed by Descartes in the seventeenth century. A traditional reading of this Cartesian model credits the mind with the powers of intelligence, spirituality and selfhood, while, in contrast, the corporeal body is regarded as simply a machine. This medical conception of the machine-like body is further explored by Turner (1992), particularly in the context of his discussions of attempts to govern and regulate the body through diet. In

his exploration of dietary science, Turner draws attention to metaphors of the body and argues,

> …the growth of theories of diet appears to be closely connected with the development of the idea that the body is a machine, the input and output requirements of which can be precisely quantified mathematically (Turner, 1992:182).

Turner argues that this development of mechanistic metaphors of the human body plays a crucial role in the emergence of a scientific discourse around the body in general and of dietary science in particular.

These discursive constructions of the nature and 'truths' of the human body were of particular interest to Foucault and are something he constantly returned to in his writings. Foucault saw these discursive constructions of the body as effects of power and knowledge, and as providing the focus for the disciplinary and regulatory techniques practised within society (Shildrick, 1997). What is of particular interest to Shildrick though is the way in which neither of these conceptions of the nature of the body, Cartesian or Foucauldian, demonstrates any awareness of the different constructions of male and female bodies (Shildrick, 1997). In his defence, Sawicki (1999) has stated that Foucault did indeed intend to write a history of women's bodies. A volume of the *History of Sexuality* was to be entitled *Woman, Mother and Hysteric* and was intended as a study of the sexualization of women's bodies and related concepts such as hysteria and frigidity.

3.7.2 The 'problematic' female body

Shildrick (1997) argues that, although female bodies have figured strongly throughout history, they have continually been conceptualised and valued in a quite different way to male bodies. The Cartesian tradition of privileging the mind over the body had the effect of attributing the potential for rational action only to men. Although both women and men have material bodies, women were regarded as unable to transcend their bodies in the way that men could. This was largely due to the perception that, because of their reproductive abilities, females were more closely tied to their bodies.

In being somehow more fully embodied then men, women have been characterised simply as less able to rise above uncontrollable natural processes and passions and therefore disqualified from mature personhood (Shildrick, 1997:26).

This focus upon the reproductive abilities of the female can be seen in more general cultural representations of women, in which, Shildrick argues, women have either been invisible as a separate category or are positioned simply as reproducers. This reproductive positioning occurs regardless of whether or not the individual woman has the ability or intention to bear children, and has the effect of attributing the reproductive role almost wholly to women rather than men. The male's role in reproduction is minimised in favour of a focus upon the long process of conception and pregnancy, which happens **inside** the female body (Shildrick, 1997). Women are therefore seen as more involved in, and responsible for, reproduction and, as a result, it is the female body that is regarded as more open to manipulation in order to achieve this end.

If we return to the idea of the medical model regarding the body as a machine, then it is possible to conceptualise the female body as a machine engaged in the production of children. In this sense the doctor may be likened to the factory supervisor or even the owner (Martin, 1987). In exploring the medical metaphors and imagery that surround reproduction and birth, Martin (1987) suggests that two pictures are juxtaposed,

…the uterus as a machine that produces the baby and the woman as laborer who produces the baby. Perhaps at times the two come together in a consistent form as the woman-laborer whose uterus-machine produces the baby (Martin, 1987:63).

The doctor is therefore attributed the role of supervisor or foreman in charge of the labour process. The doctor manages the woman's labour.

In this way then, the biological 'reality' of the female body is used to determine how women should live their social lives (Lawler, 1991). The nature of the female body, and the focus upon its reproductive role, is employed in the construction and reinforcement of female roles. In this vein, some feminists argue that the female body provides an

important mechanism through which men exercise dominance over women in patriarchal social systems. It is argued that the female body is attributed social meanings that serve to disadvantage women (Lawler, 1991). Wilton (1998) argues that, within medical discourse, women are predominantly defined in relation to their reproductive abilities and, as a result of this, can only achieve full emotional and physical health through the bearing of children. This medical model inevitably pathologizes women who cannot or do not have children, but also problematizes what are seen as 'inappropriate' forms of childbearing, for example unmarried women, older women or lesbians. These assumptions can also be demonstrated within the context of health promotion and health education. Daykin (1998) argues, for example, that these strategies commonly employ assumptions about the 'natural' or 'proper' roles of women and men. Daykin argues that assumptions about female duties have permeated health promotion strategies at a number of levels. Much health promotion literature is targeted at women because it is assumed that women will take responsibility for the health of others, especially children, and will act to protect and maintain the health of families and households.

This tendency to define women primarily in terms of their reproductive abilities has led to a negative construction of menstruation and menopause, particularly in the medical context. Martin (1987) has explored in great detail the negative metaphors used to describe these female bodily processes in medical texts. The focus upon the essentially productive nature of the female body inevitably leads to the problematisation of these unproductive processes. In particular, menstruation is seen as a fundamental lack of production, i.e. the failure to become pregnant, but is also associated with,

> …the idea of production gone awry, making products of no use, not to specification, unsalable, wasted, scrap (Martin, 1987:46).

Martin supports her argument with numerous examples from medical texts, which discuss menstruation using such terms as 'degenerate', 'leak', 'deteriorate', and 'expelling' (Martin, 1987:47-8). In comparison with this negative representation of menstruation as breakdown and decay, the regular shedding and replacement of the lining of the stomach is discussed in more positive terms of production, replenishment and renewal. Martin argues that, while it is possible to view both of these processes as

negative breakdown and decay or positive renewal and replenishment, the stomach occupies the positive side while the uterus, which only women have, occupies the negative side. The assumptions behind these negative medical metaphors of menstruation and menopause can therefore be argued to rest upon the notion that the sole function of the female organs is the transportation of eggs to a place of fertilization and growth. Martin challenges this assumption by arguing that a woman may do everything within her power to prevent this process and, therefore, in this case the purpose of her monthly cycle is in fact the production of menstrual blood. Martin suggests that there is no reason why menstruation itself should not be regarded as the desired outcome of the female cycle in such an instance.

These negative medical metaphors used in the description of both menstruation and menopause, can be argued to constitute a specific example of the more general negative views of the female body that society holds. Shildrick and Price (1999) argue that the female body is regarded as intrinsically unpredictable, leaky and disruptive. It is for this reason, as discussed above, that women are seen as being incapable of exercising rationality. This ability is attributed solely to men because women are seen as being held back by 'natural' biological processes and are therefore unable to transcend their bodies in the way that men can. The female body is seen as being unreliable and unpredictable and therefore out of control.

> The very fact that women are able in general to menstruate, to develop another body unseen within their own, to give birth, and to lactate is enough to suggest a potentially dangerous volatility that marks the female body as out of control, beyond, and set against, the force of reason (Shildrick and Price, 1999:3).

The development of abnormal cells within the cervix can be seen as an example of the unpredictable nature of the female body. Through the cervical screening programme these abnormalities will be identified and treated as soon as they develop, largely in the absence of any certainty over whether or not they would go on to develop into invasive cervical cancer. Through the identification and treatment of these abnormal cells, the situation can be brought under control and the woman's cervix returned to 'normal'. Therefore, in contrast to the self-contained and secure male body, the volatile and

unpredictable body of the female is seen as being in need of attention and regulation. It is in the context of this disciplining and regulating of women's bodies that feminists have made most use of the work of Foucault.

3.7.3 The regulation of bodies

Turner (1992) argues that one of the main concerns of the new area of the sociology of the body is the way in which the body represents a regulatory problem within society and therefore has to be trained, manipulated and disciplined. Since the government of the body is really the government of sexuality, what is really at issue is the regulation of female sexuality within a patriarchal system (Turner, 1984). It is predominantly the female body that is the focus of social control mechanisms. Using Foucauldian ideas, Bordo (1997) argues that, through the organisation and regulation of daily life, the female body is trained and shaped into the desired form. Bordo states that women are spending more time than ever on the management and discipline of their bodies. The construction of femininity to which women are argued to aspire, is seen by Bordo as always homogenising and normalising, resulting in the aspiration of all women to a coercive and standardized ideal.

> Through the pursuit of an ever-changing, homogenizing, elusive ideal of femininity…female bodies become docile bodies – bodies whose forces and energies are habituated to external regulation, subjection, transformation, 'improvement' (Bordo, 1997:91).

Bordo regards the discipline and normalization of the female body as an '…amazingly durable and flexible form of social control' (Bordo, 1997:91).

Foucauldian ideas, and particularly those surrounding the production of docile bodies, have been of great interest to some feminist writers and have been used to explore the links between the lived body and the disciplinary and regulatory practices that shape its form and behaviour (Shildrick and Price, 1999). Feminist theorists such as Bordo (1993, 1997) and Bartky (1988) have explored how the processes of both surveillance and self-surveillance are involved in creating a 'normality' to which bodies aspire. Foucault's concept of bio-power can be used in order to locate the processes through which the female body is controlled and governed (Sawicki, 1999). In particular a Foucauldian

model is of particular use in an analysis of male dominance and female subordination, which increasingly seems to be reproduced voluntarily (Bordo, 1993).

The control and regulation of female bodies can be seen to serve the interests of patriarchy in the same way that biopower is regarded by Foucault as indispensable to the development of capitalism. Sawicki argues that biopower,

> …must also have been indispensable to patriarchal power insofar as it provided instruments for the insertion of women's bodies into the machinery of reproduction (Sawicki, 1999:191).

In a similar vein, Doyal (1995) has argued that women's capacity to conceive and give birth to children is not only important to them as individuals, but also has wider social and cultural significance. Indeed, in many societies the sex life of the woman is a highly contested area over which individuals and groups will fight to maintain control (Doyal, 1995). Any discussion of the regulation of the female body must therefore begin, Doyal argues, with the social relations of production.

3.7.4 The influence of medicine

Numerous individuals and groups can be argued to be involved in these attempts to regulate female bodies and bring them under control. Doyal (1995) argues for the involvement of institutions such as the family, religion and governments. However, the main area with which this work will be concerned is the role of medicine in attempts to regulate bodies in general and the female body in particular.

One of the most influential theorists examining the way in which medicine has acted to control and regulate bodies is David Armstrong (1983, 1993, 1995). Armstrong is concerned with the way medicine is involved in the surveillance and examination of bodies and, through these processes, how the body is subjected to a complex machinery of power. The most recent version of this is the contemporary public health regime, in which the danger of illness is seen as potentially all around us and, therefore, a vast network of observation and surveillance has been deployed throughout society in order to monitor these potential dangers (Armstrong, 1993).

This increased observation and surveillance of the population has been explored at length by Armstrong (especially 1995) and has been termed *surveillance medicine*. The premise of this concept is that a new model of medicine can be seen as emerging during the twentieth century that is concerned with the observation and monitoring of apparently healthy populations. The traditional domain of medicine, seen as the hospital, has been extended and medical surveillance now penetrates wider society. However, the role of surveillance is not limited to medicine itself. Increasingly individuals themselves are being encouraged to participate in self-monitoring and, to some degree at least, the monitoring of others. This observation of the seemingly healthy population serves to break down the distinction between those that are healthy and those that are ill. Medicine is no longer concerned simply with the latter, instead, the whole population comes under surveillance (Armstrong, 1995).

This 'problematisation of the normal' constitutes a central feature of the new surveillance medicine as it attempts to bring everyone within its network of visibility. There is no longer simply a distinction between the healthy and the sick, instead, Armstrong sees bodies as being classified on a continuum with no inherent distinctions between them. The only differences between these bodies are the spaces that separate them from each other. The relative positioning of bodies is now regarded as of importance and is used to establish that no-one is truly healthy (Armstrong, 1995). What is considered to be 'normal' is no longer some form of external referent, instead,

> …the normal came to be located within the social body itself; bodies themselves defined normality (Armstrong, 1983:43).

As a result of this new focus, individuals were increasingly compared with others and their bodies were placed in the context of those of others and the differences measured. Therefore a continual comparison between bodies was brought about.

This intrusion of medical surveillance into the lives of the apparently healthy has been termed by de Swaan 'the management of normality' (de Swaan, 1990). In de Swaan's view, everyone in society lives under medical supervision to some degree. Those that have an established medical condition live under stricter supervision, but the remainder of the population are not seen as healthy, rather as not yet sick and therefore live under a

light medical regime. This is apparent primarily at the level of everyday life through the ways in which people pay attention to what they eat, take exercise and are concerned with their environment. Interestingly, while de Swaan states that this is sometimes at the urging of doctors, it is more commonly the result of individuals 'talking each other into it' in the name of medical opinion. De Swaan argues that the medicalization of everyday life can be observed in the increasing deployment of medical arguments in increasingly diverse areas where previously arguments would have been based on aesthetics or morality.

In addition, the early detection of health risks often means that the potential for future illness is identified before the individual is aware of any symptoms. Kavanagh and Broom (1998) have drawn attention to a newly developing form of risk; that which is located in the individual body. This corporeal or embodied risk is increasingly being monitored and potentially modified through the use of medical screening, Kavanagh and Broom cite the particular example of cervical screening in this context. Surveillance of this embodied risk must therefore be medical as it is typically internal, invisible and, crucially, asymptomatic.

3.7.5 *Women's experiences and reactions*

In discussing these various ways in which women's bodies can be argued to be subject to regulation, it is all too easy to assume that women take the part of passive victims in these instances. Often the discussions can portray women as simply having things done **to** them without any display of resistance. Many have found these kinds of assumptions problematic, especially to the extent that they appear to represent the regulatory strategies employed as always completely successful and therefore do not allow women the potential to resist.

In her study of the cultural representations that surround women's bodies and reproduction, Martin (1987) found that, during interviews, women continually questioned, opposed, rejected and reformulated the ways in which they lived and the ways in which society might work. While Martin acknowledges that many women have their views of normal bodily processes, such as menstruation and menopause, distorted in a male-dominated society,

> …alongside this shame and embarrassment are a multitude of ways women
> assert an alternative view of their bodies, react against their accustomed
> social roles, reject denigrating scientific models, and in general struggle to
> achieve dignity and autonomy (Martin, 1987:200).

Sawicki (1999) draws attention to the way in which the unstable power relations that surround an issue can open up the space for resistance. In exploring new reproductive technologies, Sawicki uses a Foucauldian approach and focuses not simply on the dominant discourses and practices of medical experts, but also on the moments of resistance that have resulted in the transformation of these practices. In addition, Doyal (1995) has explored what she terms 'women's movements for health', which have predominantly centred on issues such as contraception, abortion and childbirth. In the case of childbirth, Doyal argues that a 'consumer movement' has developed around maternity care, particularly in Europe and North America, which aims to increase the choice for women and give them greater control over their own labour. These movements and campaigns can hold widely divergent beliefs, for example some have actively sought 'natural' childbirth, while others have simply emphasised the right of women to determine their own labour. However, despite these differences, these movements represent a belief in the right of women to determine what happens to their bodies (Doyal, 1995).

It is important to bear in mind, therefore, that powerful discourses will not always be successful. As has been previously discussed in the case of public health discourses, these will not succeed with all individuals and certainly not all of the time (Lupton, 1995, 1997). It is therefore crucial to allow for the possibility of resistance to the discourses that attempt to regulate and control women's bodies and explore how women are affected by these and how they experience them. In her example of new reproductive technologies, Sawicki (1999) argues strongly for an exploration of the ways in which women are affected by the discourses that surround these technologies and how they affect women. As Turner (1984) has argued,

Discourses are not linguistic machines which routinely and invariably produce the same effects, but possible modes of social construction the consequences of which contain a large element of contingency (Turner, 1984:175).

In Turner's view, knowledge is too frequently extracted from its social context and discourse is assumed to operate almost without reference to the social groups that interact with it. To reiterate the theme running throughout this chapter, there will always be at least the potential for resistance to discourse.

3.8 Conclusion

The purpose of this chapter has been to frame the research in the context of relevant sociological theory. This has been achieved through the use of Foucault, employing both his earlier work on techniques of domination and his later balancing of this with techniques of the self. In addition, more recent interpretations and developments of Foucault's work have been employed, most notably how some feminists have taken up his ideas to inform their work on women's resistance.

Following this, the relevance of the research to sociological thinking about the body, and especially the female body, in society was made clear. In addition, considerations of how attempts are made to control and regulate the body were explored and the role of medicine within this highlighted. The medical control of bodies and everyday life is clearly a key concern for this research as medical screening for such conditions as cervical cancer very much concerns what de Swaan (1990) has termed the 'management of normality', as individuals with no apparent medical condition are drawn into the medical sphere.

The theme that has been apparent throughout this chapter is that wherever there are relations of power there is always at least the potential for resistance. This argument has been made in theoretical terms, with a focus upon the process through which large-scale cultural patterns come to be reproduced and how this may open up the space for resistance through the taking up of alternative subject positions. In particular, feminist writers have discussed how women may be engaged in 'negotiating at the margins' of power and how this needs to be acknowledged and taken account of. Riessman's (2000)

work on childless women in India resisting stigma, and Kaufert's (1998) work on the oppositional discourses constructed by women with breast cancer, have both clearly illustrated this while Kielmann (1998) and Abu-Lughod (1990) have alerted us to the problems associated with trying to conceptualise and research resistance and the need to develop some form of criteria for how it will be identified.

What my research on women's interactions with the official discourse on cervical cancer screening will demonstrate is that this type of resistance to discursive power and subject construction can be found within this context. As such it contributes to debates around what types of accounts or behaviours can be taken to constitute resistance and the forms that these may take.

In the next chapter I detail existing work on cervical cancer screening, from both a sociological and a health services research perspective, in order to demonstrate why this kind of research on the potential for women to resist is necessary. I also look in more detail at what can be referred to as 'empirical studies of resistance' in order to explore further the myriad forms that resistance may take and the ways in which it can be framed, exercised and legitimised or accounted for. This carries forward the running discussion of what can or should be seen as resistance and I ultimately define what I take to constitute resistance in this research.

Chapter 4
Cervical Screening, Women's Health and Resistance

4.1 Introduction

The aim of this chapter is to explore the empirical context of the research, thereby demonstrating the gap in this material that my study fills, and to employ empirical studies of resistance to consider the different forms that resistance can take. Through this, it builds on the theoretical considerations of how resistance can or should be defined, contained in the previous chapter, and sets out the criteria for defining resistance that are used in this research.

The chapter begins by looking at the kinds of empirical work that exist in cervical cancer screening, both from a sociological perspective and in other areas. As such I begin by detailing work that comes from the area of health services research. As I argue below, the vast majority of this work is quantitative and concerns itself with identifying why some women do not attend for screening and, therefore, what measures can be taken to remedy this and increase coverage. The second body of work I detail is more concerned with exploring women's attitudes, understandings and experiences of screening and is often more qualitative in nature. However, the underlying aim of the work often links back to the issue of attendance, or more specifically non-attendance, and I argue that this is still problematic. Thirdly, I explore recent sociological work on cervical screening, showing how this goes some way to remedying the problems I identify with the previous kinds of research. This is achieved through a focus on how women can feel 'morally obliged' to attend for screening and so problematizes attendance by viewing it as operating within a particular set of power relations.

Having explored a range of relevant empirical work on cervical screening specifically, I then move on to consider some research in other areas that are relevant to my study. The first of these areas centres on women and health, and is important because women's responses to a particular health intervention are likely to be influenced, to some degree at least, by the ways in which they view their own health and their understandings of health and illness more generally. Within this I include work that explores which health problems are of concern to women, how these may be influenced by factors such as age

and social class and women's lay ideas of disease causation. Moving from the general to the specific, I set out work on women's lay representations of cancer and how these may influence participation in screening programmes. I then widen back out to consider the large body of work on lay health knowledges, focusing on how these are constructed, the purposes they may serve, how they differ from professional knowledges (but also have significant overlaps), and whether they can (or should) be seen as posing a threat to these.

Finally, the chapter looks at a range of specific studies of resistance that are found within the empirical literature. This follows on from the limited engagement with such work in the previous chapter, for example Riessman (2000), Kielmann (1998) and Kaufert (1998), which was more theoretically focused. My aim in doing this is to further explore the types of resistance that are possible and the different ways these may be exercised. Ultimately, my exploration of these examples leads me to set out the criteria that I employ in my research and what I take to constitute resistance.

4.2 Work on Non-Attendance

Since 1995[14] the NHS Cervical Screening Programme (NHSCSP) has consistently achieved coverage rates of over 80%. The most recently available figures at the time of writing state that, at March 2003, 81.2% of eligible women had been screened at least once in the last five years (Department of Health, 2003). The programme therefore achieves high levels of coverage of the eligible population, with low levels of non-attendance. The majority of the work that is specifically concerned with non-attendance for cervical screening is largely descriptive and quantitative in nature and is concerned with the identification of specific factors and/or characteristics of non-attenders and how these influence whether or not a woman attends.

Elkind *et al.* (1988) suggest that, within the context of cervical screening, there exist different groupings of non-attenders and that each grouping can be seen as having different reasons for their non-attendance. Most non-attendance explored within this research is argued to be due to problems and inaccuracies within the computerised call and recall database. For example, issues such as incorrect address details, the

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[14] Data are available from this point in order to allow for a period of transition from the previous opportunistic screening arrangements to the national programme, which was established in 1988.

ineligibility of women or their unsuitability, failed communication and the incorrect classification of individual women are cited as accounting for a sizeable proportion of non-attendance. It is only the final category discussed, that of refusal, in which the beliefs, attitudes and understandings of the woman herself are considered. The category of refusal is defined by Elkind *et al.* as '…women who receive their invitation, who have no *valid* reason to believe the test is inappropriate…and who decide not to attend' (Elkind *et al.*, 1988:659, my emphasis).

It is therefore the case that this category of refusal includes within it a diverse range of explanations for the failure of women to attend for screening. Elkind *et al.* include within this category the practical problems that women may experience, for example the timing of the appointment or the venue, an invalid belief that the test is inappropriate for them, and attitudinal barriers such as fear or dislike of the test. The possibility that an individual woman may make an informed decision, based on all the available evidence, and ultimately decide not to attend for cervical screening can find no place within this typology of non-attenders.

In a similar study, Eaker *et al.* (2001a) explored reasons for women's non-attendance in Sweden and its association with other health behaviours. For example, non-attendance was found to be positively associated with not using oral contraceptives and negatively associated with the intention to participate in future mammography screening. Non-attendance was also linked with such factors as frequent condom use, not having had genital problems and living in rural or semi-rural areas. Eaker *et al.*'s study also found no evidence that high-risk sexual behaviour was more common among those that did not attend for screening. In fact, they argue that those that did not attend were more likely to always use condoms during intercourse. Eaker *et al.* suggest that this protective behaviour may therefore lead to the view that medical care, in this case cervical screening, is unnecessary.

Non-attendance, and the reasons for it, is explored by Bentham *et al.* (1995) with specific reference to the computerised call and recall programme introduced in England in 1988. The key advantage of such a population-based approach is that it permits the screening of women not likely to be reached through the previous opportunistic system. Bentham *et al.* therefore set out to identify and compare the factors affecting non-

response both before and after the introduction of the new system. Perhaps unsurprisingly, the study found that non-response rates were significantly lower under the new system. Relationships between non-response and the explanatory variables, such as age structure of the practice and its rural remoteness were weakened. However, other significant associations persisted and Bentham *et al.* argue that the new system was still failing to reach women at risk. For example, there was still a social gradient in uptake, and practices with a female GP continued to achieve higher coverage levels. Bentham *et al.* conclude by arguing that '…social and organisational barriers to participation were reduced but not removed by the new scheme' (Bentham *et al.* 1995:134). Once again, the focus of this research on the factors that affect non-response levels leaves little room for the beliefs, attitudes, opinions or preferences of individual women.

This focus upon the characteristics of women and the identification of those factors that are strongly associated with non-attendance can lead to the emphasis being placed on the 'failure' of certain kinds of women to attend for screening. Eardley *et al.* (1985) argue that the blame is often placed on the women who do not attend rather than on the screening programme itself. 'Such a view, however, is too narrow and fails to take into account the attributes of the service that is being offered' (Eardley *et al.* 1985:957). Eardley *et al.* also criticise the reliance of non-attendance studies on official records of screening attendance, which make no distinction between those women that have specifically refused an invitation and those that have missed a test for some other reason. They review the work of studies that consider what happens when women are specifically invited to attend, in order to explore the real differences between those that accept and those that refuse these invitations. They argue that, in the right circumstances, a high proportion of women are willing to have a smear test when invited.

Eardley *et al.* conclude by arguing that the emphasis on non-attendance has under-estimated the necessary pre-requisites of regular screening behaviour. They argue that, in addition to having knowledge of the test, a woman must also have a positive view of its function, a belief in its efficacy and see it as relevant to her. She must also find the prospect of the test and its implications acceptable. In relation to this argument, Neilson and Jones (1998) have explored the impact of women's lay knowledge of cervical

cancer and cervical screening and have considered its role in accounting for non-attendance. As they argue, the health beliefs of individuals can be strong influences in determining their chosen course of action and, therefore, the success of health promotion strategies and screening programmes can be heavily influenced by individuals' ideas of how best to maintain their health and prevent disease. In terms of the responses given within Neilson and Jones' research, half of the women questioned had discussed the test mostly with lay people such as their partner, work colleagues, female relatives or friends. Only 9% of the women had consulted their GP, although this figure may be misleading as the vast majority of cervical smears are taken by the practice nurse and so it is likely that questions would be addressed to them.

As previously discussed, and highlighted through this brief discussion, the majority of work in this area tends to be quantitative and largely descriptive. It is common for such work to explicitly set out to discover those factors positively associated with non-attendance in order to facilitate changes in service provision and information so that attendance levels can be increased. Such work also tends to focus upon specific characteristics or qualities of women to explain their non-attendance instead of a more in-depth exploration of women's beliefs, attitudes and understandings and how these have developed. Often the implicit, or sometimes even explicit, assumption of the research is that if only the incorrect views or understandings of women could be dispelled then coverage rates and attendance levels could be increased. Emphasis is placed more on the proportion of women that misunderstood the purpose of cervical screening, for example, than on exploring the means though which women develop and come to hold these views. As Press and Browner (1998) argue, in the context of women who refuse prenatal diagnosis, predicting which women will refuse is less useful than developing an understanding of the interaction of factors that brought the woman to that decision. Such a focus on non-attendance also relies upon this simple dichotomy between attendance and non-attendance, which suggests that women who attend do so uncritically and have no problems or reservations about doing so. In reality the situation is likely to be much more complex than this over-simplistic representation as the outcome measure based simply on attendance/non-attendance takes no account of women's experiences, understandings and thoughts on both cervical screening and the cancer itself.

4.3 Women's Understandings and Attitudes

In contrast to the predominantly descriptive and quantitative work discussed above, other work on cervical screening has gone some way towards exploring the ways in which women understand the screening programme and their views and experiences of it. Often, though, the underlying focus falls back onto how these may impact upon attendance.

Eaker *et al.* (2001b) argue that there are important differences in the attitudes and beliefs of non-attenders and attenders for cervical screening. Rather than being simply emotional however, the main barriers in this research were found to be either practical issues or rooted in misunderstandings of screening and a lack of relevant information. Again, there is the assumption that if only these incorrect attitudes and beliefs could be corrected then attendance would be increased. Similarly, Fylan (1998) has reviewed women's attitudes, knowledge and behaviour and has classified the factors that influence screening behaviour as health service related, patient centred, or obstacles to attending for colposcopy[15]. Summaries are provided of these various factors that can reduce participation, which include poor awareness of the indications and benefits of the cervical smear test, a lack of knowledge of cervical cancer and its risk factors, anxiety and poor understanding. Fylan concludes by considering the impact on screening behaviour of individuals' health beliefs and argues that women should be encouraged to take responsibility for their own health and to be active participants rather than passive attenders for screening. Here again the focus tends to fall back on attendance and how this can be encouraged and increased, rather than engaging with these issues in their own right instead of as a problem that needs solving.

McKie (1993), for example, conducted research on women's views of the cervical smear test in order to challenge the opinions held by some health professionals that women failed to attend for screening due to laziness or ignorance. McKie argues it is unlikely that many health professionals will have had contact with so-called 'non-compliers' and therefore conducted her research in order to give such women a voice. Her research found that the most commonly cited reason for non-attendance was feelings of fear and embarrassment. Other common responses were that women did not

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[15] Colposcopy is an examination to identify the type and area of cervical abnormality identified by a smear test. A decision is then taken on whether further treatment is necessary.

want a test, they felt themselves to be ineligible for screening or they felt a test was unnecessary for them as they had no symptoms. McKie concludes by arguing for the importance of women's beliefs and attitudes as major barriers to participation in the screening programme. It would appear that health education messages had failed to break the strong link between the presence of symptoms and service use in such cases. It may be that in the years since McKie conducted this research the increasing focus within society on the importance of maintaining and protecting health, and therefore on taking preventive measures, has resulted in this link being further eroded.

This is highlighted by research by Forss *et al.* (2001) who used qualitative methods to explore women's reasoning for attendance in a Swedish context. The two most striking themes to emerge from the study were the possibility of having a disease without being aware of it and/or the importance of early detection in such cases. Forss *et al.* state that, while these themes were present in almost all interviews, they were often found as a subtext rather then an explicit form of reasoning. Of particular importance for many respondents was the actual invitation letter itself. This was evident through both a specific focus on the receipt of a letter as a reason for attendance and through the letter's role in emphasising the beneficial aspects of screening. Forss *et al.* therefore argue that women's reasoning for attendance can be seen as grounded in many sources of experience,

> …in reference to gynaecological examinations and implicit or explicit information on cancer risk and prevention from media, friends and families, through which women seem to learn how to interpret and make sense of experiences in socially acceptable ways (Forss *et al.*, 2001:82).

They argue that their findings can be seen as reflecting societal discourses on womanhood, disease prevention and health control in Sweden. The women interviewed seemed to have 'learned' that it is both important and possible to detect disease in its early stages and that the technology exists through which this can be achieved.

In addition to exploring how women understand cervical screening and how they decide whether or not to attend, it is also important to consider how women feel about screening and their specific experiences of it. Crombie *et al.* (1995), for example, have

explored women's experiences at screening and found that just over half of those questioned remembered feeling concerned prior to screening. These feelings ranged from worry to anticipated embarrassment. Although in contrast to this, other women reported little or no concern prior to their test. Crombie *et al.* conclude that situational factors, such as the circumstances in which the smear is taken, or the smear taker, may contribute to the embarrassment felt. However, it is likely that many women may simply find the process to be an inherently embarrassing experience.

In terms of exploring women's views on the smear test, Gregory and McKie (1991) argue that, instead of simply those that use the service and those that don't, there is in fact a considerable variation in the type of service use exhibited. This can be affected by factors such as '…the way in which a woman is recruited into the smear test service; the knowledge she holds about the service, and her social beliefs, which may result from her age and background' (Gregory and McKie, 1991:32). In many cases women attached a low priority to their own health, especially in comparison to that of their children, and found it difficult to take time out from family responsibilities when ill. In terms of women's knowledge of cervical cancer and the smear test, this was found to be patchy and many women had received unpleasant and insensitive treatment.

White (1995) addresses the issue of women's attitudes to cervical screening with particular reference to older women. Through a series of in-depth interviews with older women in New Zealand, White explored how women's perceptions of cervical cancer and screening may affect their help-seeking behaviour. The relationship between having symptoms and seeking medical care is highlighted by White as many of her respondents said they would not think of going to the doctor if they were well. This focus on the necessity of symptoms prior to seeking medical help may well be more common in older women as, for them, health education and health promotion are a relatively new phenomenon. In terms of cervical screening itself, most of White's respondents thought that having regular smear tests was important, especially for younger women with children. This concern with doing what was best for the children was common amongst the women. White states that the older women interviewed would ensure that children received medical care before themselves and were concerned that young women protected their health for their children's sake. In this way then, it can be demonstrated that a woman's understandings of cervical screening and an assessment of its relevance

to them can have an impact on their screening behaviour. These older women's perceptions of cervical screening as important mainly for younger women with children, together with their view that symptoms must precede a visit to the doctor, construct screening as irrelevant for them and they therefore see little reason to attend. They regard cervical screening as important, but for a different type of woman.

It can therefore be suggested that the health beliefs and attitudes of individual women may influence the ways in which they understand cervical screening and their subsequent screening behaviour. In addition to those studies discussed above, Seow *et al.* (1995) attempted to identify the cognitive barriers to screening activity through a study based in Singapore. The study found that, overall, the belief of personal susceptibility to cancer was low and that a substantial proportion of women held the attitude that cancer could not be prevented. These two factors in combination would obviously have an impact on screening uptake and led Seow *et al.* to suggest the means through which uptake can be increased are culturally specific and must deal with widely-held beliefs and attitudes. The uptake of cervical screening services can also be linked to related examples of health behaviour. Gillam (1991) for example used the health belief model to understand cervical screening uptake and argues that it is necessarily associated with other health behaviours. A wide range of beliefs, attitudes and socio-economic factors is important in determining this behaviour.

When discussing women's understandings of, and attitudes towards, cervical screening it is important to bear in mind that for many women it can be a highly emotional subject. The linking of a positive smear test with sexual promiscuity and 'dirtiness', for example, is not uncommon. Indeed, as Quilliam (1990) argues following her own experiences of a positive test,

> The most overwhelming lesson is that for many women having a positive
> smear is not 'simply' a medical event. Because of the very particular nature
> of cervical cancer, it is also a highly emotional event (Quilliam, 1990:19).

Therefore what is often simply a routine procedure for a health professional can be a major episode in the life of the particular individual and may result in them feeling morally judged by others on the basis of their test result.

In terms of women's understandings of cervical screening, Hurley (1993) argues that during her time as a health visitor she encountered many women who did not have a clear understanding about the role of screening. The prospect of attending for a smear test commonly resulted in feelings of anxiety and fear. Women were embarrassed at the thought of an internal examination and many associated this procedure with pain and discomfort. Women's understandings of the results of their smear test also contain the potential for confusion. In terms of women's understandings of a normal test result, Marteau *et al.* (2001) explored the understanding of the presence of a residual risk. They found that, when informed only that their smear was normal, 52% of women in their study understood that this meant a residual risk of cancer. In contrast, when an additional sentence was added giving a probability of this risk, 70% correctly understood what this meant, although 30% still did not. At the other end of the spectrum, Kavanagh and Broom (1997) explored women's understandings of an abnormal smear result. They found that women were often concerned and confused by the news that their smear was abnormal and that few women had a conceptual framework for interpreting the symptoms, for example bleeding and discharge, they experienced after treatment for the abnormalities. Kavanagh and Broom argue that, for many women, the news of an abnormal smear affects their sense of femininity as they feel that a part of their body that makes them female has gone awry. Women often associated their cervix with reproduction and, therefore, any problems with it affected their reproductive potential and also their femininity. These perceptions and understandings of women with regard to cervical screening and the meaning of either a normal or abnormal test result can undoubtedly be of great importance in determining how they regard cervical screening and their behaviour within the programme.

These studies do engage more with women's experiences, views and understandings of screening and demonstrate the factors that may be at work in influencing these. All too often though the ultimate focus falls back onto attendance, or more specifically non-attendance. While it is important to ensure that women are adequately informed about screening, and can therefore make an informed choice about whether or not to attend, I find it problematic to explore these areas with only this apparent objective.

4.4 Sociological Work on Cervical Screening

Recent sociological work on cervical screening has gone some way towards addressing this and has altered the focus on attendance. Instead of leading from women's experiences towards exploring how these impact on attendance, much of this research is concerned with the expectation of attendance and how this affects women. As such it has explored the aspects of surveillance and regulation that can be seen within the programme. In particular, the tendency for women to feel some kind of 'moral obligation' to attend for screening has been explored, together with aspects of female embodiment.

McKie (1995) has discussed the aspects of surveillance that can be identified within the cervical screening programme in relation to the surveillance of female sexuality and sexual behaviour. As previously discussed, a positive smear test result has implications for a woman's sexual identity as it is frequently linked to sexual promiscuity and public distaste. McKie argues that this link between a positive smear result, female sexual identity and the regulation of female sexual activity is strengthened through the minimisation of the male role. The role of men in the development of cervical abnormalities, for example through transmission of the human papilloma virus (HPV), certain strains of which have been linked to the development of cervical cancer, is rarely recognised. McKie found that few of the women she spoke to were aware of men's role and nor were the men themselves. What were commonly discussed by McKie's respondents however were male views of the cervical smear test. These were commonly discussed in terms of men believing that women may actively enjoy the test and thinking that it held the potential for 'sexual thrills'. Women often told how their partners were distrustful of male doctors conducting internal examinations and linked this to their belief that only they should touch their partner in that way. McKie therefore argues that the cervix has become a site of contested control within the female body.

> Concepts of ownership and control pervaded conversations; of men owning
> women through relationships and of men surveying women through the
> cervical screening service (McKie, 1995:451).

An individual woman's participation within the screening programme may therefore, McKie argues, represent more than her concern for disease prevention. Women's sexual

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activity and cervical health are seen as operating as mechanisms for the operation of power over women. In McKie's view, the cervical screening programme creates and reinforces negative views of women and female sexuality. She concludes by arguing that the discourses that surround screening sexualise a medical process and have a negative impact on women's self-esteem. These discourses are cited as evidence of a non-centralised form of power that preserves male power over women's lives.

Howson (1999) has also problematized women's attendance for cervical screening and has linked this to wider debates about the exercise of power within society. Howson argues that much literature and research on cervical screening adopts an unproblematic view of attendance (or compliance as she terms it), seeing it as a consequence of rational decision-making and as morally neutral. Howson argues that the act of attendance for screening needs to be more fully explored and can in fact be seen as highly problematic. She argues,

> …compliance can also be understood as a response to a particular expression of power or set of normative expectations…compliance with screening cannot be viewed exclusively as a neutral, if desirable, outcome but as a social practice, which is embedded within a moral framework of responsibility and obligation (Howson, 1999:402).

Howson's interview respondents discussed the attendance for cervical screening very much as an expected response and viewed it largely as one aspect of a larger range of interventions inextricably associated with being female and having a female body. The women saw attendance for such interventions as being normal, routine and something to be expected. Although it was acknowledged that a cervical smear test commonly involved some degree of embarrassment and discomfort, it was seen as important, responsible and mature to overcome these potential barriers. This leads Howson to argue that women are placed under a form of 'moral obligation' to overcome their fears and misgivings and attend for screening. Cervical screening has become seen as a normal part of womanhood and as being the sensible, mature and responsible course of action.

This focus upon cervical screening as an inevitable part of being female has been developed by Howson in earlier pieces on the importance of embodiment in terms of cervical screening experience (Howson, 1998a&b). Many of her respondents discussed the female body as undergoing transitions and as therefore more subject to regulation than the male body. In this way, beginning to attend for cervical screening was constructed as something that could be seen as marking the transition into full womanhood in much the same way as menstruation and the development of breasts.

> The obligation to attend for a smear test and the examinations and treatment which an abnormality engendered clearly implied a compliance which could be linked to routine interventions which regulated female bodies (Howson, 1998b:227-8).

This sense of the embodied understanding of cervical screening ensures participation on the basis of perceived normalcy and expectation, rather than on the basis of personal choice.

Bush (2000) has also explored these feelings of normalcy and correctness that women so frequently use to describe and discuss cervical screening. From her qualitative study, Bush argues that these feelings presented themselves in two main ways. Having a smear test was discussed, firstly, as a normal part of being a woman and, secondly, in terms of the feelings of deviance associated with non-attendance. Many women saw themselves as having an obligation to respect and look after their own body, however within this Bush argues that there were important resistances. In common with McKie's respondents, women drew attention to the fact that cervical screening focused very much on women at the expense of any consideration of the male role. The view of non-attenders as irresponsible or lazy was also challenged by some women who, while arguing for the importance of screening, recognised that attendance should be the individual woman's choice. Bush therefore argues that the discourses that surround cervical screening play an important role in maintaining the disciplinary power of medicine through the ways in which they normalise and discipline women through their bodies.

Research of this kind therefore successfully moves away from a focus on women's experiences solely in the context of how these may influence attendance. This kind of work is interesting and valuable and it is clearly important to consider how women are affected by such health promotion messages and how they can feel obliged or constrained to act in particular ways. McKie, Howson and Bush all make reference to Foucauldian ideas in their work on cervical screening, and the influence of his ideas of power as increasingly dispersed and acting as productive and constructive is evident. However, although Bush (2000) and McKie (1995) both make reference to particular resistances, the focus of such work does tend to be in terms of how individual women are constrained by such powerful health promotion discourses. Therefore if we consider this work in the context of the previous chapter's discussions of power and resistance, then an imbalance is still discernible as the emphasis on how power is exercised in this context is not balanced with a consideration of how women may exercise resistance to such power. As such, there is the potential for this approach to portray women as passive victims who have no choice but to take up and occupy the subject positions presented to them. In contrast my research considers precisely the potential for women to resist these positions and the official discourse around cervical screening.

4.5 Women and Health

When exploring and examining women's understandings of and attitudes towards cervical screening, or any other health intervention or condition for that matter, it is important to consider these within the wider context of women and their health. The ways in which women view their own health and their personal understandings of health and illness will undoubtedly affect how specific interventions or procedures are thought about.

Charles and Walters (1994) set out to explore the ways in which women view their own health and which health issues are of most concern to them. Replicating in South Wales a previous Canadian study, the research took women through a list of various health and social problems and asked whether they had been worried about or experienced any of them in the last six months. Charles and Walters found that the most commonly cited problems were those of tiredness, stress, headaches and arthritis. Women frequently linked their health concerns with other problems including unemployment, problems with childcare and money worries. These problems were seen to increase stress which

then either directly produced ill-health or contributed to the development of 'unhealthy' lifestyles. These findings led Charles and Walters to argue that it is essential to incorporate women's health concerns into the policy-making process as many of these concerns are linked with the social conditions in which women live.

In a later piece, Walters and Charles (1997) further explored women's own concerns about their health and the ways in which they saw their health problems as affecting their everyday lives. As has been discussed above, the most commonly cited health problems included stress, depression, panic attacks, headaches and arthritis. Walters and Charles suggest that one of the most prominent themes to emerge from their interviews is that of unpredictability. Women discussed how their health problems had made their lives more unpredictable and less amenable to control. This often resulted in a change in their sense of self-identity and they often struggled to cope with the uncertainty that their health problems created. Walters and Charles further argue for the importance of gender and class and draw attention to the ways in which these can be seen to interact with an individual woman's health problems. For example they argue that,

> The very health problems women experienced created unpredictability and in many cases women were trapped by gender and class: for example, some women had lost their jobs, some were at home with young children, some had had been widowed and most faced money problems. The control they could exercise over their lives and the health concerns they reported may have stemmed from or been exacerbated by this (Walters and Charles, 1997:1729).

Charles and Walters (1998) have also explored the roles played by age and gender in women's accounts of their health and their experience of various health concerns. They argue that there are significant generational differences in the way women talk about their health. These can be linked to the women's differing social circumstances, changes in the ways health and illness are defined over time and the inevitable physical changes associated with ageing. Charles and Walters argue that the ability to perform their various social roles was often a key element in the way women discussed their health and their experiences of ill-health. However, whilst older women frequently discussed their health problems with reference to the challenges they encountered in continuing to

perform everyday tasks, younger women were more likely to talk about the stress they experienced in managing and combining their many different roles, such as being a wife, mother and worker. Younger women were also more likely to discuss the problematic nature of gender relations and high levels of unemployment. This therefore leads Charles and Walters to argue that age plays a significant role in structuring women's health problems and the differing ways in which they talk about them.

> Age is significant to women's experiences and understanding of health because, first, women's social circumstances differ depending on both their stage in the life cycle and changing patterns of employment and gender relations; secondly, ways of understanding health and ill health change over time; and, thirdly, women's bodies are subject to a process of physiological change (Charles and Walters, 1998:346-7).

Multiple factors including age, class, ethnicity and socio-economic group can therefore all have an influence on determining which, if any, health issues concern women and it is likely that these vary over time and the life course. With regard to understandings of and attitudes towards cervical screening, research has already shown that age can be a significant factor in influencing women's views (see White, 1995 above). Older women commonly regarded cervical screening as inappropriate or unnecessary for themselves, especially for those women who had experienced the menopause. However, screening was still seen as important for younger women, especially those with young families to look after. The individual woman's position within the life course, and therefore her related social circumstances, can be shown to have a significant impact on the way in which she regards both her health in general and procedures such as cervical screening in particular.

Blaxter's (1983) research into women's concepts of disease and its causes can also be of use here for its explorations of the ways in which women view different conditions and what they understand the causes of these conditions to be. With regard to the causes of disease that women discussed, explanations such as infection, heredity or family susceptibility, and factors within the environment were favoured. The women typically rejected explanations that included such factors as natural degeneration, inevitability or randomness. Blaxter argues that these models of disease processes expressed by the

women, although 'incorrect' in medical terms, were no less sophisticated than medical explanations. However, Blaxter draws attention to one of the most important features of the women's talk: the need to know about the cause of disease, the importance of producing a rational explanation and the importance of linking together life events. Disease was commonly conceptualised as some kind of malevolent entity that existed outside the body and waited to attack. The need to establish the reasons why it attacked various people, and in which ways, was seen as vital.

Of particular interest to the present research is the way in which the women in Blaxter's study discussed cancer. It is not surprising that cancer was one of the most commonly discussed diseases within Blaxter's interviews. However, given the importance women attributed to establishing cause, it is interesting that Blaxter notes how cancer, together with TB, was frequently mentioned without a discussion of cause. Blaxter suggests that women may have preferred to think of cancer as being caused randomly, therefore rejecting the idea of personal responsibility, but it was in fact this mysteriousness that gave the disease its terror. The explanations that women attribute to various diseases and conditions may play a significant role in determining whether or not they participate in health promotion programmes such as cervical screening. If a woman understands cervical cancer to have a specific cause, such as sexual promiscuity or smoking for example, then she may be either unwilling to participate for fear of being labelled as such or she may regard screening as unnecessary as she does not behave in that way. Particular views on disease causation may result in women understanding a specific type of person as more or less at risk of developing a certain condition. If that imagined person is different from herself then it can be suggested that the perceived relevance of preventive strategies will be significantly reduced, and vice versa.

Savage and Clarke (1998) have explored older women's representations of cancer, particularly in terms of comparing those of women who regularly attend for breast and cervical screening and those who are under-screened. Their interviews clearly identified a difference in the views of cancer held by the two groups of women. Those that were screened regularly were more likely to say that they were not afraid of cancer and to give examples of people they knew who had had cancer with no symptoms. In the case of the under-screened, they were more likely to be afraid of cancer and to suggest that symptoms would be present. There were few differences between the two groups when

asked about the causes of cancer: lifestyle, heredity and stress were amongst the most commonly cited causes. When asked about the possibility of treatment and a cure for cancer however, there were significant differences. Those who attended for screening were more likely to mention people who had been cured, whilst those that were under-screened expressed more cynicism about doctors and suggested that they would not want treatment if they were diagnosed with cancer of some kind. Once again, those that were under-screened were not necessarily against the idea of cervical screening completely. Several of the under-screened women in Savage and Clarke's study regarded screening as potentially valuable, particularly for younger women. The age of the women and their relative position within the life course again seems to be of relevance here as they do not disregard cervical cancer screening completely, instead they regard it as valuable to women other than themselves.

It can therefore be suggested that the beliefs and level of knowledge a woman has about cancer can influence her participation within preventive programmes. Sheikh and Ogden (1998) have explored this using both quantitative and qualitative methods. They began by using quantitative methods to assess the relationship between the knowledge of cancer symptoms demonstrated and help seeking behaviour. The association between these two factors was found to be significant, but not absolute. They therefore used qualitative interviews to explore the role of health beliefs in explaining the apparent gap. These demonstrated the complex way in which people discussed cancer, particularly in terms of fear, death and as a challenge. Many subjects discussed how they may recognise cancer symptoms but may not seek medical help for fear of finding out the truth. Non-attendance for screening programmes was often discussed in this way and related to factors such as avoidance, fear and denial. Interestingly, Sheikh and Ogden suggest that knowledge about symptoms may not be translated into help-seeking behaviour due to the perceived ineffectiveness of any available treatment. Also, a person may believe that their potential cancer is due to their behaviour or lifestyle and may therefore not seek help for fear of being labelled or judged.

4.6 The Influence of Lay Health Knowledges

The exploration and investigation of both lay health knowledges and lay/public epidemiologies has long been a concern of medical sociology both in terms of the meanings people attach to health and illness and the differences between lay and

professional ways of knowing (Brown 1992; Popay and Williams, 1996). The ways in which lay people come to understand various illnesses or diseases, together with their beliefs on the causes and available treatments for such conditions, are central concerns of medical sociology. Lay health knowledges and lay/public epidemiologies play a fundamental role in determining how people account for illness misfortune and how they assess the potential benefits of various preventive health behaviours (Davison *et al.*, 1992). Lay notions of disease causation, for example, are often very different from the official medical view. In their study of lay health knowledges around coronary heart disease, Davison *et al.* (1992) explore the lay notions of luck, fate, destiny and randomness and chaos in popular understandings of heart disease. Blaxter's (1983) more general study on women's views of the causes of disease found that women favoured such explanations as infection, heredity or family susceptibility when discussing disease causation. It is therefore likely that lay health knowledges and lay/public epidemiologies play a large role in determining how people understand diseases of various kinds and how they assess the potential benefits of preventive behaviour. In terms of cervical cancer screening, it is likely that the official medical discourse that surrounds the screening programme will be filtered through existing lay health knowledges and the plausibility of the health promotion message will be subject to assessment.

It has been argued that lay forms of knowledge are developed and formed in very different ways to professional knowledge and that, therefore, lay people develop a body of health knowledge that is very different from, but equal to, that of the professionals[16] (Popay and Williams, 1996).

The distinctive nature of lay health knowledge comes, at least in part, from its distinctive ontological purpose.

> Lay knowledge differs from expert knowledge in the sense that is has an ontological purpose, orientating behaviour in terms of an understanding to the individual's place in their life-world. It is…expressed in narrative form. This form is antithetical to traditional models of cause and effect…they

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[16] This is not to suggest the knowledge of professionals necessarily forms a coherent whole.

may also constitute a form of knowledge that challenges that of experts (Popay *et al.*, 1998).

The development of medical knowledge is rooted in the concept of disease, while the development of lay knowledge is firmly rooted in the experience of illness (Williams and Popay, 1994). Williams and Popay argue that a means of understanding the experiences of those who have various diseases is lacking from this traditional medical model. As medicine became more based in science and concentrated in the institution of the hospital, the patient's view came to be more and more excluded as somehow marginal and a threat to medicine's objectivity (Jewson 1976).

However, it should not be assumed that lay and professional health knowledges occupy distinct and separate spaces (Williams and Popay, 1994). The complexity of lay knowledges on health and illness has been acknowledged, and these may well incorporate expert knowledge or expert medical concepts, and indeed vice versa (Helman, 1978; Shaw, 2002). Indeed a range of research has demonstrated the ways in which, what appear to be lay perspectives on health and illness, incorporate biomedical ideas and concepts, albeit in altered forms (see for example Davison *et al.*, 1991; Gold and Ridge, 2001; Markens *et al.*, 1999). This leads Shaw (2002) to argue that the very concept of 'lay beliefs', defined as those not explicitly derived from the conceptual framework of medicine (Hughes, 1968), is invalid. This is because the public is so surrounded by professional messages and concepts of health that it is difficult to see how, at least in contemporary Western society, ideas about health and illness could develop completely independently of these. However, while it is highly likely that lay thinking on health will have been influenced to some degree at least by medical concepts and explanations, this professional knowledge is reinterpreted in terms of everyday life experience (Davison *et al.*, 1991). These interpretations are unlikely to be uniform and suggest the possibility that lay individuals can use their personal experiences, knowledges and beliefs to interpret and employ these professional concepts in a variety of ways and to a variety of ends.

Whether lay health knowledges and lay/public epidemiologies should be seen as posing a threat to professional dominance is a disputed area within medical sociology. Williams and Popay (1994) have explored this issue and argue that the challenge lay

health knowledges pose to medical knowledge and dominance remain largely implicit and most commonly take the form of non-compliance with medical advice. In their view, the knowledge expressed by the lay population remains disorganised and *adhoc*. It poses little or no direct challenge to the dominance of professional medical knowledge.

> However much these beliefs are part of a shared culture and society, they are expressions of personal experiences which remain outside the worlds of science and politics (Williams and Popay, 1994:118).

However, this does not mean that lay health knowledges do not have the potential to pose a significant threat to medical knowledge and medical dominance. Williams and Popay, whilst arguing that the threat posed currently is largely implicit, nevertheless see the potential threat that lay health knowledges may pose. They argue that,

> …the intervention of lay knowledge (by invitation or otherwise) into the world of public and environmental health offers the possibility of a challenge to the dominance of the medical profession (Williams and Popay, 1994:119).

Williams and Popay argue that the nature of the challenge posed can be seen as two-fold. Firstly, a challenge to the objectivity of the expert is discerned. The impartiality of expert medical knowledge can be challenged and questions raised about whether this process of objectification allows a proper understanding of health problems. An epistemological challenge can therefore be made to professional medical knowledge. Secondly, lay health knowledges can challenge the ways in which health professionals define problems in the policy arena. In this way, Williams and Popay argue, a political challenge to the institutional power of medicine is mounted.

The challenge that lay health knowledges and lay/public epidemiologies can pose to medical dominance is perhaps most developed in the areas of public and environmental health.

In these situations we can see the way in which the role of lay knowledge is politically unsettling for those who hold power in society, and for those who are accustomed to being able to have their truth claims vindicated by reference to a body of technical knowledge (Williams and Popay, 1994:123-4).

It is increasingly common for lay health concerns to develop into organised protest against specific aspects of biomedical knowledge and its uses. Williams and Popay cite the example of the Bristol Survey Support Group who challenged the medical researchers in whose trial they had been subjects. Findings of a research project considering the survival rates of women attending the Bristol Cancer Help Centre, which offers a range of complementary medicine to cancer suffers, claimed that women with breast cancer attending the centre fared worse than those receiving only conventional treatment. These findings were reported in the media and medical press without warning to the women who had taken part. The Bristol Survey Support Group was set up in response to both the findings and the way the report was released. The group took the two bodies funding the project to a hearing, where they were censured for inadequate supervision of the research. Organised challenges of this kind raise important questions about the relationship between the knowledges of lay people and those of medical professionals. It has been suggested that the trust lay people traditionally placed in the authority and knowledge of the medical expert is beginning to disappear.

However, concentrating on this kind of challenge and protest can be seen as potentially restrictive, as it focuses on overt and direct strategies of resistance. While these are unquestionably important and significant, they represent only one particular form of resistance. In many ways they can be seen as more compatible with traditional Marxist or feminist views of power, in which this is an external force located in the hands of a dominant group in society, and therefore direct challenge and protest is necessary and appropriate to rectify this imbalance. However, as I have discussed at length in the previous chapter, the Foucauldian ideas within which this research is framed suggest a very different conceptualisation of power, and therefore of resistance to it. Foucault sees power as more widely dispersed within society and as present at a multitude of levels, right down to the localised, micro level of social interactions. In this way, power is no

longer seen as only repressive and coercive but as taking a multiplicity of forms. As the points at which power operates are multiplied, so too are the potential points or sites of resistance (Bordo, 1993).

As such, it may be the case that the most useful way of thinking about how lay health knowledges can threaten or challenge professional medical knowledge, and certainly the most relevant to this research, is through an examination of the ways in which the lay health knowledges and lay/public epidemiologies held by many people influence the way in which professional medical knowledges are interpreted and understood and the perceived plausibility of modern health promotion messages (Davison *et al.*, 1991). In this way, the focus is shifted away from strategies of direct opposition and more towards exploring the process through which medical discourses are interpreted, negotiated and incorporated into lay people's lives. Such an approach recognises the many factors that may be at play in this context and takes us beyond the simple opposition of lay to medical knowledge.

In their study of lay understandings of coronary heart disease, Davison *et al.* (1991) suggest that professional medical messages on the risk behaviours associated with heart disease are readily incorporated into lay health knowledges and epidemiologies. However, these messages are incorporated in such a way as to fit in with culturally important concepts such as luck, fate and destiny. In this way, the lay process of assessing who is likely to become a victim of heart disease can look very different to that employed within professional medical circles, but need not be in direct opposition to it. The lay concept of candidacy is particularly important here.

A key theme within this work is an exploration of both the scientific and lay theorising about who is likely to become a victim of heart disease. In the context of lay health knowledges, Davison *et al.* suggest that the idea of 'candidacy' is of particular interest as it demonstrates how lay individuals,

> …assess personal risks, obtain reassuring affirmation of predictability, identify the limits of that predictability…devise appropriate strategies of personal behaviour and…go some way to explaining events (Davison *et al.*, 1991:6).

However, the development of these ideas cannot be seen as a purely individual activity. Instead, Davison *et al.* argue that it should be seen as a collective activity with many different types of input. Information from the media and official bodies, reports and experiences from personal networks, and the observations of the individuals themselves will all combine and be woven together to produce the individual's health knowledge.

In a similar approach, Calnan (1990) explores lay beliefs about food and health. It is suggested that epidemiological evidence suggests a strong association between diet and a number of major diseases and, as a consequence, a number of bodies have produced guidance on a healthy diet. However, Calnan argues it is not clear whether the public have taken notice of these guidelines and suggests that eating patterns remain relatively unchanged. Through an exploration of what individuals understand to be 'good' and 'bad' foods, a balanced diet, a 'square' meal and a 'proper' meal, Calnan concludes that there is a discrepancy between health beliefs and patterns of food purchase. Patterns of food purchase, particularly among working-class households, may be influenced by beliefs, tastes and preferences, while health concerns are not a high priority. As such the multiplicity of factors influencing food purchase and consumption is recognised, and in particular, the ways in which official discourses on healthy eating are interpreted and mediated.

Finally, Brown (1992) has contrasted lay and professional ways of knowing in the context of environmental health risks. A detailed study of the Woburn, Massachusetts childhood leukaemia cluster allowed Brown to explore the different ways in which lay and professional groups considered data quality, analysis methods, accepted levels of measurement and levels of statistical significance. Lay ways of knowing, termed popular epidemiology, were found to be very different from professional ways of knowing and to have very different purposes. Brown concludes by arguing that,

> Based on different needs, goals, and methods, lay people and professionals have conflicting perspectives on how to investigate and interpret environmental health data (Brown, 1992:267).

However, as interesting and informative as these studies are in terms of exploring the various ways in which lay health knowledges and lay/public epidemiologies can be used in the transforming and interpreting of professional health knowledges, I now want to move on to consider some more extreme examples of the uses to which these lay knowledges have been put: specific studies of resistance to professional health knowledges.

4.7 Empirical Studies of Resistance

The intention in this section is to explore a range of empirical studies of resistance in which different forms of resistance are demonstrated and ultimately to use these examples to set out what I take to constitute resistance in my research on women and cervical cancer screening.

The studies of resistance I examine here are all in the general context of health and illness and therefore involve resistance being demonstrated against forms of medical knowledge or expertise to varying degrees. In the previous chapter I explored studies outside this area and considered research on women's resistance to the stigma of childlessness (Riessman, 2000) and infertility (Kielmann, 1998). However, this was in a more theoretical context and, as such, was concerned more with attempting to define resistance than with the particular forms it may take, although the two are linked to a certain degree. Here though I restrict the focus to health and illness as that is the context of my research and there may be particular issues that are relevant to the potential for resistance in this kind of area that are not present in others.

The examples that I have chosen represent a range of situations and demonstrate the diversity of forms that resistance may take. I detail them in turn along a kind of continuum that leads from the least to the most severe forms of resistance, severity being defined in terms of the overtness or their contradictory nature[17]. Through this I compare and contrast how resistance may manifest itself in different contexts and the limitations that such contexts may place upon the kinds of resistance strategies available to individuals. I consider how these may compare to the case of cervical screening and

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[17] I deliberately avoid using the terms 'strongest' or 'weakest' here as I regard them as inappropriate and do not wish to make any kind of judgement on the strength or success of particular types of resistance.

therefore what forms of resistance may be demonstrated in this context and what I am prepared to regard as such.

4.7.1 Studies of resistance

At first glance the refusal of an offer of prenatal testing may appear a fairly overt form of resistance, however, as Markens *et al.* (1999) have demonstrated this need not be the case. In fact their research suggests that a refusal of this kind may actually demonstrate a very subtle and interesting form of resistance. Markens *et al.* argue that most of the research in the area of prenatal testing, and maternal alpha-fetoprotein (AFP) in particular, has been concerned with women who accept or actively seek out such tests. In contrast, they argue, little attention has been paid to those who decline such tests with the general assumption being that those who do so are resisting this form of medicalization and/or are opposed to abortion. In order to rectify this imbalance, Markens *et al.* explored how such refusals of AFP are framed, conceptualised and thought about by those who refuse. Importantly, they found that a refusal of AFP did not signify the rejection of, or resistance to, the offerings of science and technology. Instead, such women used the medical concept of risk to account for their decision. As such, the biomedical concept of risk was used to refuse one of biomedicine's own offerings.

However, the concepts of risk employed by the pregnant women were not always in accordance with those of medical professionals. Instead, despite medical assurances to the contrary, women refusing AFP perceived a range of risks associated with such tests, including stress, abortion and miscarriage. The conceptions of risk held by lay people and medical professionals are therefore often very different and can vary according to the particular personal and cultural circumstances of the individual (Lupton and Tulloch, 2002a&b).

Markens *et al.* (1999) are clear that the refusal of AFP testing does not constitute rejection and/or resistance to the offerings of science and technology, as it may at first glance appear to do. Instead, it can be argued that the resistance is demonstrated at a much more subtle level. Both women who accepted and refused AFP testing used ideas of 'risk' to account for their decisions, however what is important is the difference between the two lay perceptions of risk. Markens *et al.* argue that, for the acceptors, it is

the absence of prenatal information that constitutes a risk, whereas for the refusers it was the information produced by such tests that posed the risk. It is therefore the perception and interpretation of the concept of risk that influences whether or not an offer of AFP is accepted or rejected, not any form of resistance to biomedicine as such.

The importance of exploring how biomedicine's concepts and messages are interpreted and taken up by individuals is highlighted in Browner and Press' (1996) work on the production of authoritative knowledge in American prenatal care. They found that pregnant women did not accept biomedical authority uncritically, instead a process of selective incorporation was apparent. Generally speaking, women accepted those recommendations that were confirmed by embodied knowledge and experience, whilst rejecting those that ran counter to pre-existing beliefs about how to care for themselves during pregnancy or that could not be easily incorporated into their everyday lives. For instance, many women drew on their embodied experience when opting not to incorporate prenatal biomedical recommendations. Browner and Press suggest that women who have already had healthy children are particularly likely to act independently and to make reference to an earlier pregnancy when giving an explanation. They cite the example of Kitty who was reluctant to give up smoking during pregnancy, despite being encouraged to do so. Kitty explained that she smoked during her first pregnancy and had a nine-pound baby who scored a 9 on the AGPAR (a system of scoring an infant's physical condition one minute after birth, on which the maximum score is 10). Kitty therefore rejects the universal claim that smoking during pregnancy harms the unborn child as it does not conform to her embodied experience. Resistance in this example therefore comes through the selective incorporation of biomedical recommendations, in which those that do not fit with existing experiences or beliefs are resisted.

Resistance as a refusal to think about things in the same terms as biomedicine can also be seen in Potts *et al.*'s (2004) research on Viagra users, whose accounts do not necessarily support the medical understanding of their sexual difficulties. Potts *et al.* argue that the medical model of erectile dysfunction employs a mechanistic view of the body and makes no reference to factors outside that body. However, some users of Viagra challenge this medical presentation and view dysfunction as a natural part of the ageing process. They are therefore critical of the 'pathologization' of their problems as

representing some form of medical problem. In an interesting approach, Potts *et al.* juxtapose extracts from drug company pamphlets, which are targeted directly at consumers, with accounts of users in order to demonstrate the discrepancies. As such they contrast the pamphlet's framing of 'erection problems' as a medical matter that a visit to the doctor would resolve with participants' discussions of how these were simply one part of a whole range of bodily changes associated with ageing. Potts *et al.* conclude by arguing that the medical model of male sexuality assumes the universal application of the 'sexual response cycle' and therefore a commonality of experience. However, the diverse range of understandings and experiences highlighted by their research demonstrates the lack of empirical support for this and draws attention to the resistance of users to thinking in these terms and their employment of a variety of alternative meanings and significances.

Thus far the three studies detailed can be regarded as demonstrating similar kinds of resistance. In all cases the focus is on fine-grained and subtle forms of resistance that do not entail an overt, full scale challenging of medicine. Instead, the resistance comes through a reluctance to think about or perceive things in medical, or medically 'correct', terms. As such, women in Markens *et al.*'s (1999) research interpreted risk in a different way to both biomedicine and to other women who made the decision to accept prenatal screening and, although this ultimately led them to decline a biomedical offering, such decisions did not constitute a rejection or refusal of biomedicine as a whole. There was a more explicit element of rejection in Browner and Press' (1996) work on authoritative knowledge in prenatal care, in which women frequently employed embodied experiences from previous pregnancies to counter biomedical claims. However, this resistance was selective as, while some recommendations were rejected, others were accepted and acted upon. Similarly, in Potts *et al.*'s (2004) work users of Viagra demonstrated a resistance to thinking about their sexual difficulties in medical terms or employing the universal medical model. Instead, they put forward their own conceptualisations that demonstrated the heterogeneity of experience. These differences in approach led some men to stop taking Viagra, but many did not and continued to use this medical solution to their problems while maintaining alternative, non-medical conceptualisations of those problems.

More explicit forms of resistance can be found in research by Murphy (2003), which explores how mothers resist and refuse expert advice on infant feeding. All the women Murphy interviewed admitted to breaking at least some of the expert-defined rules in this area. In common with the sociological work on cervical screening (Howson, 1998a&b, 1999; McKie, 1995; and Bush, 2000) discussed above, Murphy suggests that women are subject to powerful medical discourses that clearly set out the 'correct' behaviour, for example exclusive breast feeding for the first sixteen weeks. However, rather than portraying these women as powerless in the face of such discourses, Murphy demonstrates how mothers engaged with and resisted this normalising discourse of medicalized scientific expertise and offered counter discourses through which their own feeding practices were legitimate. These counter discourses can therefore be understood as a 'rhetorical strategy of resistance' (Murphy, 2003:443).

As highlighted in the previous chapter, Rose (1992, 1996, 1998) argues that expertise plays a central role in modern forms of government and it is interesting to explore the way in which mothers in Murphy's research engaged with ideas of expertise and employed them in their strategies of resistance. Many criticised professional, scientific expertise on infant feeding on the grounds that it could not adapt to particular circumstances and individual babies. Through this, women who 'broke the rules' could legitimise their behaviour through appeals to their expertise with their particular baby.

> Expertise continued to be an important issue around which women's talk pivoted, but it was redefined and, as a result, relocated. Expertise relevant to infant feeding was now based on individualised knowledge of a particular baby. Such knowledge was, by definition, invested in the person who had day-to-day care of the baby (Murphy, 2003:449).

Therefore women do not reject the notion of expertise, instead they employ this very concept in their production of counter discourses that rely upon their status as holders of a different kind of expertise. Murphy's research therefore illustrates a type of resistance that goes further than that detailed so far, demonstrating as it does women's resistance to professional claims of expertise over the whole area of infant feeding. To a degree it echoes the work of Browner and Press (1996) on women's selective incorporation of antenatal biomedical recommendations in that women give preference to their

individual knowledge and experience. However, the resistance demonstrated in Murphy's research goes further than this as women have constructed a coherent and sustained counter discourse that they employ.

Similar examples of opposition to official health doctrines can be found in Rogers and Pilgrim's (1995) work on opposition to the mass childhood immunisation (MCI) programme. They argue that the resistance they identify in this specific context is representative of a wider phenomenon in which lay people challenge scientific expertise, as in Murphy's research, or reassemble it in order to resist it. As such lay people can develop dissenting views on disease aetiology and different assessments of risk. Rogers and Pilgrim suggest that the accounts offered by parents who chose not to vaccinate their children indicate that such 'non-compliance' develops over time and can be influenced by a diverse range of factors and processes. Some of the examples cited include discussions of the environment, healing, holism, the roles and responsibilities of parenting and a critical reading of both scientific and alternative literature. As was to be expected, the balance between such factors varied in different accounts.

Parents choosing not to vaccinate their children therefore drew on these kinds of accounts in order to resist the official doctrine that children should be included in such immunisation programmes and to justify their decision. However, what is interesting is that the position adopted by these parents with regard to immunisation was not representative of a wider conflict with bio-medicine and health promotion messages. Instead, such parents were heavily involved in reducing potential risks to their child's health in all other ways, including long periods of breastfeeding, promoting healthy eating and a focus on physical and mental well-being. In addition, their views on other forms of immunisation were mixed. While some were opposed to immunisation as a philosophy, others were more selective according to the perceived risk in each context.

Rogers and Pilgrim therefore argue that this challenging of medical authority in the context of MCI represents the breaking down of traditional patterns of authority and deference between the lay population and medical professionals. However, it is important to bear in mind that this resistance in one quite specific context does not necessarily mean a full-scale rejection of biomedicine. The final example I consider

here, although still concerned with a specific context, represents a wider rejection of biomedicine and demonstrates a refusal to adopt medical ways of thinking.

Gold and Ridge (2001) interviewed 20 HIV-infected Australian gay men who had decided not to access antiretroviral drug therapy. Their reasons for deciding not to access the treatment were varied and included side effects, toxicity, inconvenience, a threat to morale and the absence of any symptoms. With regard to the first four of these, the primary resources drawn upon were the experiences of friends who had used the drugs. Only a minority of the men interviewed had any personal experience of the drugs on which to base their decisions. In this way the resistance here differs from that based on personal experiential knowledge, as seen in Browner and Press (1996), as the experiences are not personal but based on those of friends. Many men felt that the official medical discourse trivialised the potential side effects of the drugs, for example, and employed their friends' experiences to challenge this. The final reason, absence of symptoms, was employed as a reason for not accessing treatment by a number of men. Conversely, the onset of symptoms was a reason to start drugs.

Many of the men were engaged in various self-help actions to try and maintain their health and used these as reasons for not needing the therapy. The strategies employed included regular check-ups and tests, alternative therapies, healthy eating and exercise. Gold and Ridge also identify a very interesting theme within the men's accounts, which details how they felt themselves to be resisting unreasonable pressure, from both doctors and the gay community, to access the therapy. A certain pride was felt by the men in their ability to resist this pressure. Gold and Ridge argue that these men were in conflict with the biomedical model for the management of HIV/AIDS and that their decisions not to access therapy should be seen as examples of dissent. The men had a very different way of thinking from the biomedical model and their resistance was based very much on their own experiences, or that of friends, rather than medical concepts. In this way, the values upon which medical science makes its claims to authority, such as abstraction, detachment and objectivity, are rejected in favour of knowledge drawn from the experience of those close to the individual. Therefore, not only do men reject the drug treatment offered by biomedicine, they also reject the underpinning approach and perspective therefore demonstrating that their resistance is likely to extend beyond the specific context of antiretroviral therapy.

4.7.2 Resistance in the context of my research

The discussion in the previous section has served to sensitise and alert me to the possible forms that resistance may, and indeed does, take, and how this may be influenced or limited by context. The particular example of cervical cancer screening is an interesting one as it represents an example in which, at one level, women have either complied with medical advice and had a smear test or have failed to do so. In this way there is no possibility of appearing to accept medical advice or expertise without doing so in reality. This is in comparison to examples in which individuals may give the impression of following medical advice but fail to do so in practice. In the case of infant feeding discussed above (Murphy, 2003), it may be possible for a woman to assure her health visitor that she is following expert guidance and 'rules' when in fact, in her day to day life, she is doing nothing of the sort. Bloor and McIntosh (1990) have explored different forms of resistance in the context of health visiting and suggest that this kind of 'concealment' is the most common. Within this, mothers would often conceal practices, such as early weaning, that they anticipated the health visitor would criticise. Bloor and McIntosh argue that this is a particularly popular form of resistance as it neutralises the potential for the exercise of power but does not explicitly challenge it in a way which may provoke confrontation.

However, it is difficult to see how this form of resistance could be employed successfully in the case of cervical screening. While women may be able to conceal their non-attendance from friends and family, this will not be possible with health professionals. Women cannot assure their GPs that they are presenting themselves for screening when their records show that this is not in fact the case.

This dichotomy of attendance/non-attendance is employed, for obvious reasons, in the compilation of statistics on cervical screening. However, while there are reasons why it is important to know how many women are or are not being screened, I would argue that this focus on attendance in no way adequately represents the diverse range of positions or stances that women may adopt. This is because attendance for screening need not represent agreement with all aspects of the official discourse around it, for example on risk or disease causation. In contrast, non-attendance need not represent

wholesale rejection, as women may be very supportive of screening but simply not able to find the time to attend. Therefore such a focus on attendance is misleading.

There are likely to be many possible positions within the complex interplay of factors and discourses relevant to cervical screening. Potts *et al.* (2004) show how, while many men were resistant to the problem of erectile dysfunction being medicalized, they nevertheless took advantage of the medical treatment offered. In this way, attending for screening need not represent a wholesale acceptance of the wider discourse surrounding it. At its most extreme, a woman may fundamentally disagree with all aspects of screening, such as disease causation and the efficacy of screening, but not feel able to remove herself from the 'moral obligation' (Howson, 1998a, 1999) she feels to attend.

The potential forms that resistance may take are therefore multiple and may operate at different degrees of severity. In light of this, I adopt a deliberately open definition and will regard resistance as any talk or action that differs from the official discourse. In this way I align myself more with Riessman's (2000) idea of 'transformative potential' than with Kielmann's (1998) focus on intentionality. As such the focus will be on the alternative conceptualisations or counter discourses that women produce on cervical screening and the cancer itself.

4.8 Conclusion

This chapter has served a number of key purposes. Firstly, it has set out and critically examined a range of recent empirical studies in the area of cervical screening, ranging from health services research through to the application of theoretical sociological ideas to this particular health intervention. Secondly, through a critical reading of these kinds of work, the chapter has demonstrated the particular gap that my research is designed to fill. In particular I argued that, although existing sociological work on screening is valuable for the way in which it problematizes the issue of attendance, such a focus runs the risk of overstating the extent to which women are constrained by power in this respect, at the expense of exploring the ways in which they may demonstrate resistance to such power. I argued that, in the context of Foucauldian ideas on power and resistance discussed in the previous chapter, it is important to focus on the relationship between the two and explore how individuals have the potential to resist the forces that attempt to discipline them.

Having established the need for work of this kind, I moved on to locate it within the context of relevant sociological studies that may prove useful in thinking about the way in which such resistance may be demonstrated or the means through which it may be expressed. Areas covered included women and health, lay perceptions of disease causation and cancer, and lay health perspectives more widely.

Finally, the chapter explored some recent empirical studies of resistance in the area of health and illness in order to demonstrate the different forms this may take. A spectrum of types of resistance was employed on order to illustrate the range of possibilities and to make the point that refusal of a biomedical offering should not necessarily be construed as wholesale resistance (Markens *et al.*, 1999), while using a medical treatment need not represent full acceptance of the medical perspective on a particular condition (Potts *et al.*, 2004).

This was later developed in considerations of what I would take to constitute resistance in my research. Here I problematized the tendency for work on screening to focus on attendance and the implicit assumption that attending means there is therefore no resistance on the part of women. As the NHS Cervical Screening Programme constantly achieves coverage of over 80%, such an assumption would suggest that the vast majority of women attend for screening uncritically and in absolute accordance with the official discourse in areas as diverse as risk factors, the appropriate screening interval and target age range, and the actual experience of having a smear test. As this thesis goes on to show, this is an incorrect assumption and, in reality, women can and indeed do set out very different views and understandings to those present in the official discourse.

Chapter 5
Methods

5.1 Introduction

The purpose of this chapter is to set out the way in which the research was approached and carried out. I begin by recapping on the aims of the research and how these necessarily influenced the research methods used. Due to the nature of the research a two-stage approach was needed with an initial documentary analysis being undertaken in order to characterise the official discourse around cervical screening before the main focus of exploring women's understandings, experiences and views of this health intervention could begin. In the first main section of this chapter I set out how I arrived at the most appropriate research methods to meet my particular aims.

As stated, the initial stage of the research involved a documentary analysis to establish how cervical screening is presented to women invited to participate within the programme. I provide details on why this was necessary, the kinds of material selected for analysis, how this was accessed, gathered and analysed and, finally, where the outcomes of this stage are to be found in the thesis.

Following this I move on to set out how the main stage of the research was carried out. I begin by providing information on the sample used. Important questions such as whom I wanted to include in the research, and consequently who was excluded, and how I arrived at the inclusion criteria are addressed. I detail the decision to use a quota sample, the criteria on which this was constructed and how these changed during the research, also the means through which I accessed and recruited women. The final sample profile is detailed.

Having set out how I drew up my sample and recruited participants, I move on to provide information on how the research was actually conducted and to reflect upon this process. I consider the ethical implications of this kind of research and set out the steps I took to protect the women participating. How the material collected was analysed and used is covered.

Finally, having detailed the research from the initial decision-making about choice of research methods and approach, through drawing up a sample and recruiting women and ultimately to actually conducting the research, I spend some time reflecting upon the whole process. I identify some of the issues and problems that I faced, difficult decisions that had to be made, my identity as researcher and how this may have influenced the material gathered. At times I make reference to some of these issues in the preceding discussion, but here I draw them together and introduce those not covered elsewhere. This allows the chapter to conclude with a consideration of how the research methods used, and the decisions taken, may have impacted upon the research and the material gathered.

5.2 Research Methods to Meet Research Aims

The aims of any research project are, of course, fundamental in determining how the research is approached and carried out. The purpose of my research has been to explore lay women's understandings, experiences and opinions of cervical cancer screening in the context of the NHS Cervical Screening Programme (NHSCSP) operating in England. In particular, the work is concerned with the different ways in which women demonstrate forms of resistance to the official discourse surrounding this programme through the ways in which they understand, think and talk about screening. At a theoretical level, Foucault's later work on the 'technologies of the self' is employed to consider how women interact with this discourse, in terms of how it is interpreted, made sense of and understood, therefore demonstrating resistance to the official discourse surrounding it (Foucault, 1984a&b, 1988).

5.2.1 Initial stage

As I have indicated above, the nature of my research meant that an initial stage was necessary in which the official discourse on cervical screening was characterised. It would be problematic to proceed with the main body of the research, exploring how women may demonstrate resistance to this, without having done so. The task of characterising the official discourse on cervical screening, and establishing how it is presented to women, posed some difficulties both in terms of how it could or should be represented. While it is likely that many women discuss cervical screening with Primary

Care staff[18], and receive some information from them on the subject, taking this to represent the official discourse is problematic for several reasons. Firstly, from a purely practical perspective, gaining access to these kinds of discussions could prove to be very difficult as it is likely that they would occur either in the context of a cervical examination or when a woman goes to the practice for some other reason, as attendance for screening is increasingly integrated with other visits. In the majority of cases it would not be possible to ascertain in advance whether these encounters would involve the individual seeking information and therefore a discussion of cervical screening in any detail. Secondly, as has been discussed in Chapter 2, it is likely that health professionals may hold differing views on the value and usefulness of cervical screening and that, therefore, their discussions with lay women have the potential to differ widely. Finally, although cervical screening is delivered through Primary Care, the programme itself is nationally co-ordinated and managed and so, although women have their smear tests largely in the context of General Practice, they are participating in a much wider programme[19].

The fact that the NHSCSP is co-ordinated at the national level by the National Office of the NHS Cancer Screening Programmes reflects its centralised nature and, as I go on to discuss, the information leaflet that women receive about screening is produced at this level and not by Primary Care Trusts (PCTS) or General Practice through whom screening is actually delivered. It is therefore important to ensure that what is taken to represent the official discourse on screening reflects this. It is for this reason, more importantly than the practical problems discussed above, that it is inappropriate to focus attention at the intermediate, health professional level. The underlying premise of the research, as framed theoretically in Chapter 3, is how individuals respond to a state level discourse and so to introduce a level which sits somewhere in between would be muddling. Instead I focus on the state level, which is combined with a particular form of medicine, that which feeds into and informs policy development and is not located at the level of practice.

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[18] I include here both those based in General Practice and in Family Planning Clinics as women can choose where to have their smear test taken. However, the vast majority of smear tests are taken in General Practice.
[19] The extent to which women were aware of this differed, with some women seemingly unaware that those involved in delivering their screening were operating within national recommendations and guidelines.

Having taken these issues into account I made the decision to characterise the official discourse through an analysis of the information material produced at this state level, but also to look at the locally produced invitation letters that this accompanies in order to gain a fuller understanding of how screening is presented to women. Section 5.3 provides more detail on the materials chosen and how they were accessed, gathered and analysed.

5.2.2 Main research stage

Having dealt with the necessary initial stage of the research, my thoughts turned to conducting the main body of my research. As I wanted to explore the ways in which women thought about, understood and experienced cervical screening I identified qualitative methods as the most appropriate way of approaching the research. A qualitative approach meant that I could focus on the particular ways in which women spoke about cervical screening and engage with this at a micro level to produce a fine-grained analysis of the discourses and themes on which they drew. I was keen to give women the chance to talk about screening in their own words and for me to explore the complexities and subtleties of such talk.

But how to gain access to such material? I wanted to explore how women talk about cervical screening and, since this was not likely to be a subject on which they frequently engaged in detailed conversations in the course of their everyday lives, a specific context needed to be identified or created. A possibility could have been to observe the discussions that women had with Primary Care staff about such screening, but this would have proved problematic for a number of reasons. Aside from the kinds of practical problems I have already detailed, such an approach does not fit with the aims and purpose of the research itself and introduces the very intermediate level that I was clear needed to be avoided when characterising the official discourse. Instead the research must take place outside the medical context and, since it is unlikely that women engage in detailed discussions about this topic routinely[20], I felt it both necessary and justified to create a specific context in which to ask them to generate accounts of their thoughts, understandings and experiences of screening. Dingwall

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[20] This was borne out by some women's comments during the research.

(1997) has argued that the research interview constitutes a deliberately created opportunity to talk about something that the researcher is interested in and which may or may not be of interest to the respondent. He therefore argues that interviewing is inferior to observation as a research method as the data produced are social constructs. However, as Bryman (2001) has argued, there exist a wide range of issues that are simply not amenable to observation and, as a result, creating a specific situation in which to ask people about them can be the only viable method of researching them. As I have indicated, it is hard to conceive of a naturally occurring, non-medical, situation in which women discuss cervical screening at length that would be both practical and ethical to access. I therefore feel that the creation of an interview situation is justified within the context of this research.

But should the situations created be individual interviews or group discussions? Previous sociological studies on women and cervical screening have adopted different approaches. Howson (1998a&b, 1999) used individual interviews in her research, which illustrated how women draw on specific contexts and relationships through which participation in cervical screening is given meaning. In contrast, McKie (1995) used discussion groups to find out about participation and views on screening. The use of groups has the potential to provide an interesting forum in which women can consider and respond to others' views and experiences. However, more important for McKie was the need to provide women with a level of security and informality in which they felt comfortable enough to discuss a sensitive issue. She argues that the use of established groups ensured that women felt comfortable with each other and provided important support mechanisms. She states that 'women often touched each others' hands or arms, providing visible as well as vocal support' (McKie 1995:448). It may be that women feel more comfortable discussing sensitive issues in a supportive group environment than they would in an individual interview with a previously unknown researcher. However, using this approach can have the reverse effect, with women being reluctant to talk about things in front of others that they may have otherwise disclosed. McKie gives the example of a focus group participant who approached her after the session was over and told her that she had had a positive smear test but had not wanted to say anything in front of people in case they thought badly of her. This particular individual

came forward, but it is impossible to know how many others were holding back information or an opinion during the discussion[21].

There is much discussion about the suitability of focus groups for the discussion of sensitive issues. Morgan (1988) has argued that they can be very useful in this context as they provide a forum in which participants are encouraged to share their thoughts and experiences about an issue that is relevant to them all. However, there is the possibility that people may get carried away in the moment and disclose more than they intended, leading them to regret what they have said later.

After careful consideration of each potential approach, and how they would help me to fulfil my research aims, I decided to adopt individual depth interviews as my method. I felt that these were the most appropriate method for a number of reasons. First, as I wanted to explore how women think and talk about screening, and the kinds of resistance that this may demonstrate, it was vital that I created an environment in which women felt able to talk as freely as possible. Due to potential problems with group dynamics I did not feel that discussion groups could offer this. Second, and in a similar vein, I needed to create an environment in which women felt able to put forward views and understandings that potentially ran counter to both the official discourse on screening and other women's positions. Again, I did not regard groups as creating the degree of safety required for this to happen. Finally, although as indicated earlier, groups can provide a forum to explore how people consider and respond to others' views, this aspect was not perceived as particularly important to the research. Instead it was felt that creating an environment in which women could set out their own individual positions must take precedence[22]. However, I was aware that focus groups can be used effectively as a follow-up to individual interviews as a means through which to explore issues that only become apparent during the analysis stage (Morgan, 1988) and resolved to keep them in mind for this purpose.

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[21] It is of course equally impossible to know what information or opinions individuals might keep back in an one-to-one interview situation.

[22] This was borne out by the focus in the analysis stage on how women individualised screening and made it relevant to their personal circumstances and characteristics.

In terms of the nature of my individual interviews, I decided that these would be lightly structured and allow women the time and space to talk freely about their personal thoughts, understandings and experiences of screening. Although I as the researcher had initially defined the research questions that I wished to pursue, I was keen for women to suggest to me areas that they regarded as pertinent and significant and was open to the idea of including these within subsequent interviews. I was keen that my participants should be able to shape the research and how I thought about my research questions, rather than simply regarding them as sources of the information I had predetermined as important (Oakley, 1981). Not only do I regard this as a more ethical way of conducting research, I would also argue that it is likely to result in higher quality data being produced as women feel more positive about the interview and are prepared to invest more of their time and energy into it. Finch (1984) has highlighted potential ethical problems with this approach, particularly when a woman is interviewing another woman. She argues it is problematic to create a situation in which a participant feels as if they are having a conversation with a friend and therefore reveal more than they had intended, when in fact the researcher will go away and use the conversation as part of their research project. While I agree that this is an undesirable situation, I did not feel that this was likely to become an issue in my research, and indeed it did not appear to be so on the whole. During every stage of the research women were fully aware that they were taking part in a research project and how the data would be used. In addition, as I will discuss in more detail later in the chapter, potential areas around which this kind of problem may have occurred were largely mitigated by my personal characteristics such as my age and ethnic background.

Therefore, through a detailed consideration of both my specific research aims and the relevant methodological and practical issues, I reached decisions about the most appropriate research methods for this project. In the rest of the chapter I go through how these were put into practice and the issues and problems that arose.

5.3 Documentary Analysis

The nature of my project made an initial research stage necessary. As the main aim of the research was to explore how women may demonstrate forms of resistance to the official discourse around cervical screening, it was vital that I characterised this.

5.3.1 Material chosen

As I have detailed in section 5.2.1 above, I made the decision to focus my analysis on the written materials produced and sent to women invited to participate in the programme. In practice these were, firstly, the invitation letters produced locally by PCTs and, secondly, the nationally produced information leaflet that is required to be sent out with all invitation letters. The decision to use these kinds of material brings advantages and disadvantages.

The focus upon standardised written materials allows me to bypass potential problems of different health professionals discussing screening in very different ways. As I have made clear elsewhere in the thesis it would be problematic to assume that health professionals have a uniform view on screening and so opting to use standardised written materials ensures that I am analysing what could be termed the 'official line'. However, this inevitably means that there is a 'missing link' between the individual level and the 'official' level, that is the intermediate level of health professional/patient interaction. I feel that this is justified given the way in which my research is theoretically framed and given the specific research questions I seek to address. In addition, my choice of written materials for analysis still permits the exploration of the growing disaggregation of information to some degree. The information leaflet is nationally produced and is sent to all women invited to attend for screening, while invitation letters are produced locally at the PCT level and so can vary in style, content and level of information. My decision to include material produced at these different levels allows me to explore the different ways in which information and knowledge about screening are presented and the potential discrepancies that can occur between the nationally and locally produced sources. Finally, although interactions between health professionals and women are not a level at which I explicitly focused my data collection, this perspective is not lost entirely as the women interviewed in the main research stage frequently made reference to these during interview[23].

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[23] This is not to suggest that I regard women's accounts of these interactions as a complete substitute for observation of these, merely to highlight the fact that my decision not to collect data at this level did not mean that it was completely excluded.

5.3.2 Accessing and gathering material

The locally produced invitation letters and nationally produced information leaflet were therefore identified as the most appropriate representations of the official discourse on cervical screening that women will encounter in the course of their contact with the NHSCSP. I had already obtained copies of the information leaflet in a variety of ways, for example by downloading it from the NHSCSP website and through a visit to the National Office of the NHS Cancer Screening Programmes in Sheffield. However, the leaflet itself is not sent out to women at this level, instead it is required to accompany invitation letters that are sent out locally. I therefore decided to focus my collection of these materials at the PCT level as these are now responsible for providing cervical cancer screening services for their eligible populations.

There are currently 302 PCTs in England and these receive budgets directly from the Department of Health to deliver local health care. I downloaded a list of these PCTs from the NHS website (http://www.nhs.uk/root/localnhsservices/list_orgs.asp?ot=5__) and decided to use a sample of approximately 10% of these. In order to ensure as wide a coverage of the country as possible, I grouped the 302 PCTs according to the 28 Strategic Health Authorities that monitor performance and standards and chose one at random from each area, giving a total of 28. In addition to this, the four local PCTs within the Nottingham Health Community were included as it was anticipated that those women involved in the main research stage would come predominantly from these areas and so would have received the invitation letters produced by these local PCTs.

The documentary material was then accessed through direct contact with PCTs. A standard letter was produced and sent to each giving details of the research and requesting a copy of their standard invitation letter and any material that was sent out with this. It was anticipated that the information leaflet, entitled *Cervical Screening: THE FACTS*, would be sent by all PCTs but this was not assumed. Instead the letter simply asked for any additional material that was sent out with the invitation letter.

There was an interesting range of responses from PCTs to my request for information. The most helpful contacted me either by telephone or e-mail (I had supplied my details in the letter) to discuss the possible range of materials that they could send me. I had asked for a copy of their standard invitation letter but they were keen to stress the range

of letters they employed, for example those inviting women for their first smear test or those chasing up women who had not attended. I adopted an approach of accepting all the information they were willing to send me, but after consideration only used their standard call and recall letter for analysis. This was for two main reasons. Firstly, having examined the range of letters I was sent I found that the core content was very similar, with the differences being largely restricted to a sentence or two at the beginning referring to the specific context e.g. first test or letter following non-attendance. Secondly, because the vast majority of women (over 90%) within the programme are on standard call and re-call following negative results, this standard letter is the kind that they will be receiving.

Less enthusiastic, but no less helpful, were those PCTs who promptly sent me the information I had requested. However, a sizeable number of PCTs approached proved very unwilling to supply information. Sometimes a follow up telephone call or e-mail was enough to prompt them to action but more commonly I was forced to substitute the most unhelpful with another PCT from the same area, often unfortunately with very similar results. I reviewed the materials received regularly and, as they were proving to be largely similar in nature and due to the difficulty in obtaining information from some PCTs, I took the decision to cease collection when I had received satisfactory material from 24 PCTs. This represented 75% of my original total of 32 PCTs.

5.3.3 Analysis of documentary material

I approached the analysis of these documentary materials in two stages and the results of this can be found in Chapter 6. Firstly, a largely descriptive section sets out basic information about the material addressing such issues as who the material is produced by and for, its purpose, its content, the format used and what is included or excluded. These may at times seem mundane but are important in order to fully understand the context in which these materials are produced and the way in which they are put together (Hammersley and Atkinson, 1995; Scott, 1990; Silverman, 2001). Following on from this the analysis takes a more sociological turn and explores in more detail the way in which cervical screening is characterised and how the material is put across. Important questions will centre on the language and discourses used to put the information across, the assumptions made by the authors about both the readers themselves and the information or views they already hold. These are important

questions, and ones that link to the wider Foucauldian framework within which the thesis is based, exploring the ways in which the information or knowledge contained within this material is produced, encoded and displayed (Prior, 1997), how the texts work to achieve particular ends and how they construct reality (Atkinson and Coffey, 1997; Silverman, 2001).

5.4 Sampling and Accessing Women

In this section I give details on how I decided upon who I wanted to include in the main stage of the research, how I accessed and recruited these and my final sample profile.

5.4.1 Who did I want to include?

Due to the particular nature of my research, not least its relationship with the official discourse around cervical screening characterised by the documentary analysis detailed in section 5.3, I took the decision very early on to limit inclusion to those women currently being invited to attend for screening through the call and re-call programme. This therefore meant that all my participants would necessarily be within the 20-64 year old age group, as this was the age group routinely invited for screening at the time of the research[24]. Whilst I acknowledge that women outside this age range may still have relevant knowledge and experiences of screening and the programme, even though they are not routinely invited, I felt that it was more appropriate to limit the research to those currently being invited. Whilst it was vital that the women interviewed were currently being invited to attend, and therefore were receiving the information used in the documentary analysis stage, I was clear that I wanted to include both women who were currently attending for screening and those who (for whatever reason) were not. Given that coverage for cervical screening is consistently over 80% I was aware that this would be difficult but not impossible. In addition to the simple problem of numbers, there were also potential issues regarding the willingness of current non-attenders to be interviewed. For example, a woman who has not attended due to a lack of time is unlikely to then make time for an interview. Moreover, it is perhaps those who have made a deliberate decision not to attend that may be least likely to participate. It is likely that those who choose not to attend will have had to explain and justify their decision to various people and therefore they may not wish to go through the process

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[24] As detailed in Chapter 2 the target age range for routine screening has very recently been changed to 25-64 years of age.

again, especially if they think that I will be trying to encourage attendance. In order to try and minimise this problem throughout the access and recruitment stage I routinely stressed wherever possible that I was not a qualified health professional and that I would make no judgements on women's screening behaviour. Instead I presented myself as a social researcher who was interested in exploring women's thoughts and/or experiences of cervical screening.

This therefore meant that there were a large number of women who were eligible for inclusion in the research and so, in order to try and ensure that as wide a range of views as possible was included, I decided to employ a quota sample. When drawing up the sample I identified a number of factors that may potentially be important in influencing how a woman thinks about, understands and/or experiences screening. The most important of these were as follows:

Age

This was identified as particularly important as past research has shown that older women often regard health promotion strategies as no longer relevant to them, but still see them as important for younger women (White, 1995; Savage and Clarke, 1998). The menopause seemed to be of particular significance here as post-menopausal women have discussed cervical screening as no longer relevant to them as that part of their body is 'finished with' (King, 1987, cited in Neilson and Jones, 1998). Therefore within the wide 20-64 year old age range that was eligible for inclusion, I was keen to ensure that represented a range of ages and stages in the life course.

Motherhood

It is often argued that women with children, particularly young children, can feel a stronger obligation to engage with health promotion strategies as they are seen as being responsible for maintaining both their own health and their family's health (Daykin, 1998). As discussed above with relation to age, cervical screening has been viewed as most important for younger women who may have children to look after (White, 1995). Another potential dimension to including both women who have children and those that do not is the potential impact that childbirth may have on women's willingness to present themselves for what is an intimate and personal health intervention.

Socio-Economic Position

A person's socio-economic position has been shown to be strongly associated with their preventive health behaviour (Pill *et al.*, 1995) and an important determinant in whether or not health promotion strategies are accessed. With particular reference to breast cancer screening, Maclean (1984) found that those who did not attend for screening were from lower socio-economic groups, while it was predominantly middle class women that attended. I therefore aimed to include women from a wide range of socio-economic positions, as determined by the Registrar General's classification. Whilst important in terms of attendance, it was felt that socio-economic position may also impact on women's readiness and ability to challenge the official discourse in this context.

5.4.2 Using and adapting a quota sample

I structured my quota sample using the three criteria detailed above. This is shown below.

Table 1. Initial quota sample

SOCIO-ECON.	20-34 YEARS OLD		35-49 YEARS OLD		50-64 YEARS OLD	
1,2,3NM	**3C**	**3NC**	**3C**	**3NC**	**3C**	**3NC**
3M,4,5	**3C**	**3NC**	**3C**	**3NC**	**3C**	**3NC**
	=12		=12		=12	

=36 TOTAL

Key to Notation

AGE: The target age range for screening was divided into 3 groups.

MOTHERHOOD: C = A woman with children   NC = A woman with no children

SOCIO-ECONOMIC : The Registrar General's classification is used.
   1. Professional occupations
   2. Managerial and technical occupations
   3. Skilled occupations
      NM: non-manual M: manual
   4. Partly-skilled occupations
   5. Unskilled occupations

When I had interviewed 17 women I reviewed my quota sample and the material produced from the interviews carried out so far and decided to revise the sample. The main factor driving this was the material produced from interviews I had carried out with South Asian women accessed through a local community group. The views and

understandings of screening put forward by these women were very different from those of the White British women I had also interviewed up to this point. In response to this, and after careful consideration, I took the decision to restructure my quota sample to make the inclusion of women from different ethnic backgrounds more central and to remove socio-economic position and motherhood as these were not proving particularly useful.

In order to demonstrate the position with regard to women interviewed at this point I reproduce my original quota sample to indicate the numbers interviewed in each cell.

Table 2. Part-filled quota sample

SOCIO-ECON.	20-34 YEARS OLD		35-49 YEARS OLD		50-64 YEARS OLD	
1,2,3NM	3C (2)	3NC (1)	3C (3)	3NC (1)	3C (2)	3NC (0)
3M,4,5	3C (3)	3NC (1)	3C (3)	3NC (0)	3C (1)	3NC (0)

i.e. 3C (2) means: 3 women with children needed, 2 interviewed
   3NC (1) means: 3 women without children needed, 1 interviewed

As stated I decided to make ethnic background an explicit sampling criteria in response to the interesting differences emerging between how White British and South Asian women understood cervical screening. There exists a wealth of research on how particular ethnic, cultural or religious groups can hold different understandings of health and illness, and have different experiences of health care. For example, work exists on the different beliefs about, and responses to, hypertensive therapy amongst the White population and those born in the West Indies (Morgan and Watkins, 1988), how culturally-defined concepts of health and illness can influence heart health associated behaviours (Higginbottom, 2000), the health and illness understandings of African Caribbeans, and how these may be influenced by age and gender (Curtis and Lawson, 2000), the role of culture and religion in how diabetes is managed by Kashmiri men (Naeem, 2003), and how the religious beliefs and customs of Muslim women can impact upon participation in breast and cervical cancer screening (Underwood *et al.*, 1999; Sutton *et al.*, 2001). There is also work exploring how structural factors can lead to poorer health and create problems in accessing health care amongst minority ethnic groups (Ahmad, 1993; Ahmad and Walker, 1997; Nazroo, 1997, 2003).

Up until this point I had interviewed White British and South Asian women[25], but wanted to move beyond these two groups and not limit the sample. A look at the population statistics for the Nottingham area (National Statistics, 2004b), where the research was largely based, showed that the three groups making up the vast majority of the population were White British, South Asian and African Caribbean[26]. I re-drew my quota sample along these lines and this is shown below, together with how the 17 women already interviewed fitted into it.

Table 3. Revised quota sample

ETHNIC GROUP	20-34 YEARS OLD	35-49 YEARS OLD	50-64 YEARS OLD
White British	**4 (4)**	**4 (4)**	**4 (4)**
South Asian	**4 (3)**	**4 (2)**	**4 (0)**
African Caribbean	**4 (0)**	**4 (0)**	**4 (0)**

i.e. 4(4) means: 4 women needed, 4 interviewed   **= 36**
    4(0) means: 4 women needed, 0 interviewed

Although socio-economic position and motherhood were no longer explicit within the quota sample they were not dropped completely. Instead they joined what might be called a 'secondary group' of factors that, although not explicit within the quota sample itself, were nevertheless important in determining the approach used to fill it.

5.4.3 Accessing and recruiting participants

I initially considered approaching the Trent Institute for Health Services Research at the University of Nottingham for access to their Collaborative Research Network in order to identify a small number of General Practices that would be prepared to participate in the research and therefore access women through this route. However, I ultimately rejected this approach for two main reasons. Firstly, from a purely pragmatic position, this approach would be time consuming to arrange due to the large number of requests that the Network received and there would be no guarantee that willing General Practices would be identified. Secondly, as I wanted to explore how women may demonstrate resistance to the official discourse on screening, it seemed inappropriate to access them through the medical route. As cervical screening is a universal service

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[25] By South Asian I refer to those who identify with, or whose countries of origin are in, the Indian subcontinent, including India, Pakistan and Bangladesh, although I recognise that this fails to fully appreciate the important differences between national groups.
[26] By African Caribbean I refer to those who identify with, or whose countries of origin are in, the African Caribbean, although again I recognise that this fails to fully appreciate the differences within this group.

offered to the vast majority of women, there was a large population of women eligible for recruitment to the research that could be accessed outside the medical context. This approach, while still posing some potential problems, offered a less time-consuming and bureaucratic route. It also had the advantage of going some way towards taking women out of the medical context and therefore reducing the likelihood of 'textbook answers' to questions about screening.

Instead I adopted a strategy of targeting local community groups as a means of recruiting participants. The types of groups approached were carefully selected, both in order to meet the needs of my explicit quota sample and to take account of factors such as social class and motherhood as much as possible. The kind of groups targeted therefore included:

- Ethnic minority groups
- Mother and toddler groups
- Women's Institute groups
- Church women's groups
- Lesbian and bisexual groups
- Student groups
- Sports clubs

Groups were identified using the local press and community websites. A letter was then sent to these telling them that I was currently doing some research on how women feel about cervical screening and that I would be keen to talk to women from the group. Wherever possible, the letter was sent to a named contact, but where this was not known the group name was used. In addition to each letter I enclosed several copies of an information leaflet that I had produced (see Appendix 1). I asked that the leaflets be distributed amongst the group and that individual women who wanted to participate or find out more should contact me using the details on the leaflet. Finally, I made clear in the letter that I would contact the group again shortly to see what the response had been, but that if they required any further information in the meantime then they could contact me. I also stated that I would be happy to come and speak to the group about the research and answer any further questions.

As the recruitment process progressed more groups were identified as necessary, and some types of groups were rejected as inappropriate. For example contacts in the local

Women's Institute groups I approached told me that the majority of their membership were above my upper age limit of 64 years, while, on the other hand, the change in my quota sample meant that identifying and approaching ethnic community groups took on a new significance[27]. Alongside this community group approach I also made limited use of personal contacts and snowball sampling.

5.4.4 Final sample profile

The final sample profile is shown below.

Table 4. Completed quota sample

ETHNIC GROUP	20-34 YEARS OLD	35-49 YEARS OLD	50-64 YEARS OLD
White British	**4**	**4**	**5**
South Asian	**4**	**4**	**3**
African Caribbean	**4**	**4**	**3**

Total = 35

As previously stated, alongside the explicit sampling criteria within the quota sample I had a 'secondary level' of factors, such as social class and motherhood, that I was keen to take account of as far as possible and that influenced my selection of groups to approach. More detail on the final sample profile in this respect is given below including information on current screening attendance.

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[27] This is not to suggest that women from ethnic minorities are only active in these kinds of groups, indeed a number of the African Caribbean and South Asian women interviewed were recruited outside this context.

Table 5. Sample Profile

Socio-Economic Position	
Higher (1,2,3NM)	18
Lower (3M,4,5)	17
Marital Status	
Married	23
Divorced/Separated	2
Single	1
Co-habiting	4
Widowed	2
Unknown	3
Motherhood	
Children	30
No children	5 (including one having fertility treatment)
Attendance	
Regular attender	26
Recently had first test	2
Intermittent attender	3
Never attended	1
Not currently attending	2
On accelerated recall following an abnormal test result	1

The use of a quota sample, and my targeted approach to identifying and contacting groups, resulted in a heterogeneous sample, that contains within it women with very different backgrounds and characteristics. A look at the completed quota sample (Table 4) shows that there is over-representation in one cell and under-representation in two, all in the 50-64 year old age group. The extra woman in the White British cell represents a woman who was very keen on taking part in the research, and who I identified as a key contact within a community group. I therefore decided to include her for these two reasons. The cells for South Asian and African Caribbean women of this age are both one short, which reflects a difficulty in recruiting older women in these groups.

5.5 Conducting the Main Research Stage

In this section I provide information on all aspects of my main research stage.

5.5.1 Practicalities

Having accessed and recruited women for individual interview using the strategies detailed above I set about arranging and conducting these. Interviews were usually arranged by telephone contact with individual women, but sometimes when I was visiting community groups to discuss my research further with them arrangements were

made face to face. Occasionally in these situations women volunteered to participate and suggested that I interview them there and then. However, I avoided this wherever possible and arranged a time to meet them on another day[28]. I preferred this approach as it meant that the women had specifically agreed a time that was convenient for them and that they had set aside for the purpose, rather than simply doing an *adhoc* interview in whatever time was available.

Wherever possible I arranged to conduct the interviews one at a time, however this was not always the case, especially when making face-to-face appointments with women at community groups. I sometimes found myself conducting two or even three interviews almost straight after each other when they were all to be carried out within the group's premises. This was obviously not ideal as interviewing is hard work (Mason, 1996), especially for someone such as myself who was relatively inexperienced and initially found the process quite taxing. However, the women genuinely thought they were helping me by arranging to be interviewed in succession, thereby saving me making separate journeys, and I did not want to appear awkward or difficult by rejecting this.

In terms of location, I interviewed 18 of the women in their own homes and 17 on the premises of the community group through which I had made contact with them. The groups were very helpful in arranging for a private room to be available in which I could carry out my interviews. On one occasion this involved the group leader arranging to be out of her office on a particular morning so that it was free for me to use.

Finally, the three interviews that I carried out with older South Asian women required the use of an interpreter. These three women were contacted through a community group, and the interpreter was identified in the same way. Cervical screening is obviously not an ideal topic to be discussed through an interpreter, given its highly personal and intimate nature, and I was initially unsure about doing so. However, the interpreter was female, of a similar age to the women and, perhaps most importantly,

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[28] It was often the case that I could not have conducted the interviews even if I had wanted to as I did not have my tape recorder and interview schedule with me. Even when I did, this proved a useful explanation for why the interview would have to take place at a later date and was one that did not cause offence or make me appear difficult.

was known to them. The women were happy to talk to me in these circumstances and, as I did not want to miss the opportunity to include the perspectives of these older women, I went ahead.

5.5.2 Conducting the interviews

As I have previously made clear, I was keen for the interviews to be as lightly structured as possible and that they should give women the opportunity to discuss experiences or issues that they regarded as important. Having said that it was clear that, as the researcher, I had pre-defined the broad research area that I wanted to explore. Within this I also had in mind a number of areas that I wanted to cover in each interview, these included:

- Experiences and views of cervical screening
- Screening histories i.e. past (non-)attendance and test results (if willing to disclose these)
- Whether they regard cervical screening as relevant or important for them personally
- How they understand cervical cancer and who they see as vulnerable to the disease
- The kinds of resources that are drawn upon in these discussions e.g. personal experience, information from health professionals, media coverage, social networks

On the basis of this I drew up a very flexible interview schedule that covered these issues and provided some form of structure for the interview (see Appendix 2). In practice, this schedule served two key purposes. First, it provided each participant with a framework within which to operate. While I was keen for the interviews to be as participant-led as possible, I was also aware that this may be very daunting for women. Giving women some general information on the kinds of things I was keen to hear them talk about went some way towards reassuring them that the things they were saying were the things I wanted to hear. Secondly, the schedule proved very useful during the first few interviews I carried out in terms of giving me something to work from and to fall back on when nerves got the better of me and my mind simply went blank. As I became more experienced at interviewing I found that I could 'manage' the interviews much better and so found myself using the interview schedule less and less.

I was conscious of the need to be careful about how I approached some of the areas during the interview. This was particularly important when discussing such issues as risk factors for cervical cancer or who was particularly at risk. First, it was possible that

women may feel as though they were being 'tested' on these things if faced with direct questions or requests for them to talk directly about the topic. This may have caused unnecessary anxiety and perhaps resulted in women not wishing to volunteer much information for fear of saying something 'wrong'. Secondly, and in relation, if these areas were approached directly then women may simply respond with what could be termed 'textbook answers' and give what they regard as the 'correct' answers. As the research was concerned with exploring how women may demonstrate resistance to the official discourse on screening and focusing on how they made sense of screening in their own ways, an approach that resulted in women simply presenting me with chunks of medically correct information would be of limited use.

Instead I adopted a much broader approach in which I began by encouraging women to tell me the history of their experiences of cervical screening and their contact with the programme, starting with the most recent and working backwards. This resulted in women talking about cervical screening in their own terms and their own language and provided a base from which to go on and pursue the other issues I, and they, regarded as important.

5.5.3 Using vignettes

In addition to using this kind of life history approach, I also produced a small number of vignettes that I employed as a means through which to encourage women to talk about things that were outside their personal realm of experience. The four vignettes were 'snapshots' of individual women of different ages, in different circumstances and with different views on screening (see Appendix 3).

I did not employ these vignettes in all interviews as sometimes the women had achieved a very similar result through their own discussions. It was not uncommon for women to draw comparisons between themselves and women that they knew, or just women that were in some way different to themselves. For example, one woman who did not worry a great deal about screening contrasted herself with relatives who had had abnormal results in the past and so for whom screening was much more important. It was not the discussion of the specific vignettes as such that I was interested in, more their use as a means through which to encourage women to talk about issues such as why screening

might be more important for some women than others or how they viewed other women's attitudes towards attendance.

5.5.4 Recording and transcribing

Before each interview began I asked for each woman's permission to audio tape-record what was discussed, explaining that this was so I had an accurate record of what was said. Following assurances that the tapes would be anonymised[29] all women agreed to this. However, on one occasion I had to rely on notes written up almost immediately after the interview as I found that the tape recorder had malfunctioned.

The interview tapes were all transcribed in full, apart from one which was selectively transcribed. In this case the woman, towards the end of our discussion, began to tell me about her past mental health problems and either ignored or did not recognise my attempts to steer her back towards cervical screening. I was troubled as to what I should do with regard to the tape of our conversation and eventually took the decision to transcribe the earlier relevant material and to wipe the rest as I did not feel it was ethical to keep this material.

5.5.5 Pilot focus group

In my earlier discussion of whether individual interviews or group discussions were most appropriate for the research I ultimately decided to use individual interviews but to keep focus groups as a possible follow up. On completing my interviews I organised and carried out one pilot focus group in order to ascertain whether this was an approach worth pursuing.

The group consisted of six women who worked together and was arranged through a personal contact. A meeting room at the workplace was used and the discussion took place over a buffet-style lunch which the women themselves had provided. The discussion centred around me providing the group with short quotes from my interviews and them sharing their responses to, and views on, these and how they related to their own experiences.

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[29] Tapes were identified by pseudonyms and the list linking these to the women's real names was kept locked in a separate cabinet.

While organising and running this group was very enjoyable, and I was pleased to able to develop my skills in this area, I ultimately decided that the process had added little to the research. As I had adopted a strategy of reviewing the themes emerging from the interviews regularly I had been able to incorporate these into later interviews and so using focus groups as a complementary follow up to these was unnecessary.

5.6 Ethics

In this section I consider the ethical issues raised by my particular research and the steps I took to address these and protect my participants.

5.6.1 Gaining informed consent

As Mason (1996) has suggested, the process of gaining informed consent can be difficult and complex. Securing an individual's consent to being interviewed is often only the tip of the iceberg, inevitably leading to further issues such as whether this means the researcher has the right to use the material produced in any way they see fit or to analyse it in any way they deem appropriate.

When recruiting women for interview I always made sure that I explained who I was and that I was conducting the research for my PhD. This meant that I would be writing up the research and that I may use things that they said during this process (again indicating why I needed to tape record the interviews). I also went through the arrangements I had put in place to ensure that their identities remained unknown within this (these are detailed in the following section). Finally, I gave them the opportunity to ask me any questions or to ask for more information on something they were unsure about. These typically revolved around confidentiality, such as whether their name would appear on their tape, and were easily dealt with so that all women agreed to their interviews being recorded.

More troublesome to deal with were questions around what the research was actually for and how the material would be used. Although I continually presented myself as a sociology PhD student, it was not uncommon for women to assume that I was carrying out the research on behalf of the NHS to directly improve screening provision. I was always very careful to explain that this was not the case and that my work was, above all, a piece of academic research designed to gain me my PhD. However, I was also

aware that participants can be keen to identify the wider benefits of their participation and so stressed that, although this was not the primary aim, my work may feed into these kind of debates at some later stage.

Having stressed the primarily academic nature of my research I was then faced with another difficulty: how much detail I should (or indeed could) provide about the theoretical framework or analytical approaches I was employing. Mason (1996) quite rightly suggests that most participants will be unfamiliar with the kinds of approaches social researchers adopt, indeed they may not even be particularly interested. When introducing my research to women and asking them to participate I presented it as a study to explore women's views and experiences of cervical screening. This was enough for most women, but a small number wanted to know more. This was not in terms of finding out exactly what the research was about before agreeing to take part, instead it represented genuine interest usually after the interview had taken place and I was packing up my equipment. In these situations I explained that I was particularly interested in looking at how women's experiences and views of screening fitted with how it was presented to them and to see if there were any mismatches between the two.

5.6.2 Preserving confidentiality and anonymity

As previously stated, when gaining women's consent for interview I assured them that their identities would be protected. I took several steps to ensure that this was the case. As women were recruited to the research I compiled a list containing their names, contact details and the date and time of interview that was kept in a locked cabinet. Following each tape-recorded interview I assigned a pseudonym to each woman and it was this that appeared on the tape as opposed to their real name. The pseudonyms were then added to the details I had for each woman. The list linking women with their pseudonyms and the tapes were kept in separate cabinets that locked with different keys. There was therefore no possibility that women could be identified. Immediately after each interview the individual woman became, to all intents and purposes, the pseudonym I had assigned to her. It was this name that was used during all transcription, analysis and writing up. While for some research projects anonymity is not realistic, for example if an individual is clearly identifiable from the context in which they were interviewed, this was not the case here and I feel that I took all the necessary steps to protect my participants.

5.7 Analysis

This section largely deals with the process of analysing my interview transcripts and producing the three analysis chapters based upon this.[30] However, it is important to bear in mind that data analysis does not constitute a stand-alone section of the research process. Instead, throughout the various stages of this project an element of analysis, albeit to varying degrees, has been at work, from shaping the initial research questions, through designing the research methods and, most notably, during the data collection phase.

In many ways my data analysis began during the interviews themselves as I made judgements about what was interesting and what I wanted to pursue with individual respondents. Sometimes, as I travelled back after an interview, I would be working the themes discussed through in my mind and relating them to my research questions and theoretical framework, trying to build a tentative structure. I always attempted to transcribe interviews as soon as possible so that I could have an on-going analysis process throughout the data collection phase. This meant that new ideas and issues that emerged could then be incorporated into later interviews and followed up with other respondents. In this way, my aim of wanting participants to shape the research process as much as possible went beyond simply allowing them to shape the content and coverage of their own interviews and extended to having an influence on the issues discussed in later ones. For example, very early on it became apparent that the issue of women ceasing to be routinely invited for screening over the age of 64 years was an issue that many felt strongly about. In talking about this decision they drew upon a discourse of rights and entitlements in order to construct screening as something that they should be allowed to have at any age. This was surprising to me as it turned the idea of attending for screening as some kind of obligation or duty on its head and constituted a discourse that I had not previously considered.

5.7.1 Analysis of interview transcripts

During the preliminary analysis of my data I adopted an inductive stance. While my main research question concerned the potential for women to demonstrate some forms

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[30] The process of analysing the documentary material collected is covered in Chapter 6.

of resistance to the official discourse on cervical screening, I kept a deliberately open mind about how such resistance may be manifested. Although my reading of relevant theoretical and empirical material had alerted me to potential forms that it may take, I did not approach the data looking for particular kinds of resistance from the outset. Instead I began by adopting what might be called a 'thematic approach' in order to tease out the kinds of discourses that women drew upon and the ways in which they talked about cervical screening and cancer. As I progressed with this I began to get a feel for the themes that were most common and to start to think about how they could be framed as different kinds of resistance. I was keen to keep writing throughout this period, when time allowed, and try to develop my ideas further instead of waiting until I was clear about exactly what form my analysis would take. I found this very useful as it helped to develop my thinking and allowed me to explore the relative positions of different ideas. During this time there was a good deal of movement as the significance of material ebbed and flowed. For example, an idea that I had initially regarded as playing a minor role might develop into an over-arching theme of which there were many strands, while something that I had seen as central lost significance as my thinking changed direction.

I found it very hard to identify a point at which my analysis could be said to be 'finished', indeed perhaps it still is not. However, there came a point at which I was clear about how I wanted to use my data and the kinds of resistance that I wanted to put forward. Even during the writing up though there was still an important element of fluidity to my thinking. It was not uncommon for examples to shift from one chapter to another as the process of actually putting my ideas down on paper forced me to clarify my thinking even further and to construct logical and coherent theoretical arguments backed up with solid empirical evidence.

5.7.2 Using computer assisted qualitative data analysis software (CAQDAS)
The use of CAQDAS has, quite rightly, been the subject of debate and has raised important questions. As ever there are both advantages and disadvantages to using such programmes and these need to be carefully considered. The advantages in terms of the organisation and retrieval of coded data are obvious (Coffey and Atkinson, 1996). However, an over-reliance on such software can lead to the researcher 'losing touch' with their data.

I had had experience of using these kinds of software packages prior to starting my field work and decided that I would employ a programme with which I was familiar, NVivo, to help me manage the large amount of data I produced. Due to the fact that I had conducted all the interviews myself I did not feel that I ran the risk of becoming too distanced from my data. I remained open-minded about the extent to which I would employ the software and, in the end, my use was largely limited to coding and retrieval.

When I began coding my transcripts I adopted an inductive approach and, instead of searching them for particular things, explored the kinds of discourses and themes that women drew upon and coded them quite generally. These early codes included: the idea of a trade-off between the short-term costs of screening and the long-term benefits, discussions of cultural differences and personal feelings of vulnerability. As I completed more interviews, and coded the transcripts, I began to look at my coding framework and consider how I could adapt it to capture what I considered the most important emerging themes. I began to code transcripts, and re-code those I had already completed, according to how women spoke about particular issues that were clearly important. These included: the age criteria used for screening, where women got information about screening from, the screening interval (time between smear tests), and their personal experiences of having smear tests taken. I used NVivo 'tree nodes' here so that I could further break these down, for example the different ways in which sexual behaviour was discussed or whether personal experiences were discussed in physical or emotional terms.

While I found the software invaluable in terms of ordering my data and keeping track of it, I ultimately preferred to do my analysis using traditional pen and paper. This 'low-tech' option allowed me to 'map out' the different issues within my research, building theoretical arguments around them and drawing comparisons with other empirical work. I then returned to the coding framework I had developed to help me interrogate my data in order to determine whether it would support such ideas and arguments. Having the data so well-ordered meant I could retrieve appropriate supporting examples, but also search for contradictory instances to ensure that I was not misrepresenting the material.

5.8 Reflecting on the Research Process

In this final section of the chapter I reflect upon the whole research process and consider some of the challenges that I faced, how I dealt with them and how they may have influenced the data produced. I deal with potential challenges of researching a topic such as cervical screening and the related issue of women's self-selection to the research. I consider how my personal characteristics (female, white, young and with no children) may have impacted on how participants viewed me and related to me and what this might mean for the interviews. Finally, I reflect upon the process of making sense of the data that I had produced and the concerns and problems that I encountered when trying to turn pages of qualitative interview transcripts into a coherent whole that addressed my research questions.

5.8.1 Cervical screening as a sensitive topic

From the outset I was always conscious that cervical screening had the potential to be a subject that women regarded as highly intimate and personal and that I could well have problems with recruitment and carrying out interviews. Indeed, as I have discussed above, its sensitive nature was one of my key concerns when working out whether to conduct individual interviews or group discussions. I therefore approached the research carefully and tried to make the whole process as easy for women as possible.

During the recruitment process I was always careful to stress the ways in which I would ensure that women could not be identified, through the use of pseudonyms, and that their interview tapes would be securely locked away. I was also clear to stress that I regarded every perspective as valid and that I would make no judgements about women on the basis of what they told me. Finally, I also made clear that there were no 'wrong' answers to the kinds of questions that I would be asking them. It appears that these strategies were successful as I had relatively few problems finding women prepared to participate in the research, although it must be said that recruiting South Asian and African Caribbean women into my 50-64 year old category posed some challenges and I did not manage to secure quite as many as I would have liked.

During the interviews themselves I also employed strategies to deal with the potentially sensitive subject area. When planning the interviews, and the approach that I would take to them, I decided that I would adopt a policy of answering any questions about my

personal screening experiences that women might ask me[31]. I felt that as I was asking women to reveal to me personal and intimate details about screening, that may potentially be very embarrassing for them, it was only fair that I should do the same if asked[32]. As women were telling me of their experiences and views I always tried to be as encouraging as possible, giving women the time and space they needed if they were finding something particularly difficult and I always tried to take my lead on language[33] from that which the individual used as I felt that correcting them, even if only implicitly by using the 'correct' term, may cause embarrassment and a reluctance to say more. Finally, when attempting to further explore women's views and perceptions I was careful to distance myself from the alternative interpretations that I suggested to them. I tended to frame this in terms of 'other people might say that…' so that it did not appear that it was me personally that held an opposing view and that I was directly challenging the woman and questioning her.

As I have indicated, I went into the research convinced of the sensitive nature of the subject area and that I needed to be aware of this and develop ways of dealing with it. However, while it was the case that some women did find some of the material we discussed difficult, for many this was not a problem. With some women I had very full and frank discussions that gave me a level of detail I had not dreamt of achieving prior to beginning the interviews. Indeed, in a reversal of expectations, it was perhaps me who was the more embarrassed at such times. This was also the case when women discussed their views as, in stark contrast to my concerns about them feeling unsure of putting their real feelings across, some women were very forthright in setting out their perspectives on the value or otherwise of screening and of defending their positions when I suggested possible alternative interpretations.

I would therefore suggest that, whilst it is important to bear in mind that some subjects are likely to be potentially sensitive or embarrassing, and to approach them accordingly, not all people will regard them in this way. Indeed, it may be doing participants a

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[31] I was less clear about how I would deal with any questions about my views on screening as I was aware that answering these had the potential to stop women voicing potentially contradictory opinions. I decided to explain that I was not fully clear on my personal view and that, since beginning the research, I had found that my views were changing all the time as I listened to women's points of view.

[32] In fact I never was asked.

[33] Most commonly this was in relation to body parts or screening terminology.

disservice to view them in this way, as 'delicate flowers' that will need careful handling. However, I recognise that the way I recruited women to my research meant that I was only speaking to women that had agreed to be interviewed on cervical screening and so indicating that they anticipated few problems with the subject. I turn to the potential problems of such self-selection in the next section.

5.8.2 Issues of self-selection

The approach I took to recruitment meant that the women who participated within the research were largely self-selected, that is, they had put themselves forward for inclusion. As I have suggested above, it is likely that I encountered few problems getting the women to discuss a potentially sensitive topic as they had already volunteered to do so. Women who would not have been happy to discuss such issues would not have agreed to take part in the research. This raises important questions about the material collected as it is possible that women who are happy to talk about screening may think and feel differently about it than those who choose not to do so[34]. However, due to the nature of the problem, this is something that I cannot be sure of. Instead all I can do is draw attention to the diversity of views and experiences present within the research in order to show that the way in which I recruited women did not result in a group of women with very similar perspectives.

It is a distinct possibility that self-selection will result in a group of people who feel very strongly about the particular issue and have therefore taken the opportunity to put forward their views on it. While in contrast those who do not hold such strong views may not be motivated to do so. Within my research there were inevitably those women who felt particularly strongly about cervical screening, or particular aspects of it, in either positive or negative terms and were keen to use my research as a means through which to make their voices heard. However, this did not represent the majority and many of the women did not appear to hold such strong views. Instead they were simply happy to help me out by taking part in some research on a particular topic.

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[34] It is important to bear in mind though that not wanting to talk about a particular issue may not be the only reason for non-participation. Other factors such as not having the time or simply not being interested may also play a part.

It was also not the case that such self-selection resulted in a sample of women with very similar experiences or screening histories. The range of experiences, both positive and negative, was large and Table 5 in section 5.4.3 above includes information on the women's attendance, or otherwise, for screening. This indicates that, whilst most of the women were regular attenders for screening[35], a range of other statuses, including never attended, intermittent attenders and not current attenders, was represented.

5.8.3 Myself as the researcher

My identity as the researcher will undoubtedly have had some impact on how participants behaved within the interview encounter and the accounts that they gave. While I am not suggesting that women refused to discuss certain areas with me on any such basis, it is likely that the ways in which their responses were framed or the amount of detail that was offered were influenced by the way in which I was viewed.

While I shared the same biological sex as all my participants this could only ever get me so far. As I soon found, there were other important factors that influenced how screening was viewed and experienced, and these are found within a group of individuals who are all female. Simply because I was female, and had had experience of cervical screening myself, did not mean that I had had the same experiences as them or shared the same views. Indeed it was possible that I could have little or no understanding of the factors influencing theirs. As many have argued, gender congruence does not mean that the interviewer will be able to make sense of other factors influencing an account, such as class or ethnicity, or even recognise their importance (Riessman, 1987; Hall, 2004; Tang, 2002). One of the most obvious issues I faced was that, following its re-drawing, my sample was structured to include equal numbers of women from three different ethnic backgrounds: White British, South Asian and African Caribbean. I was concerned about how my ethnic background (White British) would potentially influence my interactions with women from other groups. Indeed, some would argue that I should not be interviewing women from other ethnic or racial groups. This is most commonly discussed in the context of whether white researchers should interview black people. Barrett and McIntosh (1985) argue they should not, as they are not the best placed to tackle this. Instead, empirical studies of

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[35] As would be expected given that the national programme regularly achieves over 80% coverage.

black people's lives need to be carried out by black researchers. In a similar vein, Carby (1982) has criticised studies carried out by white researchers as operating with white supremacist assumptions. In contrast, Rhodes (1994) has suggested that, while 'racial matching' of interviewer and interviewee may often be appropriate, this strategy risks the marginalisation of black researchers and its assumptions of a single 'truth' is open to challenge.

In an account of whether she, as a white woman, should be attempting to interview black women, Edwards (1990) suggests that these arguments offer little guidance when the area studied is not directly concerned with race or ethnicity, but in which they may play a part. Therefore, in undertaking a study of mature students who were mothers, and therefore balancing education and family life, Edwards sampled women from a range of backgrounds. I would argue that this is a similar context to my study, in which race or ethnicity is not of direct concern, but the ways in which they influence understandings and experiences of cervical screening are.

While there were apparent differences between the ways in which the African Caribbean women and White British women discussed the significance of screening, for example the former often employing ideas about the sanctity of the female body, it was with South Asian women that the most noticeable differences emerged. These women commonly employed both cultural and religious ideas when talking about screening that I was largely unfamiliar with. In these instances my identity as a White British woman clearly awarded me an outsider status, in relation to which my sharing of gender was over-ridden and counted for little. However, it would be misleading to suggest that an outsider status is always problematic in research. Hall (2004) has argued that outsider status can have unpredictable results, bringing both positive and negative effects. In her case, a study of South Asian women immigration applicants, her outsider status resulted in her gaining access to respondents who would not have agreed to talk to another South Asian.

In my study, I found that my outsider status proved useful in terms of exploring the religious and cultural ideas that influenced understandings of screening. I was largely unfamiliar with these and was concerned that I would somehow cause offence because of this, or misrepresent them in some way. I therefore had to develop a strategy for

dealing with this. Rather than trying to educate myself about these issues outside the interview context I decided to adopt a strategy of presenting myself to South Asian participants as someone who was largely unfamiliar with these things and ask them to explain them to me, therefore drawing attention to my outsider status and using it as a means through which to seek further detail. This commonly took the form of my saying something like,

> 'It seems that X is important in how you think about this but I'm afraid I don't know much about it, can you please explain it to me and how and why it is important?'

This approach had the effect of giving some degree of power and control to the participant within the interview and allowed them to take on the role of educator, a role which some were very enthusiastic about. During research exploring the health beliefs and behaviours of British Asian mothers, Reed (2000) had to deal with aspects of difference, including during the interviews themselves. She argues that the differences between herself and her respondents were constantly shifting within interviews and were rarely equal. While at times she was perceived as a 'medical expert', at others this was subverted and the position of dominance shifted to the respondent as they moved on to new topics with which she was unfamiliar, for example advice on alternative, non-western medicine.

However, it also became apparent later that adopting this approach in my research had a further advantage, as it meant that I could explore the different ways in which South Asian women talked about these things and how they constructed them as important, rather than my assuming I understood the significance of these cultural and religious ideas and treating them uniformly. Instead, I could explore the differences between how they were employed in individual cases. In this way it is likely that my different background worked to my advantage as I was able to adopt a position of relative ignorance and, therefore, ask women to explain things in a way that a person of shared ethnicity or religion, an insider, would not. If an insider had requested this further detail and explanation there is the potential that the respondent would have felt unsettled as they perceived that they shared the same context as the researcher. They may perhaps feel that they had 'misread' the situation and so proceed more cautiously.

However, this is not to suggest that ethnicity was the only important factor in how I related to my participants and vice versa. Even when interviewing White British women with whom, by definition, I shared biological sex and ethnic background, there was another important factor at play. It became apparent that my age, and subsequently my position in the life course, could have an effect on how women related to me and therefore how they framed their responses in certain areas.

This was most noticeable in areas such as childbirth and the menopause where, although I shared other characteristics with women, I was in a different position and had not gone through the experiences that were important to them and influenced how they felt about screening. As these are experiences, both physical and emotional, they are of a different nature to the cultural and religious ideas discussed above. As such, the strategy adopted in that context could not be employed so successfully here. Even if women were prepared to explain these experiences to me it was likely that this would be no substitute for actually going through these processes and would not result in the kinds of shared knowledge that would make it possible for me to understand their perspectives.

I felt this particularly clearly when interviewing women who were approaching or going through the menopause as, in contrast to childbirth, it was immediately apparent that I had not yet gone through this. At 25 years of age it was quite possible that I could have had children. In fact I do not, and indeed, while some women asked if I did, others described the process as if I would know exactly what they meant. However, menopause was different and it was noticeable that when women were trying to tell me how this influenced their thoughts about screening they struggled with my inability to demonstrate any kind of empathy or real understanding.

A particular example came during my interview with Deirdre when she was discussing the associated hormonal changes and how these could make menopausal women more at risk of developing cervical cancer. Her account was not very detailed and as I attempted to clarify her views and get her to talk in more detail she became uncomfortable and told me, not unkindly, 'you wait until it happens to you'. This was followed by nervous laughter. Obviously I cannot know for sure, but it is possible that if

I had been able to make some comment about how I had felt during the menopause then Deirdre would have felt able to go into more detail.

5.8.4 Making sense of the data

When my interviews were completed I then began to think seriously about how to make sense of it all; a process that I initially found daunting. I had produced a large amount of detailed qualitative material and at times it felt as if I had so many ideas I did not know what to do with them all, while at others it felt as though I could not seem to find the thread that ran through the data and held them together. As my thinking developed, my ideas changed regularly with continuous movement and fluidity about where particular things 'fitted' and how they worked together. While I found it reasonably straightforward to identify and develop the themes from the data that I wanted to pursue, I found it more taxing to relate these back to my theoretical level and to weave the two together. However, perhaps the most difficult thing was accepting that I would have to drop some of the ideas that could not be incorporated into the overall argument of the thesis, no matter how interesting they were in their own right. This was particularly troubling if they concerned issues on which my participants had spoken passionately.

However, as much as it is possible for the researcher to be open to respondents' ideas and their views on which issues are important, it is ultimately the researcher who shapes the research process and the end product. Indeed, Glucksmann (1994) has argued that, however much we may aim for reciprocity within the interview encounter, the production of knowledge from this is ultimately the researcher's responsibility.

Chapter 6

Characterising the Official Discourse on Cervical Screening

6.1 Introduction

The purpose of this relatively brief chapter is to characterise the official discourse that surrounds cervical cancer screening. It is important to do this in order to establish how screening is communicated to women invited to participate in the national programme, to examine the material they are presented with and therefore to understand the context and circumstances within which women encounter screening and go on to develop and demonstrate different forms of resistance to it. It is of course important to stress that this characterisation of the official discourse is not to suggest that the medical profession as a whole, other health professionals and those involved in policy-making, are unified in their views on screening. Indeed in Chapter 2 the different critiques of cervical screening put forward from a range of perspectives were considered in order to illustrate this. Instead the purpose of the exercise is to characterise the official discourse and the way in which the NHS Cervical Screening Programme (NHSCSP), often through and/or with other bodies such as General Practice and Primary Care Trusts (PCTs), communicates with women and presents screening to them.

The analysis presented here explores the documentary material that women receive in the course of their routine contact with the screening programme. It represents the material received by women who have a normal recall status and does not cover the more detailed and specialised information available to women who have received an abnormal smear test result. The material used comprises the invitation letters that are sent out at the local level, and can therefore vary, and the standard nationally produced information leaflet, entitled *Cervical Screening: THE FACTS,* that all PCTs are required to send out with their invitation letters. These materials were collected through direct contact with both the National Office of the NHS Cancer Screening Programmes and a sample of PCTs within England. More detail on the collection of this material can be found in Chapter 5.

The analysis presented here explores the documentary materials and asks important questions about them. This falls broadly into two main categories: a largely descriptive

section and a more detailed sociological analysis, as I explained in Chapter 5. Following this, the conclusion sets out the particular ways in which this characterisation sets up the main body of the thesis, and the limitations of characterising the official discourse around screening in this way are also considered.

6.2 Descriptive Information

This section gives information on the descriptive nature of the documents used. For the purposes of clarity, the two types of material, the invitation letter and information leaflet, are dealt with separately at first as they are produced for different purposes and by different organisations. However, within this, the way in which the two documents work together will be considered.

6.2.1 Invitation letters

The invitation letters automatically sent to women through the computerised call and recall programme are produced by individual PCTs, or by a lead PCT in the case of collaborative arrangements. The purpose of these letters is to alert women that their next smear test is due and to invite them to make an appointment to attend for this. They are produced and sent automatically and therefore women have had no role in requesting them.

These letters sent out by PCTs were usually no more than one A4 sheet of paper in length. The one exception to this was a PCT that was taking part in an NHS pilot scheme to test the new liquid based cytology (LBC)[36]. As a result of this the letter to women in this area included specific information on LBC and the research and informed them that they may be invited to complete a questionnaire about their experiences of this new method. This additional information meant that the letter continued onto a second sheet of paper.

All except two of the letters examined were addressed *to* a named individual, therefore emphasising the personal nature of the communication and suggesting that the PCT or GP were concerned that that individual woman should attend. The two letters that were

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[36] The National Institute for Clinical Excellence has since recommended that LBC be employed as the primary means of processing cervical samples in England and Wales. More detail can be found in Chapter 2.

not to a named individual appeared to be a standard letter that was not specifically addressed to any particular woman. All except four of the letters were *from* a named individual, with the remaining four being from simply either 'Screening Department' or 'Primary Care Agency'. Of the 20 letters that were from a named individual, 12 were signed as from the woman's GP and eight were from a member of the screening department. Again this personal dimension of the communication may serve to persuade women that there is a particular person concerned that they should attend for screening and that will be aware if they do not do so.

From reading the letters it was clear that 12 of the PCTs invited women, and therefore sent out these invitation letters, every three years, nine PCTs invited women every five years and the policy of the remaining three PCTs was unclear from their letters. These different screening intervals broadly correspond to the national picture in which, although the official guidance is that women should be screened at least once every five years, over half of PCTs screen women every three. However, the screening interval is undergoing a process of change, as detailed in Chapter 2, and will become linked to a woman's age. The frequency of these invitations, together with the focus upon normal recall status letters, suggests that women will be expecting these letters and that they will come as no surprise.

The focus and purpose of the letters themselves seems very much to simply inform women that it is time for their next test and to tell them how to go about making an appointment. There is no real attempt to provide much detailed information here or to reintroduce the screening programme in any detailed way. Perhaps this is not surprising as these are re-call letters to women who have already had their first test and are simply being routinely invited to attend for subsequent ones. The assumption seems to be that, as women have already attended for one or more tests, they will continue to do so without going through a separate decision-making process on each occasion or considering what has happened to them in the meantime[37]. In this way the letter seems to be designed to simply alert women of the time since their last test and remind them to have another. As a result, the majority of the letters assume that those reading them hold at least some degree of knowledge about screening, using such phrases as,

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[37] Here I refer to the life events that may influence how women think about screening and whether they regard it as important to them, for example giving birth to a child or ceasing to be sexually active.

> *'As you know doctors recommend that all women 20 years of age and over have a cervical smear test every three years'*[38]

> *'As you know, doctors recommend that all women between 20-65 should have regular cervical smear tests'*

As suggested, the assumption within the letters is that women will attend for their next smear test and often the sole content is the information that it is time for them to do this. In over half of the letters women were simply asked, or even just instructed, to make an appointment.

> *'It is once again time for you to contact your Family Doctor or Practice Nurse with a view to making an appointment at your earliest convenience for a further test'*

> *'According to our records, it is 5 years since you last had a cervical smear test. Please could you ring the surgery for an appointment'*

> *'I would like you to make an appointment for a cervical smear test'*

Only 15 out of the 24 PCT letters give any explanation of the test and what it is for in these routine recall letters, with the remaining nine containing no reference to the test's purpose. It must be stated though that seven of these nine letters make some reference to the enclosed information leaflet and so perhaps do not see the need to replicate the information. However, the two remaining letters contain neither an explanation of the test nor any mention of the leaflet which they indicated to me that they enclosed.

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[38] The absolute accuracy of this statement is questionable given that the target age range for screening at the time was 20 to 64 years and, although this PCT's policy may have been to screen three yearly, the recommended frequency was every five years.

The explanations of the test found in the 15 letters which included this centred primarily around the role of the test in checking the health of the cervix, often indicating that this was the neck of the womb.

In only one case did the letter include guidance on what the woman should do if she did not want to have the test, advising her to contact her GP in order to receive and complete a withdrawal form that would stop the invitations. Of these 15 invitation letters offering any explanation for the purpose of the test, only six mention cervical cancer in any explicit way, the others focusing solely on the health of the cervix with no apparent indication of the possible consequences of an unhealthy cervix. References to cervical cancer occur in the context of the dangers of leaving cervical abnormalities undetected and untreated. However, one letter makes the potentially misleading claim that,

> *'Regular smear tests help PREVENT cervical cancer developing'*
> (original emphasis)

While the smear test itself can identify cervical abnormalities that may, if untreated, go on to develop into cervical cancer, it is the follow-up treatment after the detection of any abnormality that may prevent the development of cancer and not the screening itself. This kind of statement has the potential to give women the message that screening itself is protecting them against cancer development.

Finally, several of the letters take the opportunity to stress the simplicity of the cervical smear test and how little time it will take. It is described as 'a simple test', 'a simple check' and something that is 'simple and takes very little time'. However, many of the women I spoke to argued that, while the test itself may take very little time, the time it takes to make an appointment for a convenient time, get to the practice, sit in the waiting room, have the test and then get home again is much more substantial.

Therefore the purpose of these, sometimes very brief, invitation letters is often simply to request or instruct women to attend for their next test. They tend to assume both knowledge of screening and attendance, and stress the simplicity and ease of the test. They therefore appear to serve a routine administrative function and their role in

informing women about screening is minimal or even non-existent. The role of providing information is predominantly left to the accompanying leaflet and it is to this that the focus now turns.

6.2.2 Information leaflet

National guidelines state that the centrally produced information leaflet *Cervical screening: THE FACTS* must be sent out with all cervical screening invitation letters. This inclusion was anticipated when approaching PCTs for the documentary material, but was not assumed. The request for information simply asked for a copy of the invitation letter and any other information that was sent out with this. In fact all the PCTs from whom material was received stated that they enclosed this leaflet. However, in one case the material contained within the leaflet was reproduced on A4 paper and attached to the invitation letter. As a result it was not clear that the information was originally separate from the letter, it appeared that the information had also been produced by the PCT.

The leaflet entitled *Cervical screening: THE FACTS* is produced by the Department of Health in association with the NHS Cancer Screening Programmes, and with advice from the Cancer Research UK Primary Education Research Group. This leaflet, and the associated *Breast screening: THE FACTS*, were introduced relatively recently in order to provide clear information on the benefits and limitations of these kinds of screening and to meet the commitment in the NHS Cancer Plan (Department of Health 2000) that all women should receive a national information leaflet on these kinds of screening by 2001.

The leaflet itself is a ten-page booklet measuring 9.9cm by 20.8cm, and is just under 1500 words in length. It is entitled *Cervical screening: THE FACTS*. This title immediately suggests that the leaflet provides some sort of 'truth' about cervical screening, with the associated suggestion that any other forms of knowledge or information that women have acquired or developed from other sources that run counter to this must be incorrect. This theme will be pursued further later in the chapter. The document consists solely of words, with no pictures or diagrams included. The clarity of the text has been approved by the Plain English Campaign. This is important as past research has suggested that the readability levels of past health information materials

have been too low, meaning that those who are in most need of information are those least able to read them (Nicoll and Harrison, 1984).

In terms of informational content, the leaflet is divided into 18 separate sections, most of which adopt a question and answer format. The 18 sections cover the following areas:

'What is cervical screening?'
'Why do I need cervical screening?'
'Should all women have the test?'
'What is the NHS Cervical Screening Programme?'
'Who will carry out my test?'
'Will I have to undress?'
'What happens during the test?'
'Does the test hurt?'
'Is there anything I should do before the test?'
'Can I have sex before the test?'
'When do I get my results?'
'How reliable is cervical screening?'
'What does it mean if I am called back?'
'Can anything be done about abnormal changes?'
'Can cervical screening prevent cancer?'
'What happens to my sample once it has been looked at?'
Summary
More information and support

When discussing the purpose of the cervical smear test, as was the case in several of the invitation letters, the focus is upon the test as a means of checking the health of the cervix. The leaflet explicitly states that 'cervical screening is not a test for diagnosing cervical cancer'. The leaflet aims to reassure women that the majority of smear test results are normal, but that 'for one in 10 women the test shows changes in the cells that can be caused by many things'.

The leaflet gives the information that screening is offered to all women between the ages of 20 and 64 years old, thereby emphasising the universal approach adopted. However, it also makes the point that a number of factors can mean that cervical cancer is more common. These are if you:

- First had sex at an early age
- Smoke

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- Do not use condoms
- Have had several sexual partners or have had a sexual partner who has had several other partners
- Take immunosuppressant drugs (for example, after an organ transplant)

It is immediately apparent from this list that four of the five factors are lifestyle related, with three of these concerning an individual's sexual behaviour. The latter is further reinforced by the suggestion that women who have never had sex should speak to their doctor about the need for screening. It is also interesting to note, and I return to this in the chapters that follow, that not all of the risk factors associated with cervical cancer development that were covered in Chapter 2 are mentioned here. This is perhaps not surprising for risk factors that are not yet fully understood or that may be compounded by other factors, for example parity or oral contraceptive use. However, there is no mention of the most widely accepted and understood risk factor, high risk types of the sexually-transmitted human papillomavirus (HPV). Risky sexual behaviours are highlighted but the mechanism through which these work, and in particular how they can work to increase an individual's risk of developing cervical cancer, is not explicitly made clear. This is important and may be due in part to a reluctance to represent cervical cancer as a sexually transmitted disease due to the potentially negative connotations. As indicated in Chapter 2 the potential new role for HPV testing in cervical screening, particularly as a primary screen with cytology only for those shown to be at risk, is of interest here, and the way in which any new development would be communicated to women.

As previously indicated, the main aim of this leaflet is to provide women with detailed information on both the benefits and limitations of screening so as to enable them to make an informed decision about whether or not to attend. Past research has highlighted problems with both the kind of information available to women and the potential tension between providing unbiased information on the one hand and aiming to increase attendance for screening on the other. The general feeling has been that women need to be provided with comprehensive, honest and balanced information so that they are as fully informed as possible (Anderson and Nottingham, 1999; Raffle, 2001; Slater, 2000), and are in a position to provide informed consent for screening as set out in the General Medical Council guidance (General Medical Council, 1998). Advocates of this approach stress that participants in screening are autonomous

consumers of health care who should have access to the necessary information to enable informed choice (Raffle, 2001).

To this end a section in the leaflet is devoted to answering the question 'how reliable is cervical screening?'. Within this, it is acknowledged that cervical screening is not perfect and that it may not always detect early cell changes. The reasons for this are clearly set out:

- Sometimes they do not look much different from normal cells
- There may be very few abnormal cells on the slide
- The person reading your slide may miss the abnormality (this happens occasionally, no matter how experienced the reader is)

In addition the fact that about 10% of tests are inadequate and have to be taken again is highlighted and the possible reasons, such as obscuring of the cells by blood or mucus or the sample not being properly prepared, are listed. The possibility of false negative and inadequate results is therefore flagged up for women. In addition, in the summary section at the very end of the leaflet the possibility that the test may show up abnormalities that would have regressed to normal on their own is raised and there is a very clear statement that,

> *'It is not yet clear which minor abnormalities would develop into cancer and which would not'*

It therefore seems that the leaflet goes some way to balancing its inevitably very positive view of screening with information about the potential limitations and shortcomings. Whether this information is enough to ensure that all women attending for screening are fully informed and able to provide valid consent is not possible to ascertain through this kind of analysis.

6.3 Sociological Analysis

This section moves on from the previous, predominantly descriptive, exploration of the nature of the documents and the kinds of information that they contained. Here the focus turns towards a more sociological analysis of the documents in order to explore the ways in which the information is presented and communicated to women and how

cervical screening is characterised. Key concerns are the ways in which the information or knowledge is communicated (Prior, 1997), how the documents function and how they construct cervical screening in particular ways (Atkinson and Coffey, 1997; Dixon-Woods, 2001; Silverman, 2001).

6.3.1 Information as facts

One of the most obvious discursive strategies used in the material, especially the information leaflet, is the explicit suggestion that these represent undisputed facts. The information leaflet is, after all, entitled *Cervical screening: THE FACTS*. As noted before, this immediately gives the impression that the information contained within is objective, scientific and above all represents some kind of 'truth'. As indicated earlier, this strong and immediate focus on the leaflet as providing 'the facts' about cervical screening suggests that any other, potentially contradictory, forms of knowledge or information that women may have acquired or developed must necessarily be incorrect. As a consequence it serves to construct the official bodies that produce the material as perhaps the only, or at least the most appropriate, people who can or should speak on such a subject[39]. In comparison with the individual invitation letters sent out by PCTs, the majority of which were seen to be from a named individual and included 'I' or 'we', the standard information leaflet does not give the same impression of authorship. While there are uses of 'we' these are relatively uncommon and the general tone of the writing is much less personal, with no named individual as author[40]. This is a strategy used to stress the objective and factual nature of the material. As Atkinson and Coffey (1997) have argued,

> 'The absence of an implied personal author is one rhetorical device that is available for the construction of 'authoritative', 'official' or 'factual' accounts. It implies a reality that exists independently of any individual observer, interpreter or writer' (Atkinson and Coffey, 1997:59).

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[39] As such it is possible to frame this in terms of the increased role of expertise within neo-liberal societies that I discussed in Chapter 3.
[40] This is not to suggest that invitation letters are necessarily personally written by the individual named, merely that this is the impression created.

The material sent out to women in the course of their contact with the NHSCSP, in particular the more detailed information leaflet, therefore seeks to establish itself as authoritative, objective and above all factual. It presents women with a particular construction of cervical screening, further elements of which will be discussed below, and in a sense instructs them in how to view cervical screening (Prior, 1997).

6.3.2 The importance of health

The increasing emphasis placed upon achieving and maintaining good health has been discussed in earlier chapters. In particular, attention to the ways in which health status and the means for achieving good health have come to be amongst the predominant concerns of modern society (Lupton, 1995; Petersen and Lupton, 1996) have been highlighted. Of particular interest, both to the thesis as a whole and this documentary analysis in particular, is the well-documented shift in the focus of health care policy towards the need to promote good health and to encourage populations to take individual responsibility for monitoring and maintaining their own health (Nettleton, 1995; Nettleton and Bunton, 1995).

Within both the invitation letters and the information leaflet there is a strong emphasis on the importance of health, and in particular the emphasis placed on cervical screening as a means through which cervical cancer can be identified in the pre-malignant stage and its development prevented. This strong focus upon the importance of protecting and safeguarding health is central within the material and the possibility that women's primary concern could, or should, be anything other than their health appears not to be considered.

Previous sociological work on cervical cancer screening has highlighted how women may feel under a 'moral obligation' to attend (Howson, 1998b, 1999) and the focus upon the importance of health within this material offers some support for this. As detailed above, the standard, nationally produced leaflet provides information on the limitations and potential problems of screening in order to balance the positives and to allow women, at least in theory, to make an informed choice. Indeed, that women have a choice to make about whether or not to attend is explicitly stated in the summary, which recaps on the information to help women decide. However, in contrast this element of choice is not so apparent within invitation letters. Here, as detailed above,

the focus is very much on alerting women that it is time for their next test and telling them how to make an appointment.

It has been suggested (see for example Bush, 2000; Forss *et al.*, 2001) that many women regard cervical screening as simply routine and do not engage in any explicit decision making process about whether or not to attend. To a degree, the way in which women are invited for these tests reinforces this, as women are automatically invited and do not need to signal their desire to do so in any way. Further, the language used in many letters encourages this view of screening as phrases such as 'it is once again time for you to attend', 'it's time for your next test' and 'it's been x years since your last test' are common. Tied up within this perception of routine is the assumption of attendance. While the information leaflet gives information to allow women to make a decision, within invitation letters attendance is assumed[41].

However, it is clear that the importance of health and the need to do everything possible to prevent disease is tied up with this assumption of attendance. As has been widely suggested in debates around the increasing focus upon health, the role and responsibility of the individual in maintaining and protecting their own health is key. Elements of this can be found within the material women receive on cervical screening, particularly the invitation letters. The emphasis within these is strongly on prevention, and the role and responsibility of the individual woman in this respect. The cervical smear test is represented as necessary to protect a woman's health although, as has been highlighted, its ability to do this is occasionally misleading. The importance of having the test, and women's individual responsibility, is stressed to varying degrees within individual letters, but perhaps the strongest exposition of this comes in the following extract.

> *'The cervical smear test really can make a difference to your health – don't miss this important opportunity to protect yourself'*

This kind of sentence contains several important elements and fulfils a range of functions. It reinforces the effectiveness and importance of the smear test, stresses the

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[41] I have signalled above that there may be a potential complication here given that these routine recall letters are sent to women who have already attended at least once.

difference it could make to your health, emphasises the importance of health and also, perhaps most importantly, highlights individual responsibility. The focus is clearly on the difference it can make to **your** particular health and how it represents an important opportunity to protect **yourself**. Tellingly, the onus is on the individual not to miss the opportunity that is being offered them. In tandem with stressing the importance of the test and attendance is the implicit consequence that those who do not attend, for whatever reason, are behaving in a less than responsible and sensible way and are therefore open to charges of failing to take the appropriate steps to safeguard that most precious of things, their health.

6.3.3 Individual engagement with screening

As the previous section, and indeed other research, has shown, individuals are encouraged to behave in ways identified as sensible and responsible and to take appropriate actions to protect their health, in this case attend for regular cervical screening. However, it is not simply attendance for smear tests that is required, within the material women are encouraged to engage with the screening programme in a particular way.

Firstly, the description of the experience of having a smear test is presented in such a way as to minimise its significance and intrusion. The test is repeatedly constructed as a simple test that will take very little time to perform and one that will usually be completely painless. Women are told that 'the test takes just a few minutes' and that the smear taker will 'gently put a small instrument… into your vagina to hold it open'. The test itself is therefore constructed in a particular way and one that, as later chapters will demonstrate, does not match many individual women's experiences. Perhaps the implicit assumption is that, even if women do have reservations about smear tests, these should be overcome in the longer term interests of safeguarding their health.

In addition to this, women's responsibility does not end with attending for their smear test and overcoming any potential reservations or problems they may have about it. They are charged with several other responsibilities as well. Firstly, women must make sure they attend for their test at the appropriate time as tests cannot be taken during a period. Secondly, they must not use spermicide, a barrier method of contraception or a lubricant jelly for 24 hours before the test as the chemicals contained may affect the test.

Finally, women are told that they must make sure they have received the appropriate information on how, where and when they will get their results from the doctor or nurse before they leave the surgery or clinic. It is therefore apparent that women have responsibilities that extend beyond simply presenting themselves regularly for screening. They must ensure that they do so at the right time, they must not use products in the 24 hours before the test that may affect the result and they must make sure that are fully informed about where, when and how they will receive their results. Simply presenting themselves for screening will not be enough, women must engage with the screening programme in a particular, responsible way.

6.4 Conclusion

This chapter has set out a documentary analysis of the locally produced invitation letters and national information leaflet, *Cervical screening: THE FACTS*, that women routinely receive in the course of their contact with the NHSCSP. This has allowed a characterisation of how screening is presented and communicated to women, how women are recruited into the programme and how the NHSCSP puts itself and screening across.

This began with a predominantly descriptive section on the nature and content of these materials, covering such issues as who they were produced and read by, their format and the information contained. A more sociologically-based analysis of the kinds of language and discursive strategies employed within these materials followed. The main themes examined here were: the emphasis on the materials as providing objective, balanced and, above all factual, information, the importance of health and disease prevention, the routinization of screening and assumptions around attendance and, finally, the responsibilities of the individual.

It has been necessary to characterise the official discourse around screening in this way in order to provide the context in which women encounter the screening programme and the information with which they are provided. It would not have been possible to explore how women think about and understand cervical screening, and the way in which it is presented to them through the official discourse, without first establishing the form this takes.

The use of official documentary material to achieve this aim is, of course, not without its limitations. As I discussed in the previous chapter, the decision to focus on this state level discourse fits with the underlying premise of the research, exploring how individuals respond to such a discourse, and ensures that the material used is uniform and standardised. I acknowledged that this inevitably meant the intermediate level of health professionals in practice was missing, but argued that this would have been problematic practically and, more importantly, did not fit with how the research is framed theoretically.

I recognise that this documentary material is not the only means through which women receive information on cervical screening, indeed the extent to which they read and engage with this type of material can be questioned. However, for the reasons discussed, I decided that this was the most appropriate material to examine in order to characterise the official discourse as it represents the standard, state level discourse on screening. The use of locally produced invitation letters alongside the centrally produced leaflet means that the potential for variation is not lost completely, and allows some exploration of the growing disaggregation of information, i.e. from the national leaflet to the local invitation letter.

The characterisation of the official discourse on cervical screening set out in this chapter sets up the material presented in the following three chapters through establishing what it is that women in this research are demonstrating resistance to. In this way it represents the state side of the state/individual relationship that is the underlying premise of the thesis. As I have suggested throughout, it is possible to regard this official discourse as one of the techniques of government at work within neo-liberal societies that govern through the production of individuals who will voluntarily regulate their own conduct, therefore removing the need for coercion (Barry *et al.*, 1996; Burchell, 1996; Foucault, 1991; Rose, 1996, 1998). Indeed, sociological work has explored how women can feel obligated to attend through such a discourse (Howson, 1998b, 1999; McKie, 1995). It is also possible to link the attempts to produce the 'facts' on cervical screening, and to locate these with a particular body, to the discussions of the increased role for expertise within such forms of government explored in Chapter 3 (Rose, 1992, 1996, 1998). What I seek to do in the following chapters is demonstrate how women within this research resisted this discourse in various ways.

Chapter 7

Making Sense of the General Official Discourse on Cervical Screening

7.1 Introduction

As was demonstrated by its characterisation set out in the previous chapter, the official discourse on cervical screening is important for the way(s) in which it presents screening to women and encourages them to think about it. It is disseminated through the material that women receive when they are invited to attend for their routine smear tests and, as such, is necessarily general and uniform in nature[42]. Although the invitation letter itself may vary across different Primary Care Trusts (PCTs), the information leaflet that is required to accompany all such letters is produced and published centrally. Therefore women encounter a very general discourse on cervical screening, one that is designed to address a large number of women. What I seek to do in this chapter is explore the various ways in which individual women interpret, negotiate and transform this through a consideration of their own individual circumstances, experiences and/or characteristics, therefore producing conceptualisations of, and discourses on, cervical screening that differ from those contained within the official discourse. The key concerns of this chapter are therefore: how women work out their own position in relation to the official discourse; the practices and techniques employed to achieve this; and how these can be seen as constituting resistance.

An exploration of the practices used by individual women, and the resources they draw upon in pursuing these, is important as it demonstrates the potential for them to resist the official discourse and the very general subject position it suggests. Instead, it allows a consideration of how these women work out their own individual and personal position in relation to cervical screening.

Throughout the chapter I argue that these practices of individualisation, through which women work out their own subject positions, can be framed as resistance through the employment of Foucault's work on 'technologies of the self'. These ideas were

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[42] I refer here to the approximate 84% of women within the screening programme who are on routine recall following a normal smear test result (Department of Health, 2003). Women who are on more frequent recall are likely to receive additional information.

discussed in detail in Chapter 3 and are central to the theoretical framing of this research. Through these Foucault is able to suggest, and begin to explore[43], a more flexible relationship between discourse and the individual (Foucault, 1984a,b&c, 1988). Instead of a process of straightforward imposition, which much of his earlier work appeared to suggest, the emphasis is placed upon the formation of a relationship and on the methods and techniques used to work this out (Burchell, 1996; McNay, 1994). Therefore a space is opened up between discourse and the individual within which there can be interpretation and negotiation, and the working out of individual subject positions.

In what follows I explore the practices, and the resources on which these draw, that women within my research use to consider and explore their particular position in relation to cervical screening. Among the practices explored in this chapter are the physical and emotional experiences of having a smear test taken, the impact of bodily changes (most notably the menopause) on the significance and meaning of cervical screening, and finally the process of 'making the discourse fit' with a religious discourse, in this case one based in Islam.

I explore how, and in what ways, these practices influence the understanding and interpretation of cervical cancer screening and what these mean for women's individual positions in relation to the official discourse. Following this I consider the position that these lay experiences and beliefs occupy in comparison to the official and medical discourses, and how far women pursue the alternative conceptualisations and discourses that they produce. It will be shown that the resistance identified is located at the thought and talk level and is only rarely pursued through behaviour. The chapter therefore concludes with an exploration of the potential for women's resistance within this context and the limitations that may be placed upon this.

7.2 Individualisation Practices as Techniques of Resistance

Within the research it is possible to identify several different ways in which individual women negotiated their own particular positions in relation to the official discourse on

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[43] As I made clear in Chapter 3, Foucault has been consistently criticised for his failure to fully explore the relationship between techniques of domination and practices of the self, with some arguing that he ends up simply juxtaposing the two.

cervical screening. These draw on a range of resources and lead to women resisting various aspects of the official discourse and producing alternative conceptualisations and discourses that are pursued to differing degrees and through different means. In this way, the interpretation and negotiation of the official discourse in response to individual experiences, circumstances and contexts provide the means for the 'transformative effects' through which women resist by pressing their own claims in response to others' (Riessman, 2000).

In this section I focus on two particular types of practice that can be broadly divided into the following categories. Firstly, those rooted in personal experience, and further separated into the physical and emotional experiences of screening and the impact of bodily changes. Secondly, the influence of a Muslim discourse concerning the importance of virginity at marriage.

7.2.1 The employment of personal experience

One of the most common ways in which women I spoke to went about personalising and individualising the general official discourse around cervical screening was through a consideration of the experiences and the feelings, both physical and emotional, that they had gone through. It was not uncommon for women to combine the physical and emotional aspects and suggest that they may be closely linked, for example if they were nervous and tense about having a smear test then it was perhaps more likely to be uncomfortable or painful because of this.

When discussing their experiences, women frequently suggested or highlighted things about themselves that could explain their particular feelings or that meant that their experiences were likely to be different from the general presentation of cervical screening or what they took to be other women's experiences[44]. This is most commonly the case when women regard their experiences as more difficult or troublesome than those of others and engage in a consideration of what it is about them, in particular, that makes this the case. Given that the presentation of cervical screening within the official

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[44] It is not always clear whether women are comparing their experiences to that which they find in the official discourse or to what they perceive other women's experiences to be. It is likely that women tend to assume others' experiences fit the general presentation and so the two are interwoven to a certain degree.

material stresses the ease and simplicity of the test, it is perhaps not surprising that it is those who experience difficulties that engage in these considerations. It is as though they feel a need to negotiate a particular position for themselves in relation to this discourse and to find a way of saying 'this is who I am and this is what it is like for me.'

These discussions are inevitably based upon a certain kind of knowledge, as what women can directly know about cervical screening is largely rooted in their own experiences and, to a much lesser degree, the experiences of those known to them. All of the examples that I employ below draw upon women's own experiences and an awareness of their bodies and emotions. This form of knowledge is necessarily specific and particularistic in nature. A woman knows what having a smear test is like through her own experiences[45]. In this way, a great deal of the knowledge available to women is embodied and experiential (Abel and Browner, 1998; Williams and Popay, 1994). Women experience cervical screening through their bodies and, in comparison to health professionals who have access to wider technical and biomedical material, this is one of the few resources on which most[46] have to draw (Howson, 1998a&b).

I turn first here to two women who discussed the particular problems they experienced with the emotional side of cervical screening. While the majority of women discussed feeling slightly nervous and apprehensive before having a smear test, and many spoke of embarrassment during the test itself, these two women stood out as particularly extreme cases.

The first of these is Debbie who talks about how much she hates going to have her smear tests and finds it very difficult to 'pluck up the courage' to go. Debbie says,

> *'It's just something that I just hate, I think it's, you know I don't know what it is, and I know to the nurse it's nothing but I think it's just, perhaps because I'm such a private person'* (Debbie 35-49 WB[47])

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[45] Elsewhere I cover how some women regard having a smear test as something that can only be known through experience.

[46] Of course some women are health professionals and have access to a wider range of resources.

[47] For a guide on how to read these identifications please refer back to the Glossary.

So we can immediately see that having a smear test is a very difficult thing for Debbie to do, and indeed Debbie told me at length about how she took months to 'pluck up the courage' to make an appointment for her smear tests. On the last occasion she had been asked to make an appointment she had 'plucked up courage for about six months to actually ring up the doctor's'. On speaking to the receptionist, she was told that she needed to ensure that the appointment was between the tenth and fourteenth day of her menstrual cycle: something she had not encountered before. Debbie was unable to determine when this would be immediately and so had to say that she would call back. Having then gone away and worked it out she had to 'pluck up the courage' to make an appointment all over again.

However, what is particularly interesting about Debbie within this extract is the way she negotiates her own position in relation to cervical screening and attempts to explain why it is that she has such problems with it. She appears to suggest that she finds it particularly problematic, and goes on to suggest that it may be because she is such a private person that her experiences are so difficult. In this way Debbie takes steps towards setting herself apart from other women who perhaps are not so private and do not have the same worries about exposing intimate and personal parts of their body in this way[48]. The fact that it is in the context of a medical encounter that this exposure takes place appears to make little difference to the way Debbie feels about it. In the extract above she tells us that she knows 'to the nurse it's nothing', implying that she is aware that the nurse has seen this kind of thing numerous times before and that it holds no special significance for her, but this does not help Debbie. For a private person such as herself this kind of thing will always be troublesome, and in this way Debbie negotiates her own space in relation to the discourse on cervical screening. In doing so she resists one of the central tenets of public health strategies such as screening: namely that individuals should make their bodies available to the gaze of health professionals and that this should be simply routine. This is very much the way that cervical screening is presented within the official discourse as it is discussed in terms of a simple and routine test that will take very little time. Debbie problematizes this and redraws the boundary between the public and the private by drawing on cultural ideas of certain

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[48] Here again it is unclear whether Debbie is comparing herself to other women or to the presentation of screening within the official discourse.

body parts being taboo. Through this she resists the assumption that the medical gaze is permitted unlimited access to the body.

Julia also related how she felt very anxious and nervous about going for smear tests, but suggested a different reason to Debbie and highlighted a different issue that meant her experiences were personal to her. Julia says,

> *'I'm not a sick sort of person, in fact I can honestly say the last time I went to the doctor's was three years ago for my last screening, so I think going to the doctor's for me is quite an ordeal you know, I get quite nervous and feel sick about the fact'* (Julia 35-49 WB)

So in a similar way to Debbie, Julia is offering an aspect of herself or her circumstances to explain why her feelings about cervical screening may be different from those of others. Julia very rarely visits the doctor and so the presentation of the cervical smear test as a simple and routine test does little to allay her fear and anxiety. Going to the doctor is not a routine occurrence for Julia; it is an unusual and unwelcome event and, as such, is something of an ordeal for her. She does not regard herself as the type of person who regularly visits the doctor; indeed elsewhere in the interview she stressed her very good general health and her reluctance to rely on doctors to resolve minor health complaints. Julia therefore resists attempts within the official discourse to construct screening as routine and stress its role in maintaining good health by associating it clearly with illness and literally with 'feeling sick' at the prospect of submitting herself to the medical gaze.

Similar practices of resistance through individualisation can be seen within women's discussions of the physical aspects of having a smear test. Again, whilst many made some mention of the test being uncomfortable and even painful, the two women I discuss below told me how their individual bodies made screening particularly difficult for them. I start with Alice, who discussed her experience of smear tests like this,

> *'every time uncomfortable and painful, they're just horrible…apparently erm I've got a funny shape so when the instrument goes in to open your cervix up it doesn't always go properly because of the shape'*

(Alice 35-49 WB)

So here Alice, in common with Debbie and Julia before her, explains how and why her experience is in some way different and unique to her. In this way she personalises cervical screening to her own particular experiences, and indeed to her own particular body. Roberta does a very similar thing in the following extract, in which she discusses the difficulties she has experienced when having smear tests.

'I've had a few, well I have difficulties with them I must admit because they can't get at the cervix, I think it's up and back or up and to the side and the nurse has done it the last few times and has apologised profusely for not being able to do it' (Roberta 50-64 WB)

Again, Roberta has marked her experiences out as exceptional and shows how her personal circumstances and her particular body set her apart from others. As such she goes some way towards challenging the presentation that a cervical smear test is a quick and simple test.

Through these discussions, both Alice and Roberta are resisting a further assumption of public health strategies such as screening programmes. I have already suggested that such programmes are premised on the ideas that, firstly, individuals should make their bodies available for inspection by the medical gaze and that, secondly, this gaze needs to be routinized if it is to protect the health of citizens. A third premise is that the gaze requires a population of bodies that are homogenous. By surveying a large number of bodies that are 'normal' the gaze can identify the small minority that are pathological and therefore require further intervention in order to prevent illness. Through discussions of their particular bodies as different and problematic, Alice and Roberta are challenging and resisting this notion of homogenous bodies. Further, they are using a form of medical knowledge in order to achieve this as the reasons for their problematic experiences have been provided by health professionals.

The four women discussed above all therefore offer aspects about their particular circumstances to mark themselves out as somehow different, and to account for their particular experiences within the cervical screening programme. They explore their own

personal and particular positions and go some way towards carving out a niche for themselves within the very general official presentation of cervical screening. These practices serve to highlight their particular positions and work out their own relationships to cervical screening whilst also resisting particular assumptions or tenets of the programme.

The second type of practice within this general grouping involves changes to the physical body. A noticeable resource on which some of the older women within my research drew when discussing cervical screening was the way in which their bodies had and were still changing, and how these changes influenced how they thought about screening and the significance that they attached to it. The majority of these discussions revolved around the menopause and the bodily changes associated with this. First, however, I explore the case of Vanessa who, at 57, was one of the oldest women I spoke to. Vanessa had gone for screening in the past but her attendance had lapsed of late due to a particularly bad experience when Vanessa felt she had been treated unsympathetically by the smear taker. What is interesting about Vanessa is the way in which her bodily changes have, in combination with her negative experience, affected her willingness to go for screening and how she feels about it. Although she had always found having a smear test embarrassing, the way in which her body was changing made the experience even more troublesome for her. Vanessa told me,

> *'as you get older you get, like your breasts aren't as firm as they used to be, your belly starts hanging down and, you know, little bits of you start going out of shape and you think 'I don't want anybody looking at me like that' you know, I suppose if you're younger and your body's still, like not losing any of its elasticity you kind of like, maybe you're not that bothered but as you get older I think you become a bit more conscious about how you display yourself, for me anyway that's how I feel'* (Vanessa 50-64 AC)

The way Vanessa's body is changing with age is influencing how she feels about going for screening and having to display her body to people. The changes to her body she discusses have altered the way she views herself, and her physical attractiveness, and have made her even more reluctant to display her body in such a way. Like Debbie, Vanessa engages in a redrawing of the boundaries between the public and the private to

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some degree. She draws upon cultural ideas of the older body being less attractive in a society which, it could be argued, attractive bodies are associated with youthfulness and with 'everything being where it should be'. Again the idea that individuals should readily submit themselves to the medical gaze is problematized and resisted.

The bodily changes associated with the menopause also influenced women's thinking on cervical screening. Existing research on age and views on cervical screening (see for example White 1995) has suggested that menopausal women often regard screening as of little importance to them due to a feeling that that part of their body is 'finished with'. This is supported to some degree by the views expressed in my research, as some women suggested that screening was more important for younger women who, they argued, were likely to be more sexually active[49] and to have young children to consider. However, the menopause was also discussed in terms of being a time during which screening may be particularly important due to the perceived uncertainty and 'riskiness' of the body that the menopause brought about. For some women this feeling of vulnerability, combined with an awareness of how their body was changing, made screening more important to them and served to alter its meaning and significance. For Julia in particular cervical screening had developed from simply a test to check the health of the cervix to providing a more general reassurance that the bodily changes she was experiencing were normal. Julia told me,

> *'I feel more wary and in fact I feel more frightened than I have before because my body, since my last smear, has changed completely and I'm told it's normal for my age but I'll be glad when I've had the test and I think 'yeah, that is right' you know, there is nothing untoward happening and I think maybe it is a very uncertain time for women of our age and maybe it is the most important period of your life to go* (attend) *through'*
> (Julia 35-49 WB)

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[49] Other women challenged the assumption that increasing age necessarily meant declining sexual activity. It is interesting that some of the strongest arguments against this came from younger women. One of these suggested that, even though one of the vignette characters was in her sixties, she could be 'a swinger for all we know'.

Here Julia responds to the increased uncertainty and vulnerability that she is feeling by re-appropriating the smear test to serve her own purpose. She develops it into serving a wider purpose that than within the official discourse and emphasises its potential to reassure her that the bodily changes she is experiencing are normal. So while she is even more nervous about attending for her next smear test than she has previously been, she welcomes what she regards as its potential to put her mind at rest. In this way then she has tailored cervical screening to fit in with her particular feelings and concerns at this stage in her life and to fulfil the role that she currently requires. However, by doing so, Julia demonstrates unrealistic expectations of screening and what it can tell her about her general health status. While a normal smear test can tell Julia that the menopausal changes she has experienced have not brought about cervical abnormalities, it cannot provide more general information. Through stressing the changes to her body Julia also goes some way towards questioning the assumption of homogenous bodies discussed previously. By drawing attention to such changes Julia is drawing a boundary between herself and other women.

It is apparent from both Vanessa and Julia's accounts that the bodily changes they have experienced have altered the way they view cervical screening and this highlights an important point about the fluidity of the boundaries between different subject positions in relation to cervical screening. While women carve out a particular position for themselves in relation to the very general discourse, this is likely to shift and change as their personal situations do. Cervical screening may mean different things to a woman at different stages in her life, factors such as childbirth and menopause for example may alter its significance and meaning. Factors that were once important in defining her relationship to screening may cease to be so important and new issues may develop that take their place.

7.2.2 The influence of a Muslim discourse

In the preceding section I explored how the official discourse on cervical screening interacts with, and is influenced by, other important societal and cultural discourses and I will introduce further examples in later chapters. In this section I seek to contrast the previous focus on practices rooted in personal experience with one which draws on more widely held religious beliefs. This centres on the importance, significance and

definition of women's virginity at marriage and was drawn upon by the majority of the Muslim women I interviewed.

It is worth mentioning that the general issue of religious/cultural difference, and the potential barriers to screening, was discussed by several non-Muslim women within the interviews, but in very general terms and based on certain assumptions rather then concrete knowledge. For example, there was a general awareness amongst the sample that smear tests may be more problematic for Muslim women and that there may be issues around displaying the female body. However, what I want to do here is use some material from interviews with Muslim women to explore how the smear test is constructed by them and the particular significance and meaning attached to it[50]. I use this as a further example of how a general discourse is personalised or individualised, and how it is 'made to fit' with another influential discourse, in this case a religious one[51].

It was the view of the majority of the Muslim women I spoke to that the cervical smear test should not be performed on an unmarried woman, as the internal nature of the test meant that the woman's virginity would be compromised because the hymen would be broken. The following extract from Samira is typical of how these women brought a new significance to screening and highlighted the possible consequences,

> *'we're not supposed to have boyfriends or have any sexual activity before we're married because we're just for our husbands…like I said the sexual thing, it's like if they do find out. Obviously the husband's going to know first and then the father's going to know but erm if you do have the smear test obviously they put the thing inside you and they obviously break the virginity because of the thin line of skin there and I think that's why it puts like a doubt on things'* (Samira 20-34 SA)

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[50] I intentionally focus upon Muslim women's own interpretations of this discourse rather than attempting to present the 'official version' as I regard these interpretations as the more relevant.

[51] I use the term religious here as this is the language used by Muslim women within my research. I explored the distinctions between religion and culture with a south Asian contact who arranged three of the interviews with south Asian women. From this discussion it is clear that both religious and cultural imperatives influence how cervical screening is thought about, but for the present discussion the focus is on religion.

This extract clearly demonstrates the way in which Samira equates virginity with the intact hymen. For her the smear test is an internal procedure, which therefore involves the insertion of an implement into the vagina, and this 'obviously' breaks the virginity because of the thin line of skin (the hymen) which will be broken. The significance of the intact hymen is clear from this extract and Samira describes how the discovery that a woman's hymen is not intact will be problematic. Samira told me that the husband will discover that the woman has 'lost her virginity' when she fails to bleed at first sexual intercourse with him and even if she were to explain that she had had a cervical smear test taken it is probable that she would not be believed and would be accused of trying to 'cover up' her previous sexual activity.

The only Muslim woman I spoke to about this issue who did not discuss it in these terms was Namirah (20-34 SA), who did not place such an emphasis on the intact hymen being equated with virginity. She mentioned the other ways in which the hymen can be broken for example, horse riding or strenuous exercise, and did not share the other Muslim women's strong views that a smear test should not be performed before marriage. Namirah's acceptance that a broken hymen does not automatically equate to a loss of virginity means that her view on the appropriateness of screening unmarried women does not match that of other Muslim women within this research.

However, it remains that the majority of Muslim women equated a broken hymen with a loss of virginity. This had the potential to be extremely damaging for the woman involved, and some went as far as to suggest that girls' lives would be destroyed by this and the stigma that would accompany it. So for Muslim women, particularly those that are not married, the smear test takes on a whole new significance that is not present within the official discourse nor within the talk of women from the other two ethnic groups contained within the research[52].

The particular significance attached to a cervical smear test by this group can be explored through the case of Nisha, who had had a cervical smear test before she was

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[52] It is of course possible that women from other groups may view cervical screening as compromising virginity in this way but these were not present within this research.

married. She had received a standard invitation letter from her GP and attended for a test without knowing what it was. Her discussion of how she thought it was just a routine test, and the reaction of her mother on finding out what had happened, illustrates the particular significance of an internal procedure of this kind. Nisha told me,

> *Nisha: 'I didn't know what it was, I thought it was just like a test thing, you know, I mean like you go for a blood test or something'*
> *NA: 'did you speak to anyone in your family or your friends and say 'what's this, should I have it?''*
> *Nisha: 'I think my mum said 'yeah, you can go down and have it' but she didn't, she didn't realise, even she didn't know until afterwards when I told her how it happened and what they did and then she said 'oh no I don't think you should have had that'* (Nisha 20-34 SA)

This clearly demonstrates the significance attached to this kind of internal procedure, as for Nisha the smear test she had had was not simply another routine test, it had a different meaning and significance. Having a cervical smear test without realising in advance what it was had had an enormous impact on her and she felt that there had been a failure to take her particular circumstances into account. As she told me,

> *'it's like I lost my virginity before I done anything...which I didn't think was right'* (Nisha 20-34 SA)

In this case a religious discourse has taken precedence over the official and is prioritised in determining how the test is viewed. However, this was only the case before marriage and after a woman was married, and could legitimately be sexually active[53], smear tests were acceptable and most of the Muslim women I spoke to approved of them. When I explored this further the distinction between married and unmarried women was clear. Amina (35-49 SA) who had told me that unmarried girls' lives could be destroyed by

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[53] Given the widespread view that Muslim women are expected to be virgins at marriage, the issue of sexual activity and risk is an important consideration here. It was assumed by many of the Muslim women that, as unmarried women should not be sexually active, they did not need cervical screening. The NHSCSP guidance states that women who have never had sex are at lower risk, but they are careful to state that this does not mean no risk.

having this kind of test, later went on to stress the importance of having smear tests after marriage and that this could co-exist quite happily with religious ideas. After marriage the point of resistance imposed by employment of the religious discourse is removed and the medical presentation of cervical screening as an important thing to do for the good of one's health regains its dominant position.

However, the way in which discourses are interpreted and employed by women is not uniform and the interplay of different discourses can produce different outcomes. While the majority of the Muslim women interviewed maintained the view that virginity at marriage was fundamental, Amrita was an interesting example of how this need not always be the case. She suggests that, for some Muslim women who have been brought up in the UK, as she herself was, this religious discourse may be less influential and therefore may not influence their thoughts and behaviour to the same degree. When I asked her opinion on what women like Nisha and Amina had said she told me,

> *'it depends how religious they are, but erm with us like being brought up*
> *here we are very like westernised now to what's going on around us'*
> (Amrita 35-49 SA)

This case emphasises the fact that, although similar discourses may be at play in influencing the position adopted by women, this need not necessarily lead to the same end result. While the majority of the Muslim women were clear about their commitment to the importance of virginity at marriage, and employed this discourse in working out their views on cervical screening, for Amrita the influence of such a discourse has declined due to her being brought up in Western culture where such views are not so widespread. In this way, the influence that the religious discourse has on a woman's position in relation to screening is diminished and weakened in the face of the more 'westernised' views which she may now hold. As such, the issue of virginity at marriage may not be so central to her views on cervical screening.

Again this demonstrates how individual women go through a process of personalising and individualising the general medical discourse around cervical screening, and engage in a process of 'making it fit' with other influential discourses. Widespread views on the different status of smear tests for married and unmarried women is a nice example of

how these women negotiate cervical screening in the context of their religious beliefs and attach a new significance to the test that is not present for women from the two other ethnic groups within this research. Again this can be viewed in terms of questioning some of the assumptions of the official discourse, in particular that individuals should readily submit themselves to the medical gaze. What is interesting, in comparison to the cases of Debbie and Vanessa above, is that the redrawing of the boundaries is pursued slightly differently. The boundaries of the former are constructed in terms of a topography, with certain zones of the body excluded, while the Muslim women introduce a chronological element in which certain zones are excluded until a particular point in time.

This example also demonstrates that the negotiation of discourse need not always take place at a solely individual level. While these Muslim women do talk in individual terms, there is also an appeal to a group identity and a consideration of what cervical screening means to 'women like us'. While this may be implicit in other accounts discussed above, for example Debbie is presumably not suggesting that she is the only private person, for this group of Muslim women the appeal to a group religious identity is more explicit. The appeal to a group identity can open up potential new forms of resistance in addition to those that are more individually based (Bloor and McIntosh 1990). This is because, while there is a personal and individual level apparent here, there is also the potential to appeal to a group identity that is not so immediately present within the earlier discussions of women's experiences and bodily changes. Therefore the potential for resistance goes beyond the individual and particularistic and can appeal to a more widely held religious belief. In a more explicit way than those discussed previously, these Muslim women can make some kind of distinction, and draw some kind of boundary, between themselves and other, non-Muslim women. It is to the status of these different forms of knowledge, and the implications this has for the types of resistance they allow, that I now turn.

7.2.3 The status of such practices

As the discussion above has demonstrated, individual women frequently engage in a consideration of their own personal relationship to cervical screening and carve out their own particular position in relation to the very general official discourse. What is clear from these accounts is that they allow women to 'place' themselves and make sense of

screening in ways that are meaningful to them as individuals, even those women who draw upon the religious discourse rely fundamentally on their identity as a Muslim woman for this to be evoked. Given the purpose that they serve this is not surprising, but what is interesting to explore is how these individual knowledges are regarded and the status that they can have in relation to the more universal and abstract official discourse on cervical screening.

In this section I explore the position that these two forms of non-medical knowledge, those based on physical and emotional experiences on the one hand and a religious discourse on the other, can have in relation to the biomedical authority that they implicitly, and sometimes explicitly, challenge. Important issues here surround the production of authoritative knowledge, what kinds or forms of knowledge are seen as legitimate and who is entitled to produce such knowledge. As Code (1991) argues, the forms of knowledge considered to be authoritative tend to be abstract, universalistic and to transcend individual experiences. Knowledges based on these criteria are seen as more objective and scientific and are accorded a higher status. It is relatively straightforward to frame biomedical knowledge within this context and much has been written about the high status accorded to medical knowledge and the increasing medicalization of everyday life (see for example Clarke *et al.*, 2003; Conrad, 1992; Illich, 1975; de Swaan, 1990; Zola, 1972). The role of expertise within neo-liberal forms of government was discussed in Chapter 3, drawing mainly on the work of Rose (1992, 1996, 1998), and in particular the ways in which individuals are encouraged to rely upon this in regulating their conduct. However, the potential for resistance to such expertise, or its location, still exists, and is demonstrated through empirical studies of resistance (see for example Murphy, 2003; Mayall and Foster, 1989; Bloor and McIntosh, 1990) within which expertise is relocated to individuals by virtue of their experience of, and familiarity with, particular cases.

As I have argued, the knowledge that is directly available to women about cervical screening is largely experiential and particularistic. This is most clearly the case in relation to the physical and emotional experiences of screening and the bodily changes which serve to influence the meaning and significance attached to it. These are inevitably individual and personal in nature. The religious discourse used by the Muslim women within this research to transform the meaning of the smear test for an unmarried

woman relies less on such personal and experiential knowledges, although Nisha's personal experiences are nevertheless important. However, to a certain degree the transformation of the biomedical presentation of the smear test still takes place within the context of the female body in the sense that the significance attached to virginity and an intact hymen is essentially embodied.

The types of knowledge that women within this research employ, particularly those based on physical and emotional experiences and bodily changes, can immediately be seen to be at odds with biomedical authority. Their base in individual emotional and/or bodily experiences may serve to diminish their status as knowledge when compared to the biomedical authority based on science and reason. Different kinds of evidence are accepted by, and available to them, because, while biomedicine is concerned with what can be observed and measured, lay individuals are concerned with what can be experienced. This may mean that it is easier for women's appeals to the experiential to be dismissed. The appeals to a wider religious discourse may be viewed more favourably both by health professionals and wider society. This is not limited to a philosophical or political level. There are examples within my research of individual lay women attaching a different significance to religious/cultural imperatives than to physical or emotional experiences. When Selma and I were discussing women not attending for cervical screening, she had little time for those women whose non-attendance was based on fear, embarrassment or physical discomfort/pain. However, towards the end of our interview, we touched on potential issues for women from minority ethnic groups. The way in which Selma dealt with the potential non-attendance on religious and/or cultural grounds was markedly different from her quick dismissal of emotional and/or physical grounds. Selma was more understanding towards the potential problems that women from minority ethnic groups may encounter,

> *'presumably for them it would be because of their religious beliefs and that, I don't know is it against their beliefs to go and have a smear done? Because I know that being a virgin in their culture is very important...I can imagine, because for some ethnic minority groups they can't even show an ankle or a wrist or anything so to go and expose that...'* (Selma 20-34 WB)

Here Selma clearly makes a distinction between different reasons for non-attendance, and is noticeably more accepting of those based on religious and/or cultural grounds. She begins by marking this form of non-attendance off from others that she is less sympathetic to by stating that 'presumably for them it would be because of their religious beliefs'. She acknowledges the importance of virginity for such women and is understanding of the problems.

It might be assumed that individuals will accept authoritative knowledge, which has a clear medical or official basis, when it contradicts their own experiences or beliefs, but the possibility to challenge these dominant ideas remains. Instances of this can be found in empirical work. When exploring the resistance techniques possible within the context of health visiting, Bloor and McIntosh (1990) suggest that many of the mothers they interviewed challenged the legitimacy of the health-visiting discourse through a strongly-held view that mothering, or infant care, was an essentially lay skill that was developed through practical experience and could not be learnt from books. Health visitors that did not have children of their own were particularly seen as lacking credibility. In their work on HIV-positive gay men's decisions not to access anti-retroviral therapy, Gold and Ridge (2001) argue that much of the men's dissent from the biomedical model was rooted in fundamentally different modes of thinking to that required by the model. They argue that biomedical thinking requires abstract thought that is removed from the immediacy of personal experience and that the accounts of men they interviewed placed a strong emphasis on those features devalued by the biomedical model. They based conclusions on evidence drawn from individual cases with which they were familiar and were not willing to think in the abstract way that accordance with the biomedical model would require.

In common with these examples some women within my research have questioned and challenged the official medical discourse that surrounds cervical screening through the use of the non-medical knowledges discussed above. However, others have minimised or questioned their own knowledges and experiences in the face of biomedical authority. In the next section I go on to explore how far the lay and individual knowledges discussed thus far are used by women and the extent to which it is possible for them to resist the official discourse.

7.3 The Pursuit of Practices

The aim of this section is to explore how far women pursue these practices in the face of biomedical authority. However, as I will go on to discuss, the particular nature of the cervical screening programme itself can serve to limit the possible opportunities for such resistance and may influence the forms of resistance that may be possible.

7.3.1 Deference to biomedical authority

Within my research women deal with their individual, non-medical knowledges in different ways. Some minimise or even seem to invalidate their own experiences through an 'it must be just me' approach so that, faced with the problem of reconciling their personal experiences to the official presentation of cervical screening, which is often taken to represent the majority of other women's views and experiences, these women question the validity of their own experience and engage in strategies to minimise its significance.

Very early on in my interview with Deirdre she told me about the last time she had had a smear test taken and described it as a 'horrible experience'. She had found the nurse taking the smear to be very abrupt, had therefore found it difficult to relax and so it had been painful for her. Deirdre had not had that kind of experience before and it had made her unsure if she wanted to continue attending. In fact she had been contacted about her next smear a couple of months earlier but had not yet done anything about it.

Later in the interview Deirdre engaged in a comparison of her last, negative experience of cervical screening with the material contained in the information leaflet she had received. She went some way in exploring the discrepancies between the two,

> *'I can't remember them saying it can be a painful experience but it certainly was this time and so I don't think in the leaflet it ever...I can't remember reading that, it said it might be a bit uncomfortable but I don't think it actually says painful erm so no probably not, it didn't say that I mean it probably was just me and I got there on a bad day and, you know, all these kind of things'* (Deirdre 50-64 WB)

In this extract Deirdre shows the potential to challenge the medical presentation of screening, as found within the information leaflet, through a comparison of this presentation of the test with her negative and problematic experience. She uses her embodied knowledge of the smear test as a painful procedure and suggests that this is not the way in which the test is portrayed. However, Deirdre stops short of making such an explicit challenge and begins to back-peddle by minimising and questioning her own experience. In contrast to the earlier part of the extract, in which she uses her personal experience strongly, in the latter part she seems to almost invalidate her experience by suggesting that is was probably just her and going on to suggest that she may have just got there on a bad day or there might have been other mitigating factors that threaten the validity of her experience. She is apparently unwilling to use her negative and problematic experience as an alternative way of thinking about cervical screening, despite her earlier strong discussions of it as a 'horrible experience'. Faced with such a possibility Deirdre opts to question herself rather than the medical discourse and presentation.

7.3.2 A plurality of experience

The next stage along this kind of continuum are those women that maintain the validity of their own experiences, but without directly challenging opposing views or opinions, whether these are put forward by other women or are found within the official presentation of cervical screening. For these women it is enough to acknowledge the plurality and diversity of experience and the various subject positions possible. They draw strongly on the notion that women are a heterogeneous group and that they are likely to experience and think about screening in different ways (Lock and Kaufert 1998). While they may identify themselves with a certain position, for example regarding a smear test as unproblematic or experiencing it as an ordeal, they do not usually suggest that any one position is more valid than any other. They simply continue to stress the heterogeneity of experience and view.

Matilda illustrates this well in the following extract, in which she acknowledges how different women have different experiences of screening and view it in different ways. In the context of telling me about her own views on screening Matilda said,

'it just so happens that it doesn't bother me too much err to go through that procedure but other women I know find it upsetting, painful, invasive, embarrassing and err, you know, we're not even talking about Muslim women for example here' (Matilda 34-49 WB)

Here Matilda sets out her own attitude towards cervical screening before going on to acknowledge that other women she knows feel differently from her and find having a smear test more difficult. She then goes further to suggest that for Muslim women these problems are likely to even more severe, although in common with Selma earlier in this chapter her awareness of this is quite vague and does not make the important distinction between married and unmarried women, which is the crucial point for the Muslim women I spoke to.

7.3.3 The maintenance of individual, non-medical knowledges

Whilst other women within my research either played down their own experiences or acknowledged a plurality of experience without challenging the validity of the medical presentation of cervical screening and having a smear test, a number of women went further than this and used their personal experiences, their knowledge of others' experiences or their religious beliefs to challenge the way that cervical screening is presented within the official documentary material and in some cases to transform cervical screening's meaning and significance. Within this section I consider challenges based on personal knowledges and experiences and those based on religious beliefs separately. I maintain this distinction here, as in previous sections, in order to draw out the different strategies of resistance demonstrated and the different resources that women in varying situations have available to them.

I begin by considering the challenges women make to the official medical presentation of cervical screening and the process of having a smear test through the employment of their own personal experiences, and those of women known to them. I start by demonstrating how women question the official presentation of having a smear test by exploring some of their considerations around the objectivity and neutrality of this medical presentation and how it is possible to have knowledge of what having a smear test is like.

The documentary material that women receive about the smear test stresses the simplicity and ease of the test. The information leaflet that is required to accompany invitation letters describes the test as being simple, quick and usually painless. The language and phrasing used within this leaflet serve to minimise the intrusion and significance of the test. For example, women are told that 'the test takes just a few minutes' and that the smear taker will '…gently put a small instrument, called a speculum, into your vagina to hold it open'. As will be immediately clear from a comparison of this presentation with the experiences of women such as Debbie, Julia, Alice and Roberta that I have discussed earlier in this chapter, many women do not recognise their experiences within this presentation. It was not uncommon for women to report very different experiences from that portrayed within the official medical material, based on their physical and/or emotional experiences.

This comparison between the official presentation and their own experiences led some women to question the official medical discourse, and this approach stands in contrast to Deirdre who, when faced with this sort of mismatch, adopted a strategy of minimising her own experience and almost seemed to invalidate this. Other women though were willing to place more emphasis on their own experiences and this therefore led them to be more questioning of the official medical presentation of screening and to explore the possible reasons why this did not match their experiences. Perhaps the key here is that these women examined the medical to see why it did not match the personal, whereas Deirdre examined the personal to see why it did not match the medical: a subtle but perhaps important distinction.

We have already explored examples of women considering why there are differences between the medical presentation and their experiences, for example Debbie discussed how her being 'such a private person' influenced how she experienced screening, and Alice and Roberta discussed how their particular bodies meant that the procedure of having a smear test taken was particularly difficult and problematic for them and so the official presentation was too general and had failed to take account of their particular characteristics. However, here I want to move a stage further and explore cases of women using their experiences to question the official presentation more explicitly.

As I have already discussed, many women report very different experiences of screening from that portrayed within the documentary material and this leads some, but by no means all, to question the way in which the test is presented within this material. These women question the presentation and argue that it may be unrealistic as it is very 'polished' and puts a 'very positive spin on things'. It was suggested that this may be a result of the need to encourage women to participate within the cervical screening programme and not put them off attending. Ally in particular discussed the difficulties involved in giving women sufficient information about having a smear test on the one hand and the aim of encouraging attendance on the other. Ally was stressing the importance of giving women attending for the first smear sufficient information, but then went on to suggest there was a danger this would put them off attending,

> *'probably a letter should be given out beforehand to say what it is, or a little leaflet in fact...so therefore they know what needs to be done, but there's another thing as well because if people do get that and it's embarrassing or it's going to be uncomfortable then therefore it could react a different way where they don't go'* (Ally 20-34 AC)

In this extract Ally suggests that there has to be a delicate balancing act through which women are given information about what to expect and what the experience of having a smear test will be like, but not to the degree that they are reluctant to attend. In this way Ally implicitly questions the neutrality and objectivity of the information given to women through the recognition that it is intended to serve a specific purpose.

Following on from this, Audrey makes a more explicit claim about the form or type of information a woman can expect to receive from health professionals and contrasts this with the type of response one will receive when discussing smear tests with female family members or friends,

> *'the GP will give you the very formal whereas your friends or family will give you the 'oh my god, it's not very pleasant', or whatever you know 'you need to think about such like, or this is something that might happen to you' and so you'll get those little bits of things so that you won't be as shocked'* (Audrey 50-64 WB)

Here Audrey makes a clear distinction between the different forms or types of information that a woman is likely to receive from different sources and suggests that this will be drawn from a different base. She uses the term 'the very formal' to suggest that the GP, or other health professional, will base their information on medical knowledge and procedure, or, as another respondent put it, 'the nuts and bolts'. In contrast, the response from female family members and friends will be more concerned with the experience of having a smear test and preparing the woman for what it will 'really be like'. The knowledge that other women share about smear tests is inevitably drawn from their own experiences of having such tests and was valued for precisely this. For some women this was a more valid and relevant source of knowledge on which to draw.

April made a similar distinction between her response to information from a health professional and the more experiential knowledge from lay women who had had the test themselves.

> *'I tend to believe more obviously what doctors tell you and stuff, erm…but I think you listen to people more if they've been through it themselves, gone through the test themselves'* (April 20-34 WB)

So while April acknowledges that she 'believes' what doctors tell her, she still values the knowledge received from women who have gone through the test and suggests that she would listen more to these accounts. April suggests that while the doctor is the source for medically accurate information, as Audrey suggests the 'very formal', the experiential knowledge from women who have had a smear test themselves is still very much valued. Indeed several women told me that, before having their first test, they had asked female family members and friends what the test was 'really like'. These personal experiences were frequently placed above the information given in the official medical material as many women were of the opinion that you had to have a smear test to know what it was like. While there was an acknowledgement that not all women experienced having a smear test in the same way, the experiential knowledge shared between women was somehow seen as more realistic or 'down to earth' and was therefore valued for this.

While many of these personal experiences included some degree of embarrassment and/or physical pain, there were perhaps four women whose accounts of having smear tests stood out as particularly extreme and within these there is a strong focus upon the invasive nature of the cervical smear test. Interestingly, three out of these four women were of African Caribbean origin and so it may be that cultural ideas of the sanctity of the female body are particularly important within this group. However, in contrast to the religious discourse on the importance of virginity at marriage, these ideas are never made explicit within women's discussions and are not sustained to the same degree. As such it would perhaps be inappropriate to do much more than suggest that this is an interesting observation and highlights an issue that requires further investigation.

While all four of these women discussed cervical screening using such strong terms as 'degrading' and 'horrific', and argued that little care is taken by smear takers, the most extreme account comes from Joanna and incorporates such issues as power and control within the medical encounter as well as having a sexual undercurrent,

> *'it's almost like an invasion of privacy and sometimes I think to myself, like you think of some doctors that abuse patients and I think to myself 'I wonder if they get off on it'…you've got no control at all especially when they've got instruments up you, it's not like you can say 'look drag it out' and get down because you could injure yourself…it's almost like being tied up, you know there are people into bondage, and you've got no control over it until they say 'ok that's it'* (Joanna 35-49 AC)

In this extract Joanna uses her personal experiences to transform the smear test into something quite different to the simple, quick procedure as set out in the literature. In common with the Muslim women who used their religious beliefs to transform the smear test, Joanna constructs the experience of having a smear test as something much more significant than that identified within the official presentation. She brings issues of power and control to bear on it and there is a strong sexual tone to what she says. Within the official discourse, the process of taking a smear test is presented very clearly as a medical procedure and the insertion of instruments into the vagina is in no way linked to penetrative sex. However, Joanna clearly makes this connection and

introduces a sexual element to the process. This is not just from her own perspective though as she also suggests that those taking the test may 'get off on it'. Joanna obviously feels very strongly about this issue and maintains her firmly held view through her experiences. However, in contrast to the transformations brought about by the Muslim women, Joanna can only appeal to her individual experience, whereas the Muslim women can appeal to a more widely held group identity and belief to support their case. So while both have engaged in a process of transforming the meaning and significance of cervical screening, perhaps the fact that the Muslim women can call upon a religious group identity and belief ultimately means that their strategy of resistance is the more successful and based upon the firmer foundation of the two. As I have previously discussed, different forms of knowledge have different statuses within our society and, although individual women such as Joanna hold very strong opinions based on their experiences, the ability to appeal beyond the individual to a well-established group religious identity may ultimately mean that the resistance demonstrated by the Muslim women may be the more successful and sustainable in the face of biomedical authority and the official discourse on screening.

7.4 Conclusion

In the course of this chapter I have outlined and discussed the various ways in which women work out their own position in relation to cervical screening and the official discourse which surrounds it. I focused here on two main resources upon which these women drew: firstly, personal experience, further divided into the physical and/or emotional experiences of screening and the impact of bodily changes, and secondly, the importance of a religious discourse. Throughout I argued that these practices can be seen as forms of resistance to the ways in which cervical screening is presented through the official discourse and that, through such practices, women can develop alternative conceptualisations of, and discourses on, screening which differ from and resist those contained within the official.

Following this, I went on to consider the statuses that such practices, and in particular the resources upon which they draw, can hold in relation to biomedicine. Here I drew attention to the important differences between both the nature and relative statues of practices rooted in personal experience and those that can draw upon a more widely held religious discourse. Finally, the chapter explored the extent to which these

practices are maintained and pursued by women through a comparison of strategies of minimisation, plurality and challenge. As I made clear at the outset, the kinds of resistance that I have explored within this chapter are located at the thought or talk level and are not pursued through behavioural means. Indeed, throughout the thesis I have repeatedly stressed the inability of a focus upon attendance to adequately capture the diverse range of positions adopted by women.

It must be made clear that the women within my research who advanced these alternative ways of thinking about cervical screening were not doing so to account for, or seek to justify, non-attendance. Only one woman interviewed had never had a cervical smear test taken and, of the remaining 34, 26 were regular attenders[54]. This talk does not serve that kind of function, as even women who discussed cervical screening in very problematic terms stressed that they overcame these problems in order to attend. They were keen to stress that they had considered these problems in the context of the long-term protection of their health, therefore establishing themselves as responsible citizens (Howson, 1999; Lupton, 1995; Petersen and Lupton, 1996).

The kinds of resistance discussed in this chapter are important for the means through which they allow women to make sense of cervical screening in ways that are meaningful to them through the consideration and incorporation of their particular experiences, circumstances and characteristics. Women were generally reluctant to think about screening in the very general way presented in the official discourse and were keen to stress the heterogeneity of women and experience and to carve out their own position in relation to the very general. Indeed, some went as far as to use the personal to question the validity and objectivity of the medical presentation. Women were therefore keen to take back some sort of control over how screening is thought about and what meaning and significance the smear test holds for them. I would argue that resistance within this context be framed in terms of women's employment of various resources and practices in order to interpret, re-appropriate and even transform cervical screening and the cervical smear test. In this way, women are drawing upon particular resources, such as their own experiences or religious beliefs in order to bring

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[54] The different kinds of attendance patterns that women within this study demonstrated was summarised in Table 5 of Chapter 5.

about 'transformative effects' and to press their claims in response to those of others (Riessman, 2000).

This chapter has shown that, far from a straightforward imposition, the relationship between the official discourse on cervical screening and how it is understood and made sense of by individual women is in fact more flexible. There is clearly a space between the large scale discourse and individual subject positions within which women draw upon a range of resources and practices that allow them to resist particular aspects of the discourse and make sense of it in the context of their own everyday lives and identities. The fact that these do not commonly lead to them resisting screening through a refusal to attend should not lead us to think that this resistance is inconsequential. They are important for the ways in which they influence the interpretation of health promotion messages (Davison *et al.*, 1991) and, at times, challenge the objectivity of medicine by questioning the purpose of the official discourse. The resources drawn upon in these kinds of resistance then are important for their ability to suggest and impose points of resistance at the level at which discourse and the individual meet. I therefore argue that these practices should be viewed as examples of the kinds of 'technologies of the self' Foucault envisaged when considering how resistance may be possible (Foucault, 1984a&b, 1988; McNay, 1994; Burchell, 1996). Personal experiences or religious beliefs impose potential points of resistance which disrupt the flow of discourse and can lead to interpretation, negotiation and transformation.

Chapter 8

Self-Positioning in Relation to Risk and Vulnerability

8.1 Introduction

In the previous chapter I outlined and explored the various ways in which women within my research engaged in a process of individualisation in relation to the very general presentation of cervical screening that they encounter within the information material that they receive. I argued that considering cervical screening in the context of personal experience, including physical and emotional aspects, and religious beliefs led to individual women working out their own relationship to cervical screening and negotiating a particular position for themselves within, or in relation to, the general official discourse. In the present chapter I further develop this idea of individualisation within a very specific context, that of women positioning themselves with regard to their personal feelings of risk and vulnerability. By this I mean the tendency for women to work out their personal relationship to cervical screening, and its relevance to them, through a consideration of their personal risk and feelings of vulnerability based upon particular understandings of cervical cancer risk factors.

It is necessary here to refer back to the material that women receive on cervical screening, which was analysed in Chapter 6, and to recap on the information contained within this on risk factors for cervical cancer[55]. The information leaflet that is required to accompany all invitation letters states that screening is routinely offered to all women between the ages of 20 and 64 years[56], therefore emphasising the uniform nature of the approach. However, it also states that a cervical cancer is more common if women:

- First had sex at an early age
- Smoke
- Do not use condoms
- Have had several sexual partners or have had a sexual partner who has had several other partners
- Take immunosuppressant drugs (for example, after an organ transplant)

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[55] As in previous chapters I would again stress that women on accelerated recall following an abnormal smear test are likely to receive additional information.

[56] As I explained in Chapter 2, the age at which screening begins has recently been raised to 25 years.

It is immediately clear that the first four of the five factors that the leaflet identifies are related to lifestyle, by which I mean they are linked to individual behaviours, and that, of these four, three are linked to sexual behaviour, i.e. sex at an early age, not using condoms and number of sexual partners. The focus on sexual behaviour in relation to the risk factors associated with cervical cancer may have an important influence on how women consider their personal risk in terms of the acceptability of considering oneself as at risk of cervical cancer due to current or past sexual behaviour.

When considering their personal risk and vulnerability women drew on a number of different themes including factors such as genetics/family history, sexual activity the menopause and their general health. They also considered their risk both in purely individual terms and also in relation to other women, either generally or in relation to those known to them personally. My intention in this chapter is to explore more fully the process of self-positioning that these women engage in. I argue that resistance in this context can be framed in terms of women's reluctance to adopt the general 'at-risk' position suggested by the official material and instead to consider their personal situation through positioning themselves in relation to cervical screening. As in the previous chapter, this form of resistance manifests itself largely at the thought/talk level and many of the women who did not consider themselves to be at risk of developing cervical cancer continued to attend for screening. However, there is an interesting minority of women whose screening attendance is influenced by their considerations of their own risk and who tailor, or attempt to tailor, their participation within the programme accordingly.

This chapter begins with a consideration of the growing literature on risk, paying particular attention to the ways in which risk can be perceived from a governmentality perspective, and material concerned with how individuals understand and interact with risk. I move on to exploring individual women's considerations of their personal risk status and the themes they draw upon in the course of these considerations. Following on from this, I consider the relative status of different risk factors and the willingness of women to draw upon varying themes. Finally, I turn to the minority of women highlighted above whose perceptions of personal risk influence their screening attendance. This allows the chapter to conclude with a consideration of how these

women's self-positioning and their personalising of risk and, on occasion, attendance can be conceptualised as resistance.

8.2 Conceptualising Risk

Before going on to explore how individual women engage with ideas around their personal risk of developing cervical cancer, I briefly explore the growing significance of risk within contemporary society and particularly the links between risk and the ideas of governmentality that frame this research.

Awareness of risk has grown considerably within contemporary society and different kinds of risk are increasingly coming to the fore. Risk has acquired a new prominence in western society and developed into a central cultural construct (Lupton, 1993). A new meaning or dimension to risk is emerging. No longer a neutral term, risk has come to be associated with danger and, in the context of health at least, education campaigns aim to warn the public about health risks and how these are best minimised or avoided all together. As such it is possible to highlight the ways in which individuals are seen as largely in control of their health, with risk increasingly seen as a consequence of lifestyle choices. The consequences of risk are present at both the individual and the societal level and so issues around morality also come into play. As Lupton (1993:429) argues '…if individuals choose to ignore health risks they are placing themselves in danger of illness, disability and disease, which removes them from a useful role in society and incurs costs upon the public purse.'

Risk has become an important area of theoretical debate in recent years that has concerned the phenomenon of risk and the role that it plays in social life. It is possible to identify three main approaches to thinking about risk, which emerged in the 1980s and gained momentum during the 1990s (Lupton, 1999a&b). These perspectives stand in contrast to technico-scientific approaches to risk by taking into account broader social, cultural and historical contexts. I provide brief summaries of two of these perspectives before going on to explore the most relevant for this research, that of governmentality, in more detail.

The first of these perspectives comes through the work of Mary Douglas (see for example 1985, 1990, 1992) and is rooted in her earlier writings on the notions of purity

and danger and how these construct cultural boundaries (1969). In her later work, Douglas showed how risk can be used as a means through which to maintain cultural boundaries within contemporary western societies. Risk has come to be associated with blame and, therefore, particular individuals and/or groups can be singled out as 'risky' and dangerous. Risk is argued to act as a 'forensic resource', providing explanations for things that have gone wrong. Douglas argues that risk has come to be the dominant forensic resource in western societies due to its association with scientific neutrality.

The second theoretical perspective on risk is thought of in terms of the 'risk society' and focuses on what is seen as an intensification of concern with risk in late modern societies. Risks under the conditions of late modernity are seen as growing and globalising and are therefore more difficult to calculate and manage or avoid. Central theorists within this perspective are Beck (1992, 1996) and Giddens (1990, 1998) who argue the importance of the concept of 'reflexive modernity'. Within this, the processes of modernity are seen as producing the many dangers by which society feels threatened. Within these late modern societies a trend towards individualisation is perceived; influencing how risk is perceived and dealt with. Individuals are seen as choosing how they personally think about and deal with danger and therefore as exercising a high level of control over how much they expose themselves to risk.

However, it is the third theoretical approach to risk, that which comes from a governmentality perspective, that is the most relevant to how this research is framed and that will feed in to how resistance is conceptualised in this chapter. As I discussed in detail in Chapter 3, Foucault and other governmentality proponents have described the development of a huge network of expert knowledge, that has been accompanied by apparatuses and institutions through which these knowledges are constructed, reproduced and disseminated (Foucault, 1981, 1991a; Barry *et al.*, 1996; Burchell, 1996; Dean, 1990; Rose, 1996). This network was the outcome of a new system of liberal government within which the emphasis is placed on the individual voluntarily disciplining themselves rather than the use of coercion. Within this perspective, risk is understood as one of the governmental strategies of disciplinary power through which individuals and populations are monitored and managed. The concept of normalisation, which again I dealt with in Chapter 3, plays a central role in such liberal government, with those significantly deviating from the norm designated as 'at risk'. The implication

of this is that risk is ultimately controllable if properly subjected to expert knowledges. The focus is therefore on personal responsibility for avoiding and/or managing risk and, in common with 'risk society' theorists, attention is drawn to the self-management and personalization of risk. Risk as a governmental strategy works through individuals taking responsibility for themselves, with risk avoidance seen as a moral enterprise (Dean, 1999; O'Malley, 1996; Petersen, 1997; Lupton, 1999a&b).

However, in common with Lupton (1999a&b) I would argue that, valuable though this attention to risk as a governmental strategy undoubtedly is, these perspectives are in danger of focusing too much attention on the discourses and strategies employed at the expense of considering how people respond to them in diverse and dynamic ways.

It is often the case that lay people hold perspectives on risk that differ from those posited by 'experts'. This is not to suggest that experts are all in agreement, rather to make the point that ideas or views differ both in terms of content and the kinds of evidence that they accept[57]. As Lupton argues,

> 'The existence of varying perspectives on 'risk', among both experts and
> lay people, suggests that the phenomenon of risk is a production of
> competing knowledges about the world' (Lupton, 1999a:106).

Lay ideas on risk draw upon situated knowledges, the everyday and the localised (Lupton and Tulloch, 2002a&b) in order to construct risk understandings and respond to expert judgements on risk (Wynne, 1996). In this way lay people do not merely accept the expert pronouncements on risk, instead they are interpreted and understood through the context of everyday lives and experiences (Tulloch and Lupton, 2003). Therefore, in what follows, I explore how women discuss their personal risk of developing cervical cancer based upon particular understandings of risk and risk factors.

8.3 Self-Positioning in Relation to Risk

In this section I explore the various ways in which women within this research discussed their perceived risk of developing cervical cancer or their vulnerability to the

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[57] This reiterates the discussion in Chapter 4 on the different natures of lay and professional health knowledges.

disease[58]. I argue that these considerations can be seen as a means though which women position themselves in relation to cervical cancer and screening. These discussions, and the themes on which they draw, allow women to explore their personal relationship to cervical cancer and present them with mechanisms through which they position themselves both in relation to the medical discourse on screening and to other women, both generally and specifically. Women drew upon such themes as genetics/family history, issues around sexual behaviour, the impact of the menopause and leading a healthy lifestyle. In what follows I explore women's use of such themes to place themselves at more or less risk of developing cervical cancer. I divide these into two distinct categories: firstly, those that can be termed 'bodily' and are therefore rooted in the physical body and, secondly, those that are linked to lifestyle and behaviour and which, crucially, are seen to be under the control of the individual.

8.3.1 Bodily risks: genetics and the menopause

As I have suggested, it is possible to draw distinctions between different categories of risk. In sociology, this has largely been in terms of the difference between environmental risks on the one hand and lifestyle or behavioural risks on the other. Lupton (1993, 1995) and Gabe (1995) in particular have both argued for a distinction between these two forms of risk. However, Kavanagh and Broom (1998) have argued for the existence of a third form of risk, what they term corporeal or embodied risks. These are so called because, instead of being located in the individual's environment or lifestyle, they are cited in the body of the person seen to be at risk. Therefore the risk comes not from where or how the individual lives, but from who that individual is. In this section I explore different examples of women within this research employing the idea that their bodies, or who they are, mean that they are at increased risk.

A dominant theme when women discussed personal feelings of risk and vulnerability was the possibility that cancer runs in families. The most common example that women drew upon was breast cancer. This is perhaps not surprising for several reasons. Firstly, although men can develop breast cancer, it is commonly perceived as a female disease in the same way as cervical cancer. Secondly, both breast and cervical cancers are concerned with parts of the female body linked to sexuality. Thirdly, women may be

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[58] I employ the terms risk and vulnerability within this section as women used both of these terms.

particularly aware of the extensive media coverage of breast cancer and its genetic element. However, the genetic aspect of breast cancer is only one of a range of medically-recognised risk factors, others include: increasing age, the number of children a woman has had and at what age, not breastfeeding and taking the contraceptive pill or hormone replacement therapy (HRT). Cancer Research UK (2003b) state that, although people who inherit faults in the breast cancer susceptibility genes BRCA1 and BRCA2 have a higher risk of developing the disease, these gene faults are rare and cause only 2-5% of cases.

In contrast, cervical screening is not thought to have a genetic or hereditary aspect to it and no mention is made of a genetic risk within the information material women receive[59]. However, many women discussed cervical cancer in this way and also tended to combine it with other cancers as if to suggest that cancer was simply one disease that could develop in different locations around the body. This will be discussed further in the following chapter. For the present discussion I focus on the perception that 'having cancer in the family' increases a woman's risk of developing cervical cancer and vice versa.

Women discussed the genetic influence of cancer in different ways. The idea was used by some to place themselves as at greater risk due to a family history of cancer, while others used the absence of cancer amongst close family members to distance themselves from the possibility of developing cervical cancer. For the women who discussed a family history of cancer, this had often served to make them more aware of cancer in general and make them more aware of the risks. For example, Christine's father had died of cancer and she discussed how, in retrospect, there were signs that he was ill and if he had had regular health check-ups then his condition may have been picked up earlier. For Christine, this knowledge of her father's cancer had increased her awareness and she talked about how this experience meant that she thought differently about cancer screening from other women who perhaps had not experienced the same thing.

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[59] There is however no specific refutation of this either.

Christine: 'I think that what makes it a big thing for me is that my father died of cancer and in retrospect he had all the symptoms a long time ago...so I think that's why I'm different'

NA: 'different from?'

Christine: 'well I know a lot of people would prefer not to know or they'd prefer not to go and find out, or until they know that something is wrong that's when they go, but I'd prefer to find out' (Christine 20-34 AC)

So for Christine her experience and knowledge of her father's cancer, and his subsequent death, has served to make her aware of the need to have regular check-ups. This is because she holds the view that if her father had been having these regularly then something could have been done for him. As she clearly states, she feels this experience has made her different from other people who may not share her desire to know if anything is wrong. So, while Christine does not draw on a specific vulnerability as such, she demonstrates an increased awareness and is therefore more diligent about screening.

Debbie provides a similar account, in which she relates how a lot of people in her family have died of cancer and the impact that this has had on her feelings towards cervical screening. She indicates a strong commitment to screening for this reason, but also introduces a moral aspect by arguing that if screening is available then people should take up this offer.

NA: 'would you say that cervical cancer is one of your main health concerns?'

Debbie: 'yeah, I think it is yeah'

NA: 'is there any particular reason for that?'

Debbie: 'well not with cervical cancer, but I mean there has been a lot of people with cancer in the family and who've died of cancer erm, so I think anything you can do, you know, to prevent anything developing if there's something there (in terms of screening provision) *then go for it'* (Debbie 35-49 WB)

Both Christine and Debbie use their experiences of having cancer in the family. Noticeably neither is specifically using cervical cancer, to discuss their personal views

on screening and how these experiences and knowledge have influenced these. Both appear to feel vulnerable to cancer in general and so present themselves as committed to the idea that women should have regular check-ups and do everything possible to prevent something developing. Christine in particular explicitly states how she feels her father's cancer means that she feels differently about cancer screening than do other women.

While these two women discuss the influence quite generally, and in a measured way, Zena has a more extreme response. She draws on the idea of a genetic predisposition in particular, while Christine and Debbie talk more generally in terms of 'cancer in the family'. Zena discusses her family history of cancer in a more detailed way than do the previous two women. She told me that,

> *'well every person in my family has died of cancer…my grandparents died of stomach cancer, lung cancer, cancer of the bowel, three of my aunties have got breast cancer, the one that hasn't has had to actually have her breast off, one's had radiotherapy, the other had to have a lump removed. My cousin's now having, two of them have had lumps removed, both of which have not been found cancerous but they've had to have their breasts operated on. Mum has to go for mammograms all the time and genetic counselling. I don't have to go unless my mum develops breast cancer. If she develops breast cancer then I'll have to go, so it's all very sort of big in my family, awareness of cancer and let's just say we've obviously got cancerous genes'* (Zena 20-34 WB)

As can immediately be seen within this extract, Zena engages with the specific genetic aspects of cancer in a more detailed way than either Christine or Debbie. For them, having 'cancer in the family' has served to increase their awareness of cancer in quite general terms and increased their commitment to regular screening. However, Zena's knowledge and awareness of the particular cancers present within her family, and the associated potential risk to her own health, allow her to engage in a more explicit consideration of her own position in relation to cervical cancer, and the potential for her to develop the disease. At the end of the extract she uses the cancer in her family, and ideas around genetics, to construct herself in a very particular way. She states that 'let's

just say we've obviously got cancerous genes'. Her membership of a family with such a prevalence of cancer means that Zena positions herself as at a much higher risk of developing cervical cancer; indeed she suggests that cancer of some kind is almost a certainty due to her 'cancerous genes'. In this way she goes beyond the increased awareness expressed by both Christine and Debbie and positions herself as at a specific and very real risk.

As previously stated, a genetic dimension to cervical cancer is not medically-recognised, and the way in which women's accounts do not take account of this will be discussed in the following chapter. What is of importance here is the way in which Zena draws on her family history of cancer to assert that they have 'cancerous genes' and the way she uses this to position herself in relation to cervical cancer and cervical screening. Perhaps understandably, Zena's views on the risk of developing cervical cancer are very extreme. When I asked about her views on women that did not attend for screening she argued,

> *Zena: 'you're putting yourself at risk by not going and getting it checked out, like if you meet someone who is HIV-positive and he had the choice of using a condom or not and you go 'oh no' then that's what it is'*
> *NA: 'you see that as an equivalent sort of thing?'*
> *Zena: yeah, because you're taking the choice of I can be screened and actually see that I've got a healthy cervix or I can not be screened and find out later on down the line that you've got cancer that could have been easily prevented'* (Zena 20-34 WB)

So the idea that there is 'cancer in the family', or that the family has 'cancerous genes', can heavily influence an individual woman's views on screening and her perceived level of risk or vulnerability to the disease. These three women use their family backgrounds to position themselves as individuals for whom cervical screening is very relevant and cervical cancer a real danger.

In contrast to this, having a family background that is free from cancer was used by other women to position themselves as not at risk of the disease. When I asked Davina if cervical cancer was something that she thought she might get she told me,

'I think a lot of cancers do tend to run in families, you know, like if your mother's had breast cancer then I would, I mean I've had five sisters and none of us have ever had, you know, breast cancer, cervical cancer and I think sometimes it does tend to run in families, you know, I think maybe if three of my sisters had it I probably would have been a bit worried you know, but no' (Davina 50-64WB)

Here Davina positions herself as at low risk of developing cervical cancer and suggests that it is not something that she needs to worry about, and indeed does not appear to. She does this by drawing on the argument that cancers tend to run in families and, as neither her mother nor any of her sisters have been affected, she is unlikely to be. Again I do not intend to focus on the accuracy or otherwise of Davina's argument here, all I aim to do is demonstrate the way in which she uses this theme to go about positioning herself as not at risk.

A second perceived bodily risk upon which some women drew was the idea that the menopause increased cervical cancer risk. In the previous chapter I discussed how, for some women, the menopause was discussed as a period during which cervical screening may be particularly important due to the perception that the body was uncertain and 'risky' at this time because of the changes that the menopause brought about. I explored the case of Julia who explained how she felt more vulnerable during this period of her life and that, therefore, screening had taken on a new significance for her and had the potential to reassure her that the changes she was experiencing were normal. However, it was apparent that Julia was using the example of screening to explore a more general feeling of vulnerability and uncertainty and it is likely that she would feel more at risk of other conditions during this period as well.

In contrast, Vanessa discusses the menopause bringing about an increased risk of developing cervical cancer quite specifically. During our interview Vanessa told me that she had a certain level of mistrust about doctors, based on her own personal experiences, and that she was keen to manage any health problems she had by herself. She told me that she had, as a result, 'done some research' on women's health issues

and considered herself quite knowledgeable on the subject. Vanessa told me that her age (57) made her feel vulnerable to cervical cancer.

> *'They say people my age, because people will be in the menopausal period, so because there are different hormones that no longer function or are not reproducing in the body...so I know that there are hormones that are no longer, they don't have their zeniths or their high points as when you were younger so because of those hormones they now say that you are more likely to'* (Vanessa 50-64 AC)

Here Vanessa draws on, and develops, a theme that was commonly expressed when women were discussing how the menopause makes women more susceptible to disease; that during this time a woman's hormones are out of balance and her body somehow unstable. She explains how the menopause influences hormone production and means that some hormones stop being produced or are not produced in the same quantities as before. Vanessa does not spell out how this causal pathway has been established, but states quite clearly that it means women in this age range are more likely to develop cervical cancer. As with the section above, in which women discuss the potential influence of genetics and family history, I do not wish to go into the medical accuracy or otherwise of these views here. My intention is solely to demonstrate how women employ these themes in a consideration of their personal risk and vulnerability. In this case, Vanessa draws heavily on the link she sees between declining hormone production associated with the menopause and an increased risk of cervical cancer in order to position herself as at risk based upon her age and menopausal status. However, in an interesting contrast to women whose high risk perception meant that they were regular attenders for screening, Vanessa's feelings about her high personal risk are not translated into screening attendance. She had attended in the past, but had had a bad experience and so had ceased attendance as a result. What is interesting here is that Vanessa's high perception of risk is not enough to overcome this past negative experience.

8.3.2 Behavioural risks: sexual activity and leading a healthy lifestyle

As I highlighted in the introduction to this chapter, the information leaflet women receive on screening lists five factors that can make cervical cancer more likely. Three

of these factors relate to sexual behaviour: sex at an early age, not using condoms, and having several sexual partners or a partner who has had several other partners. In contrast to what I have termed 'bodily risks', I would argue that sexual behaviour as a risk factor carries potential implications of individual irresponsibility, and it may therefore be more problematic for a woman to consider herself as at increased risk due to this. I return to the relative acceptability of different risk factors later in this chapter.

While sexual behaviour is discussed and recognised as a risk factor by many women in general terms, there are very few references to it as having increased risk in individual cases. Many women told me that they had started having cervical smears when they became sexually active, but none used their current sexual behaviour to position themselves as at increased risk. In fact the only woman who mentioned her sexual behaviour as a factor that increased her risk in any way was Matilda, and this was only in the context of past behaviour that she no longer engaged in. When I asked her if she considered cervical screening to be an important thing for her she told me,

> *'I think it probably was when I was younger, I was very well aware of the health education programme and also that I was aware of the fact that the more sexual partners you had the more important it was to do and when I was younger I had more sexual partners so I thought 'yes, something I'd better do''* (Matilda 35-49 WB)

Therefore, whilst Matilda is willing to consider her past sexual behaviour as putting her at more risk of developing cervical cancer, and therefore meaning that screening is an important thing for her to do, she contrasts this with her current sexual behaviour and stresses that she now lives in more settled circumstances. She told me that she does not now consider screening to be as important as she once did but said,

> *'I would prefer to continue having screening than not, erm, because of having a wild and rumbustuous past, you know, I know that this increases my risk that err, you know because for a long time now I've lived in settled circumstances I know that my risk hasn't gone on increasing'* (Matilda 35-49 WB)

As I will go on to discuss later, it may be that there are moral implications related to seeing oneself as at risk due to sexual behaviour. Matilda is the only woman within this research who discussed her sexual behaviour as risky in any way, and this was limited to her past behaviour at a younger age, and is contrasted with her present more settled circumstances.

In light of this it may be easier to employ sexual behaviour as a factor that reduces an individual's risk of developing cervical cancer. Maureen (50-64 WB) told me that she does not feel particularly at risk as there is no cancer in her family and she is not currently sexually active. For Maureen her current sexual inactivity means that her risk is not so great as for other women. She explicitly went on to tell me that she would feel more at risk of developing the disease if she were very sexually active and had lots of different partners. Maureen has therefore considered the increased risk associated with sexual activity, particularly having several partners, and used her contrasting behaviour to position herself as at less risk of developing cervical cancer based on her current personal circumstances.

Zahida, a 53-year old South Asian woman I interviewed, also employed her lack of sexual activity to position herself as not at risk of developing cervical cancer. However, in this particular case the process of self-positioning was influenced by other important factors. Zahida told me that she was familiar with cervical screening and had had two smear tests taken, both of which had been normal. However, very early in the interview she began to tell me that she kept receiving letters asking her to go for her next smear test and that she was 'sick of them'. Further discussion revealed that Zahida was frustrated by these letters as she had been for the test and nothing was wrong therefore, in her mind, there was no further need for her to attend. This was further influenced by the fact that Zahida was a widow and not sexually active. She drew on her identity as a Muslim woman strongly here to emphasise that, as her husband had died, she would no longer be sexually active and to draw a distinction between herself and other, presumably non-Muslim women.

'I'm not like other ladies and going with other men, I stick with one man, I've been twice and there is nothing there and now I have no husband because he has died so I have no sexual relation with anyone so after going twice I don't need them now' (Zahida 50-64 SA)

Zahida's particular case is very interesting as it combines several factors which lead her to demonstrate a particular form of resistance to cervical screening and the general medical discourse that surrounds it. Firstly, Zahida is certain that two normal smear tests mean that she no longer needs to attend for screening, as they have demonstrated that nothing is wrong. This is further influenced by her lack of sexual activity and the way in which she draws on her identity as a Muslim woman to emphasise that her sexual activity was limited to her late husband and to draw a boundary between herself and 'other ladies' in this respect. While this is not necessarily demonstrated in the extract above, it was clear within the context of the interview that not being like 'other ladies' meant women who were not from the same religious and cultural background and so who behaved in different ways. In common with the Muslim women discussed in the previous chapter, Zahida employs her religious identity to work out her own relationship to cervical screening. This, combined with her understanding that two normal smears means that everything is fine, ultimately leads her to the conclusion that cervical screening is irrelevant to her. As will be seen later in this chapter, Zahida is one of the small group of women who have taken, or who plan to take, steps to tailor their cervical screening participation to their personal feelings of risk or vulnerability.

A second behavioural risk that women drew upon concerned their general health status and whether they pursued a healthy lifestyle. It is perhaps not surprising that when considering the risk of developing a particular disease women consider their general health status. There are several examples of women within my research doing this and emphasising the steps they took to maintain their health. Many women, both generally and in some detail, discussed the steps they took to look after their health, including eating a balanced and varied diet, not smoking, only drinking in moderation and taking regular exercise.

During my discussion with Audrey I asked her whether cervical cancer was a main concern of hers and if she felt particularly vulnerable. Audrey immediately drew on the

theme of general health and told me how she had always been very, very healthy and that, apart from what she called 'niggling small things', her health had not been a big issue and perhaps this was why the possibility of developing cervical cancer was not of concern to her. Audrey began by describing herself as fortunate to have had such good health throughout her life, but later emphasised her healthy lifestyle in terms of not smoking, not drinking a lot and eating healthily. This therefore changed the emphasis from being fortunate to have good health towards having worked hard to achieve this good health. When considering her risk of developing cervical cancer, Audrey drew particularly on the theme of taking individual responsibility to keep herself well and healthy in order to minimise her risk. She told me,

> *'I don't smoke, I don't drink a lot, that's not to say that you don't enjoy yourself or whatever, but we* (her family) *try to eat healthily and therefore, because you're doing these things, hopefully you're looking after your body'* (Audrey 50-64 WB)

Audrey therefore draws on the measures she takes to safeguard her health to suggest that, because she has taken this responsibility to look after herself, she has less need to be concerned about potentially developing cervical cancer. Of the five risk factors specifically set out in the information leaflet *Cervical Screening: THE FACTS*, Audrey touches on only one in her account. She mentions that she does not smoke, however, this is almost certainly in relation to the general damaging effect of smoking rather than in specific relation to positive smears being more common amongst smokers (Haslett, 1994) or a higher risk of cervical cancer (Ylitalo *et al.*, 1999). In this consideration Audrey makes no mention of the three sexually-based risk factors detailed in the leaflet, instead she relies on the measures she takes to look after her general health being enough to protect her. She seems to be suggesting that, as she looks after her health, she does not 'deserve' to develop the disease.

8.4 Considering Risk Themes

In this section my aim is to further develop the discussion of the risk factors explored above and to consider such issues as their relative status, acceptability and origins. To reiterate, the risk themes under discussion in the chapter are, firstly, those which I have

termed bodily risks, specifically genetics and the impact of the menopause, and, secondly, behavioural risks, specifically sexual activity and leading a healthy lifestyle.

The first of the themes explored, genetics/family history, was used by some women to position themselves as at little risk of developing cervical cancer while others, most notably Zena, used the theme to place themselves as at increased risk. For Zena we saw that the idea of 'cancerous genes' was important to the way she thought about her risk and what cervical screening meant to her as an individual. In this way Zena drew some sort of boundary between herself and those without a family history of cancer. What is interesting is that the theme of genetics allows Zena to construct and position herself as at risk in this way without opening herself up to charges of irresponsibility and a failure to protect her health. Her assertion that her family have 'cancerous genes' serves to remove any sense of individual responsibility for the development of disease.

This is not to suggest that there are no elements of responsibility within the context of genetic risk, as work in this area has highlighted the responsibilities and obligations that stem from the identification of such a risk. Hallowell (1999) has researched women attending genetic counselling for hereditary breast/ovarian cancer and argues that, while genetic risks are constructed as 'internally imposed involuntary health risks' (1999:599), this does not absolve the individual of responsibility for their health. Women in this situation saw themselves as having a responsibility to their families to establish their risk and to take appropriate action to manage it. In addition, there are issues around being responsible for passing on their, and potentially their partner's, 'faulty' genes, a responsibility which, it is argued, is almost exclusively borne by women (Steinberg, 1996). Polzer *et al.* (2002) have also explored individual responsibility for genetic risk and have situated genetic testing as a neo-liberal technique of governance. By fulfilling the obligations of determining and managing their risk, individuals can construct themselves as healthy and responsible citizens. However, I would argue that while these responsibilities for the identification and management of genetic risk do undoubtedly exist, and could be extended to the responsibility of women in this situation to attend for regular screening, this is not the same as being ultimately responsible for the condition in the first place. How can an individual be held accountable for something which they have inherited? By definition, it has come to them from others and through a process over which they can have no

control. The theme of genetics and family history was therefore used by different women to both increase and decrease their likelihood of developing cervical cancer without opening up the potential for individual blame.

In contrast to the status of genetics, risk factors associated with sexual activity occupy a different position and have a different status. I have suggested that this theme is morally charged in a way that genetics is not. Identifying oneself as at increased risk of developing cervical cancer due to one's sexual activity potentially attracts charges of irresponsibility and fecklessness, particularly, it might be argued, for women. The sexual behaviour of women is still subject to greater social scrutiny than men's and therefore women may have to consider the potentially negative consequences of identifying themselves as at increased risk of cervical cancer on this basis. In comparison to the genetic theme, there is potentially a stigma attached to drawing on this theme to increase one's personal risk. Notably, although many women demonstrated an awareness of the ways in which sexual activity influences cervical cancer risk, none of them drew upon their current sexual activity to position themselves as at risk, the only woman who discussed her 'risky' sexual activity was Matilda, and only then in the context of past behaviour and whilst taking care to stress that she had for some time now lived in more 'settled circumstances'. In contrast, several women told me that their current sexual inactivity meant that they were at little or no risk of developing cervical cancer.

It is therefore the case that, within this research, sexual activity is almost exclusively used only to minimise cervical cancer risk. It may of course be the case that none of the 35 women I interviewed engaged in sexual activity that would put them at increased risk. All I do here is suggest that it may be potentially problematic for women to identify and position themselves in this way. This is because, in contrast to the status of genetic risk, sexually-acquired risk is morally charged and potentially carries implications of individual responsibility and blame. In a similar way, failing to pursue and maintain a healthy lifestyle can also leave women open to charges of irresponsibility, this time in relation to failing to take adequate measures to protect their health. As I highlighted in Chapter 3, writers within the New Public Health perspective in sociology have argued that health has come to be a central concern of contemporary society. As such, the achievement and maintenance of good health has become

inextricably tied to the status of the individual as a good and responsible citizen. Opening oneself up to charges of irresponsibility through claiming an increased risk of disease on the basis of poor health or risky sexual activity is therefore problematic.

I would therefore argue that the risk themes identified in this chapter occupy very different positions in terms of their relative social acceptability and status, and are therefore likely to be employed differentially on this basis. It is more acceptable to draw upon a genetics theme than current sexual behaviour to position one's self as at increased risk of developing cervical cancer, as this theme carries with it little or no individual responsibility for the actual development of the disease. Therefore this theme is used freely by women to either increase or decrease their personal risk. In contrast sexual activity and health status are treated much more carefully, being almost exclusively used to minimise risk.

From the above discussion, it is clear that women do not simply adopt the general 'at risk' status suggested by the medical information material, and reinforced by the universal approach to screening for all women within the 20-64 year old age group at the time of the research. Instead, women engage in a more active, personalised and individual consideration of their cervical cancer risk, based largely on the themes discussed above, that serves to establish and develop their position in relation to both the official medical discourse on screening and to other women. However, as I discussed in Chapter 3, Foucault (1984c) argues that the means through which the individual works out this relationship are not simply invented by the individual themselves, instead they are models that are found within society and are proposed, suggested and imposed upon the individual. While individuals are not free to create these means, they have the potential to use them creatively. For example, in a study of how pregnant women in the US accounted for their decision to refuse prenatal screening, Markens *et al.* (1999) discuss the women's employment of the biomedical concept of risk and stress the importance of women's interpretation and application of biomedical concepts.

If we consider the themes drawn upon in this research we can begin to identify the areas from which they are drawn. I have discussed how some women drew upon ideas of genetics and family history when considering their risk, although cervical cancer is not

one of the cancers thought to have a genetic influence. However, whilst there is no mention of genetics within the material on cervical screening, some forms of breast cancer are specifically discussed in terms of genetics and some have argued that our society is becoming more and more 'geneticized' with an ever-increasing number of human problems being seen through a 'genetic lens' (Conrad, 1997). Media reports that scientists have isolated the 'gay gene' or the 'obesity gene' serve to simplify the complexity of genetic association and causation (Conrad and Gabe, 1999) and so it is perhaps not surprising that lay women seek to understand cervical cancer risk through this means. For Zena, who talked in terms of her family having 'cancerous genes', this increased media and societal focus on the genetic aspect to many medical conditions has been reinforced by her family's strong history of cancer. Therefore it is almost inevitable that Zena will draw upon a genetic theme when considering her personal risk of developing cervical cancer.

Women's use of the menopause is also interesting, as again there is no mention of this within the official material as increasing a woman's risk of developing cervical cancer. However, much has been written on the increasing medicalization of the menopause, and also cultural images of menopausal women, and it is perhaps the combination of these that constructs the menopause as a risky and uncertain time in women's minds, leading them to position themselves as at more risk during this period.

The consideration of sexual activity as a risk theme is not unexpected as the information leaflet women receive lists this explicitly. If women are told that cervical cancer is more common if they first have sex at an early age, do not use condoms and have many different partners or a partner with several partners, then it is not surprising that they will draw upon this theme when considering their own risk. What is of interest is the very specific way in which this is employed.

Finally, as I have suggested, maintaining one's general health is a dominant health promotion message in our society and many women within the research made connections between their good health and disease prevention.

Therefore, although many of the themes that women draw on when considering their risk, and positioning themselves accordingly, are not contained within the medical

information on cervical screening specifically, they can be identified in other aspects of medical and health promotion discourse and within society more widely. It is therefore the case, as Foucault (1984c) suggested, that individuals do not bring these to the arena independently, instead the women here are transferring and employing themes suggested to them in other contexts to actively work out their risk and position in relation to cervical cancer and screening.

8.5 Impacts on Participation

In the previous chapter we saw that the techniques of resistance employed by women to individualise the general medical discourse on screening were predominantly limited to the level of talk; they were not translated into behaviour in terms of influencing women's attendance for screening or their conduct during encounters with health professionals. To a certain degree the same limitations can be seen with regard to the resistance strategies shown in this chapter. The majority of women who regard themselves as at little or no risk of cervical cancer still continue to attend regularly for screening, suggesting that perhaps risk perception is not an appropriate means of thinking about attendance in these cases. It may be that the particular way in which the NHSCSP is structured, i.e. an opt-out programme that assumes attendance, means that responsibility or 'moral obligation' (Howson, 1999) are more appropriate concepts within which to frame attendance. The decision to attend for screening based upon a personal assessment of risk will be much more apparent within a programme structured along opt-in lines, in which an individual makes a conscious decision to attend due to a perception of risk. For example, in a study of decision-making about attendance for bowel cancer screening (not currently a nationally co-ordinated programme), McCaffery *et al.* (2001) found that perceived low susceptibility to the disease, based upon current health status, family history or absence of any symptoms, was an important factor in the decision to decline the offer of screening. People making this decision therefore drew on similar themes to the women in my research, for example general health and family history, to make an assessment of their risk of developing a particular disease. It is unlikely that the people declining bowel cancer screening were any more determined to demonstrate resistance, through tailoring attendance based on risk perceptions, than the women in this research. What is more likely is that the differing structures of the screening arrangements, and the implicit assumptions about attendance that follow, mean that those considering bowel cancer screening are more able to refuse this

screening based on low perceptions of risk than those asked to attend for cervical screening. In many ways the routine nature of cervical screening, and the in-built expectations of attendance, mean that a conscious decision to attend based on personal risk perception, or anything else for that matter, is simply not necessary. In many women's minds attending for cervical screening is something that one just does (Bush, 2000; Forss *et al.*, 2001).

However, it would not be fair to say that perceived risk has no impact on women's screening attendance. Despite the majority of women in the research continuing to attend for screening regardless of their personal risk perceptions, there is a small, but nevertheless interesting, number that have tailored their attendance based on their personal feelings of risk and vulnerability. These considerations of personal risk draw upon some of the themes discussed above and lead women to base their screening attendance upon these criteria. In what follows I explore how this can lead women to both attend regularly or reduce their attendance.

8.5.1 Maintaining high attendance

Two women who explicitly linked their regular attendance to their personal assessments of cervical cancer risk were Matilda and Zena, both of whom were discussed above as specific examples of different themes being used to increase risk. Matilda drew on her past sexual behaviour, while Zena focused on her family's 'cancerous genes'.

Matilda, although taking care to stress that she had for some time lived in more 'settled circumstances', recognised that her past sexual behaviour had put her at increased risk and, although she perceived that her risk had not gone increasing over the past few years, she said that she would rather continue to have screening because of this past behaviour. As a result Matilda was a regular attender for screening and this, coupled with the emphasis she places on her current circumstances, serves to further reinforce her current responsible approach compared with her past behaviour.

Zena had also been a strict attender based on her perceived high risk, this is despite a very bad smear test experience she told me about that resulted in heavy and prolonged bleeding and led her to make a complaint about the smear taker. In fact so at risk did

Zena feel that, instead of waiting for the automatic invitation letter to first arrive, she took herself to the doctor's as soon as she became sexually active at the age of 16, as she had read that screening was necessary for all sexually active women.

As I have previously suggested, it may be easier for women to tailor their attendance based on a perception of increased risk as this is the anticipated behaviour within the programme. Women are simply doing what is expected of them. If cervical screening were organised along opt-in lines then the conscious decisions Matilda and Zena have made would be more apparent and not masked in this way. Given the structure of the NHSCSP, it is perhaps more interesting to examine women who have gone against expectations and have either reduced or ceased their attendance for screening.

8.5.2 Reducing or ceasing attendance

In contrast to those whose tailored attendance fits with that expected, it may well be more difficult for women to reduce or cease attendance based on perceptions of personal risk. While many women who told me that they felt at little or no risk continued to attend, it is unlikely that all of them would do so in the context of an opt-in programme. Indeed, they may never have participated at all given that they would have had to make a conscious decision to attend, that research has suggested is likely to be based on perceived susceptibility.

Maureen and Zahida were both also discussed above and had both, although for slightly different reasons, tailored their screening attendance according to their perceived low personal risk. Maureen, based on current sexual inactivity and no family history of cancer, did not feel at risk. This particular case is interesting as, although Maureen felt that you should take advantage of any medical tests available and the fact that this view had been reinforced by two friends' recent diagnoses of gynaecological cancer, her personal risk perception was still the dominant factor in determining her level of attendance.

Maureen had not ceased to attend completely, rather she had reduced her attendance to every other time she was invited, meaning that she was now being screened at least every 10 years instead of at least every five, which is the current guidance. It was

apparent that, given her perceived low risk, Maureen felt that this was an adequate level of screening for her.

Zahida's view of her risk as not only reduced but non-existent was as a result of her previous two smear tests being normal, and her husband's death meaning that she was no longer sexually active. She drew on her religious and cultural identity to stress that, unlike other women, she would not be sexually active again. Zahida told me that, while she had felt a little embarrassed during her previous smear tests, she had experienced no physical pain and that, because she had given birth to four children, she was used to that kind of internal examination and it therefore posed no problems for her. It was therefore her perceived non-existent risk of cervical cancer, and her opinion that it was utterly pointless for her to attend, that was the driving force behind her decision. She was ignoring the reminder letters that arrived at her home and seemed to suggest that they must be being sent in error as she simply could not understand why she would need to attend and therefore why they were being sent out. She repeatedly asked me why she was receiving letters when they did not apply to her. I responded by saying that it was simply routine and that the letters were sent automatically. Zahida told me that the next time she went to see her GP she would tell him to stop sending the letters.

Therefore, although these women are a very small minority, they do show that it is possible to employ one's personal perception of cervical cancer risk to tailor screening attendance accordingly. It may be the case that the opt-out nature of the NHSCSP, and the expectation and 'moral obligation' that women feel, mean that others do not feel able to tailor their attendance in this way. Alternatively, women may not feel confident enough in their own assessment of their risk to translate this into a different level of attendance. Some women suggested that others may not have enough information, particularly about their partner's sexual behaviour, to make an accurate assessment. For this reason they may continue to attend routinely 'just to be on the safe side', but again this is unlikely to be the case with an opt-in system. The current arrangements for cervical screening permit this routine attendance that appears not to be based on any kind of conscious decision. In cases where participation is opt-in this routine of receiving letters and attending, without ever having to signal an interest or intention, does not apply.

8.6 Conclusion

At the outset of this chapter I explored the potential for seeing risk as one of the strategies employed within neo-liberal forms of government, and referred back to theoretical literature of this kind introduced in Chapter 3 in order to consider how risk links back to the importance of expertise and the role of experts in encouraging individuals to conduct themselves in particular ways. It is therefore possible to conceive of risk as a governmental strategy employed to encourage particular ways of thinking and behaving amongst individuals. However, by drawing on work exploring how individuals engage with ideas around risk, and how they understand and respond to them, I suggested that this governmentality perspective on risk, in common with the kinds of work discussed at length in Chapter 3, is in danger of focusing too much attention on the discourses and strategies employed to discipline individuals at the expense of exploring how they respond to these. In this way, resistance was framed in terms of how individual women within my research refused the general 'at risk' position suggested to them through the official discourse on screening, and that is reinforced by the universal approach to screening adopted, and went about working out their own position in terms of their perceived risk of developing cervical cancer.

In the main body of the chapter I outlined and considered the different themes that women draw on when considering their personal risk of developing cervical cancer and how these impact upon how they think about cervical screening. The two types of risk focused upon here were, firstly, bodily risks, comprising genetics/family history and the menopause, and, secondly, behavioural risks, comprising sexual activity and general health status. Aspects of these were used in differing ways by women, with some drawing on a theme such as genetics to increase their personal risk, while others drew on their family history to suggest that cervical cancer was not something they should be worried about.

A consideration of the relative status and acceptability focused on how, in comparison to the uses of the two other themes, sexual activity as a risk factor was only used to minimise personal risk in terms of considering current sexual behaviour as decreasing one's risk. An exception was Matilda who discussed her past sexual behaviour as putting her at risk, however this was limited to **past** behaviour. I therefore suggested that the particular theme of sexual activity was used much more carefully than others as

it may be seen as morally charged. Women may be concerned about how others will view them, indeed there may be implications for a woman's self-identity, of placing herself as at increased risk on this basis. The notion of sexually-acquired risk may therefore be particularly problematic.

It is interesting to consider the selective use of risk factors, and their origins, in terms of thinking about resistance as a dynamic process of risk assessment that does not necessarily fit with that contained within the official discourse. Risk associated with sexual behaviour was discussed by many women and, given that this figures prominently in the information leaflet, this is not surprising. However, the other main themes discussed, genetics/family history, general health and the menopause, are not explicitly covered in this leaflet and so have been brought to the arena from elsewhere. The chapter considered how these are dominant themes within contemporary society, and more specifically within health promotion discourses, and therefore women do not create these themes independently. Instead they are suggested to the individual and employed creatively by them in their considerations of their personal risk.

The argument running throughout this chapter has therefore been that individual women respond to the presentation of risk within the official discourse in diverse and dynamic ways, and that to focus simply on how the notion of risk can be employed to discipline individuals is misguided. Through exploring how women work out their own individual positions in relation to cervical cancer risk I demonstrated that they are generally reluctant to accept the official presentation of a general 'at risk' status and so resist through pursuing their own understandings and ways of thinking about cervical cancer risk and what it means to them. In common with the previous chapter, the resistance here was mainly at the thought or talk level and appeared to be influenced by the social acceptability of different risk factors. Although there was a clear focus on sexual activity as a risk factor, it was not adopted as a factor currently increasing personal risk by any of the women interviewed. It may of course be the case that none of the women was actually in this position, but there is also clearly the potential that they were reluctant to position themselves in this way due to the social unacceptability of risky sexual behaviour and being seen as responsible for their own risk. As I argued, individuals are much more likely to position themselves as at risk of those risk factors that are not individually controllable. I would argue that discourses on risk are

interpreted and understood not simply in terms of individual notions of risk, and whether or not they are relevant to them personally, but also by perceptions of how society is likely to view such risks.

Ultimately, the NHSCSP may not be overly concerned with how individuals think about and understand risk factors so long as attendance remains high. Therefore, for example, it may not matter whether or not women are reluctant to identify themselves as at increased risk due to risky sexual activity, or how they position themselves in relation to cervical cancer risk, provided they continue to attend. The current uniform approach to screening, and the opt-out nature of the programme, means that it is not stigmatising to do so[60].

Although I have demonstrated that the majority of resistance within the context of risk is demonstrated at the thought or talk level, there are notable exceptions to this. While the universal approach to screening, the opt-in nature of the programme and the consistently high attendance rates meant that cervical screening was an unlikely case through which resistance would be in the form of behaviour, there was a small minority of women who pursued their personal position in relation to cervical cancer risk through into behaviour. As I argued within the chapter, due to the nature of the programme the most visible of these are those women who reduce or cease screening attendance on the basis of their perceived risk. These women rejected the general 'at risk' status present within the official discourse and resisted the regular calls to attend for screening that they received.

It is apparent that individual women do not simply accept the general way in which cervical cancer risk is presented to them within the official discourse. Instead they actively engage with them and interpret and understand them in particular ways, which do not always fit well with medically recognised risk factors or ways of understanding and thinking about risk.

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[60] Although the potential incorporation of HPV-testing to identify those at high risk for whom screening is most important may impact upon this.

Chapter 9

Creating a Rational Framework of Understanding

9.1 Introduction

In the latter stages of the previous chapter I explored the different ways in which some women bring risk factors, other than those contained within the official material they receive, to bear within discussions of their personal perceptions of risk and vulnerability to cervical cancer. In the present chapter I further develop and expand upon this in order to explore how women engage with the information that they receive on cervical screening and cervical cancer in the context of the NHS Cervical Screening Programme (NHSCSP) in order to understand and make sense of it in ways that are meaningful to them. As such, a different kind of data is presented here than that within the previous two chapters. There the focus was on women resisting the general, official discourse on screening and risk through the consideration and employment of their personal experiences and contexts. In this chapter the focus is less on the individual and comes from women thinking and talking more generally. Here women are moving beyond the context of themselves as individuals and are engaging with screening, and the official discourse surrounding it, in a more general way.

The chapter is concerned with how women make sense of the information with which they are presented, largely through the information leaflet analysed in Chapter 6, and how they attempt to fit all of this together into some kind of rational framework. This notion of a framework comes through the way in which many women engaged in constructing links, or building bridges, between particular pieces of information, therefore filling in the gaps they perceive so that the information forms a coherent whole that makes sense to them. Women therefore demonstrate active imagination through the production of explanations and pathways between established pieces of information, and the selective omission or rejection of items that do not fit within their framework.

Women are working within different kinds of contexts and with different kinds of resources or evidence, for example in contrast to doctors employing epidemiological evidence or policy makers using cost-effectiveness information. The ways in which

women understand the information, the bridges that they build and the explanations that they produce can therefore vary enormously and frequently do not fit well with the official discourse or with medically recognised explanations or causations. Therefore, while making sense of the information presented to them, and attempting to fill in the gaps that they perceive, women can produce very different conceptualisations of, and discourses upon, screening, cervical cancer and the current screening provision. These can vary enormously from those contained within the official discourse.

In this way, resistance comes through women's active engagement with the information presented to them and their determination to make sense of it by attempting to fit it all into some kind of rational framework that is meaningful to them and 'links up' all the pieces of information by building bridges to fill the perceived gaps. The kinds of resources that these women draw upon throughout this process vary widely and can lead to the production of a range of conceptualisations and discourses. This further reinforces the point I have made throughout this thesis that resistance is not a uniform process that produces homogenous results. Instead, the employment of different resources potentially leads to variations in interpretation and understanding, which can ultimately lead to very different outcomes.

In casting the processes discussed within this chapter as resistance I again make reference back to the theoretical work on the potential for resistance, and the forms it may take, that were discussed in Chapter 3. I employ the work of Riessman (2000) on transformative effects to explore how the employment of different resources, in order to build bridges and fit everything into a rational framework, can be framed as resistance. These resources, or ways of making sense, represent the means through which alternative conceptualisations and discourses are produced and maintained. As such they are also the means through which a space is opened up between discourse and the individual and the relationship between the two develops the potential to become more complex than one of straightforward imposition. This idea is at the heart of Foucault's exploration of how resistance may be possible (Foucault, 1984b&c, 1988; McNay, 1994; Burchell, 1996). Through the opening up of such a space, the individual can engage more critically with discourse rather than simply accepting it and being controlled by it. In this way, the individual can become more active through considering the kinds of information or ways of thinking contained within the discourse and

ultimately regarding them as valid or invalid on particular criteria. Thus, lay women engage with particular aspects of the official discourse, such as risk factors, cervical cancer incidence and causation, or screening provision, and make sense of them in particular ways whilst attempting to fit them into a rational framework through which they can understand cervical screening and the cancer itself.

Within the chapter I cover four main areas. Initially, I briefly return to the existing sociological work on lay and professional perspectives on health introduced in Chapter 4. This is important as it 'sets the scene' for the forthcoming discussion by summarising the key themes within this important area and alerting us to important issues that need to be borne in mind during the chapter. The relative construction and development of the two kinds of perspective, including the basis of each, the kinds of evidence accepted and incorporated and the purpose that each serves, will all be considered. However, this is not to suggest that lay and medical perspectives can be neatly divided into two discrete and separate categories. Instead, the growing literature on the overlaps and 'grey areas' between the two will be discussed as the chapter considers the points of convergence and the potential for points of slippage or divergence between them.

In moving on to consider specific examples from my research, the chapter begins by exploring how women understand and make sense of cervical cancer risk factors and disease causation. The discussions of risk factors in this context are very different from those in the previous chapter, where they were explored in terms of how individual women employed them in order to work out their position in relation to the risk of cervical cancer development. In the current context I explore how women make sense of risk factors and disease causation and understand them in different ways. During the research interviews it was immediately apparent that women take up, and 'validate', some of the risk factors set out in the official material, while others are apparently ignored or rejected. In addition, as was seen to a certain extent in the previous chapter, some women bring risk factors to bear on cervical cancer that are not present within the material and do not fit with those medically recognised. The chapter both explores how and why risk factors are differentially treated and also the way in which women can take up a medically recognised risk factor, such as sexual activity, but interpret and understand it in such a way as to make it 'incorrect'.

Moving on from risk factors and disease causation, the chapter widens to consider women's perceptions and understandings of cervical cancer in particular, and cancer in general. This is important as perceptions of cancer, both generally and specifically, can influence how cervical screening is understood and thought about. Issues around the perceived incidence of cancer, the linkages between different types of cancer and the speed of development can all have important implications for women's views on cervical screening provision and the structuring of the NHSCSP.

This leads in to the final section of the chapter, which considers how different women think about and employ their lay understandings and how their attempts to fit all the information they receive into a rational framework leads them to regard the NHSCSP. This is in terms of the wider concerns around how women may demonstrate resistance to the official discourse on cervical screening. Areas of interest here include whether women are aware of the divergence between their understandings and the official discourse, how this divergence is accounted for and, finally, whether women acknowledging their divergent views and understandings use these as a challenge.

This then allows the chapter to conclude with a consideration of how lay women's interpretations and understandings, and their attempts to fit all of the information they receive into a rational framework by linking it up to form a coherent whole, can be framed as resistance. What can this particular example tell us about the nature(s) of resistance and technologies of the self when compared to the two previous chapters, which dealt with very different kinds of data?

9.2 Lay and Professional Perspectives on Health
Lay and professional perspectives on health were discussed in general terms during the review of the relevant empirical literature in Chapter 4. In this section I adopt a more targeted approach and consider the sociological material on lay and professional perspectives on health in relation to how women make sense of the information of cervical screening that they receive. I begin by exploring the relative natures of both perspectives, their characteristics, purposes and the sorts of evidence that each accepts. However, it is vital to bear in mind that lay and professional perspectives are not two distinct bodies of thought, and so the influences, overlaps and similarities will also be discussed. Following this, I briefly consider the different terms used to discuss lay

perspectives on health and illness, for example the increasing use of 'lay health knowledges' rather than 'lay beliefs'. I explore the relative appropriateness of these terms and the connotations and assumptions that each carries. I consider which of these terms is most appropriate in the context of this particular chapter. Finally, I outline how I deal with lay and professional perspectives in the chapter, how each is characterised and operationalized.

9.2.1 Nature of lay and professional perspectives

Lay perspectives on health and illness are of interest to medical sociologists both in terms of the meanings individuals attach to health and illness and the differences between lay and professional ways of knowing (Brown, 1992; Popay and Williams, 1996; Popay *et al.*, 1998; Williams and Popay, 1994). How individuals come to understand a particular illness or disease, together with their perceptions of disease causation and the available treatments, can play a central role in determining how they account for illness misfortune and how they assess the potential benefits of various preventive health behaviours (Davison *et al.*, 1992).

Williams and Popay (1996) have argued that lay perspectives on health and illness are very different from professional ways of knowing, although they suggest that lay ideas should not necessarily be seen as inferior as they can be equally complex and sophisticated. The differences emerge because lay people and professionals produce knowledge in different ways and to different ends. Popay *et al.* (1998) have argued that the distinctive nature of lay perspectives stems, to some degree at least, from their specific ontological purpose. This is because, in contrast to the professional, the lay person constructs their perspective in order to help them understand what is going on around them and to orient their behaviour accordingly. Popay *et al.* (1998) argue that lay perspectives are frequently expressed in narrative form and are therefore antithetical to traditional models of cause and effect. This finds support in Blaxter's (1983) well-known research into women's concepts of disease and disease causation. Here she draws attention to a number of important features of the women's talk: the need to know about the causes of disease, the importance of producing a rational explanation and the importance of linking together life events in order to establish reasons why disease affects certain people and in certain ways.

Lay and professional perspectives therefore serve very different functions. The development of professional medical knowledge is rooted in the concept of disease, while the development of lay knowledge is firmly rooted in the experience of health and illness (Williams and Popay, 1994). However, it should not be assumed that lay and professional health perspectives occupy distinct and separate spheres. The complexity of lay perspectives on health and illness is increasingly becoming appreciated, and lay ideas may well incorporate expert knowledge or expert medical concepts and vice versa (Helman, 1978; Shaw, 2002). Indeed, a range of research has demonstrated the ways in which what appear to constitute lay perspectives on health and illness in fact incorporate medical ideas and concepts, albeit in altered forms (see for example Davison *et al.*, 1991; Gold and Ridge, 2001; Markens *et al.*, 1999). This leads Shaw (2002) to argue that the very concept of 'lay beliefs', defined as those not explicitly derived from the conceptual framework of medicine (Hughes, 1968), is invalid. This is because the public is so surrounded by professional messages and concepts of health and illness that it is difficult to see how, at least in contemporary Western society, lay ideas could develop independently of these. However, while it is highly likely that lay thinking on health and illness will be influenced to some degree at least by medical concepts and explanations, this professional medical influence is almost inevitably interpreted, and made sense of, in terms of everyday life experience (Davison *et al.*, 1991). Such an argument leads back to my initial assertion, in the introduction to this chapter, that the ways in which lay individuals make sense of the official information with which they are presented, and the means through which they do so, can be framed as resistance through the active engagement with such information and how it is dealt with.

9.2.2 Terminology

The kind of terminology or language employed when discussing lay perspectives on health and illness has important implications for the ways in which these are perceived and the relative status attached to them. In examining the changing representations of lay perspectives on health and illness, Prior (2003) has charted the interesting changes in the language employed. Prior argues that there has been a discernible shift from talking in terms of 'lay beliefs' to regarding these as 'lay knowledges'. In a similar vein he highlights the apparent shift from a concern with lay concepts of aetiology and disease causation (see for example Blaxter, 1983), towards a focus on lay or popular epidemiology (Brown, 1992; Davison *et al.*, 1991). This changing language

undoubtedly has implications for the way in which these lay ideas or perspectives are regarded. As Prior argues,

> …my feeling is that the change of language indicates the emergence of an entirely new organism. Epidemiology, after all, is a form of highly-skilled practice and quite different from having some (untested) ideas about what may or may not cause a disease. In a similar way, the concept of belief has a far less sturdy status than the concept of knowledge (Prior, 2003:44).

Prior is keen to stress the limits of lay knowledge, and particularly expertise, in the context of health, illness and medicine, calling for a re-assessment of what lay individuals can offer and drawing a boundary around the domain of expertise. Prior argues that the concept of an expertness amongst the lay population has been circulating within medical sociology for some time, but questions exactly how lay people **are** expert. He accepts that individuals can have extensive knowledge of their own lives and can also (indeed sometimes they have to) turn themselves into experts in order to challenge medical hegemony. However, for the most part, Prior argues that lay people are not experts as they are rarely skilled in 'fact gathering' for example, and can often just be plain wrong. The thrust appears to be that, while lay people can be expert in their experience of a particular condition, this does not mean that they are expert in that condition *per se*, for example through skill or experience in the analysis of epidemiological data.

This concern with who can, or should, be seen as the rightful holders of expertise leads back to the discussion, in Chapter 3, around the importance of expertise for neo-liberal forms of government. Within these, expertise is seen to provide a solution to the apparent opposition between the need to govern on the one hand and at the same time to limit such government in the interests of liberty and economy (Rose, 1992, 1996, 1998). The point here is that individuals do not possess this kind of expertise, they have to rely upon experts for guidance on how to conduct themselves, therefore binding subjects to experts in new ways and positioning expertise as central to the process of self-formation. However, what I seek to explore in this chapter is how the process of women interpreting and making sense of cervical screening and cancer can lead to them constructing and maintaining very different ways of understanding, and therefore

resisting through an active engagement with the official discourse instead of simple acceptance.

9.2.3 Lay and professional perspectives in this chapter

In the context of this chapter the material contained within the information leaflet *Cervical Screening: THE FACTS* will be taken to represent the official, professional perspective. This is not to suggest that the medical community has a uniform and uncontested view on cervical screening. As was shown in the review of the policy in Chapter 2, there are those who have their doubts about screening in general (Stoate, 1989; Shickle and Chadwick, 1994), about cervical screening in particular (Moss, 1996; Narod *et al.*, 1991; Van Oortmarssen and Habbema, 1991), and those who disagree over the way in which the NHSCSP is, or should be, structured and organised (see for example Cruickshank, 2001; Phillips and Whynes, 2001; Waugh and Robertson, 1996). However, individual lay women invited to attend for cervical screening are unlikely to be aware of such debates. During the interviews carried out for this research I asked women about where they got information about screening from. By far the most common source were the information leaflets sent to them and/or that they picked up in their doctor's surgery. A much smaller number mentioned seeing things on television or in newspapers and magazines, but these tended to involve incidents regarding the mis-reporting of smear test results in a particular area. I have therefore chosen to adopt the information contained within *Cervical Screening: THE FACTS* as representing the official discourse on screening and as that which underpins the NHSCSP itself. In addition to this, when I turn to examining the 'medical correctness' of lay women's ideas on cervical cancer and screening, I incorporate further material taken from the very informative website of the NHSCSP and from wider research on cervical cancer and screening. However, these are only employed as secondary material as, while it is possible that an interested individual may have visited the website for further information, none of the women I interviewed indicated that they had done so and it is still more unlikely that lay women are aware of the research evidence on cervical cancer and screening. Again, this is supported by the accounts of women interviewed.

In contrast, the lay perspective constitutes the ideas, understandings and views on cervical cancer and screening put forward by the individual women who were interviewed in the course of this research. In light of the above discussion on the

different status and assumptions attributed to various terminology, I have given careful consideration to the way in which I discuss this lay perspective. This has taken account of a number of important factors.

Firstly, the views of the 35 individual women interviewed do not form a coherent single perspective, instead the ideas put forward by different women come from a range of perspectives and are frequently not in agreement. It is therefore important to stress the plurality of views expressed. Secondly, the material covered in this chapter stands at odds with the nature of material discussed elsewhere and this impacts on the kind of language appropriate. In particular, the material discussed here on women's ideas about the risk factors, incidence and development of cervical cancer, and their perceptions of cancer more generally, are very different from their experiences of cervical screening discussed in Chapter 7. In that chapter I used the language of 'knowledge' as, in common with work on lay knowledges of illness and disease, the individuals concerned had personal experience of the phenomenon and this formed the basis of their accounts. In contrast, the material that will be presented in the course of this chapter does not have the same kind of basis. None of the women I interviewed had personal experience of cervical cancer, although a small number had had a smear result showing abnormalities. It is therefore the case that the material used here is not drawn from, or rooted in, personal experience. It is for this reason that I have chosen to adopt the term 'lay understandings' in the context of this chapter in order to reflect both the plurality of views expressed and my reluctance to refer to these ideas as knowledge.

9.3 Women's Lay Understandings on Risk Factors

To briefly recap, the five risk factors for cervical cancer specifically set out in the information leaflet *Cervical Screening: THE FACTS* are:

- You first had sex at an early age
- You smoke
- You do not use condoms
- You have had several sexual partners or have had a sexual partner who has had several other partners
- You take immunosuppressant drugs (for example, after an organ transplant)

As I have highlighted elsewhere, three of these risk factors concern sexual behaviour i.e. first had sex at early age, do not use condoms and having several sexual partners. The

links between certain types of sexual activity and the development of cervical cancer therefore come across very strongly in this leaflet and indeed almost half of the women interviewed independently raised sexual activity as being linked to its development. Awareness of sexual activity in general as a risk factor would therefore seem to be reasonably well-known. However, a more detailed exploration of the different ways in which the women who mentioned this understood its influence suggests that these lay ideas do not fit so neatly with the medical perspective.

While many women mentioned sexual activity as being linked to the development of cervical cancer, in the vast majority of cases this was in a very general way. When asked to expand, women tended to talk simply about 'being sexually active' and the importance of having smear tests when you started having sex. Only a much smaller number engaged with the specifics of this in any way. Few demonstrated an awareness that having several sexual partners could increase a woman's risk of developing cervical cancer, while only one mentioned starting to have sex at an early age and none discussed not using condoms as posing a risk. This suggests that, while many women have taken up sexual activity as a general risk factor, only a few demonstrate more detailed knowledge around the specifics of how this may work to increase risk. This is further reinforced by the way in which a small number of women who, although they discussed sexual behaviour in general as a risk factor, went on to interpret how exactly this would work in very different ways to that of the medical perspective (Calnan, 1990; Davison *et al.*, 1991, 1992; Maskarinec, 2001).

Foremost amongst these was Davina. Towards the end of the interview I had asked Davina to comment on the four short vignettes[61], one of which contained Lucy, a 34 year old mother of two young children who had been married to David for eight years, and who did not regard cervical screening as a high priority for her. Davina's initial response was to pick up on the woman's responsibility to keep herself well for the sake of her two young children. When I suggested that perhaps Lucy did not feel herself to be at risk because she was in a long term monogamous relationship and therefore did not have a lot of sexual partners Davina strongly rejected this as important in the following way,

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[61] I described the use of these in Chapter 5, and they can be found in the appendix.

'well no no no, it doesn't work like that...you know, because you haven't had lots of partners it doesn't mean to say that she's not having lots of sex with David, you know it's the same difference isn't it, you know, you could have twice a day, you know, with David and maybe if she didn't have David have, you know, two or three partners every fortnight so it doesn't really make any difference does it?' (Davina 50-64 WB)

Here Davina regards the amount of sex as the most important factor and explicitly rejects any distinction between sex in a monogamous relationship and sex with several different partners in terms of the risks posed. She uses the phrase 'it's the same difference' to make her ideas clear. In considering that Lucy could be having more sex in her relationship with David than if she was single and having several partners, Davina appears to be suggesting that Lucy may in fact be at more risk, based on the assumption that she may be having more sex than other women. What is most interesting here is that, although Davina has taken up sexual activity as a risk factor, she has interpreted it in such a way as to place a woman in a monogamous relationship as potentially at more risk than a women having several different partners. Although initially taking up a medically 'correct' risk factor, Davina's interpretation of it makes it 'incorrect'.

Zena does a very similar thing when considering another of the vignettes, a 23 year old, Jessica, who has a long term boyfriend and is not sure whether she will continue attending for smear tests as her first experience had been embarrassing and painful. Zena strongly recommended that Jessica should continue having tests, indeed her initial reaction was simply 'attend, don't be stupid'. When I suggested that perhaps Jessica and her boyfriend had only ever slept with each other, and so maybe she did not feel at risk, Zena challenged the idea that the number of sexual partners was so important.

'It doesn't matter, it's not all to do with sexual partners it's to do with the change in your cervical cells, it doesn't matter at all. Apart from that, as you get a bit more adventurous with your sex life, you might do it in different positions and that might have a different effect on how your cervix is any way, and whatever else they want to experiment in' (Zena 20-34 WB)

Here Zena explicitly separates the number of sexual partners from any potential change in cervical cells, stating that 'it doesn't matter at all'. In contrast Zena argues that being more adventurous in your sex life and starting to have sex in different positions may have more of an effect on the cervix and may pose more of a risk. She therefore seems to be suggesting that sexual activity poses a risk of cervical abnormalities through the potential for some kind of damage to the cervix, and that this risk is increased if women have sex in different positions.

The theme emerging here is that, although women take up the idea of sexual activity as a risk factor for cervical cancer, not surprisingly given the focus upon it in the information leaflet, this is in very general terms and a more detailed understanding of exactly what kinds of sexual activity are seen as posing a risk, and how these may work, is lacking.

From the medical perspective, sexual activity as a risk factor for cervical cancer works predominantly through certain types of the human papillomavirus (HPV). There is considerable evidence that certain types of this sexually-transmitted virus are involved in the development of cervical cancer. However, research shows that women's knowledge of HPV infections and the associated risks of cervical cancer is low (Pitts and Clarke, 2002). In common with my research, the most frequently endorsed risk factors concern sexual behaviour. However, women in Pitts and Clarke's research demonstrate a more detailed understanding of the specific types of sexual activity that may increase risk, as 60.3% highlight early age at first sexual intercourse and 67.8% mention an increased number of sexual partners.

However, it is important to bear in mind that Pitts and Clarke's research was specifically designed to examine women's knowledge of cervical screening, displaysia (a form of cervical abnormality) and HPV. In contrast, my research did not have this specific aim, although women's ideas about what might cause cervical cancer were frequently discussed in the context of how they understood and made sense of cervical screening. Interestingly, although the women in Pitts and Clarke's research appeared to demonstrate a more detailed understanding of the specific types of sexual activity that increase cervical cancer risk, their awareness and knowledge of HPV was limited. Only

30% had heard of HPV and of these many had only vague or even inaccurate knowledge. This research, in common with the research on which this thesis is based, was carried out in the UK relatively recently and women in both studies are likely to have received the information leaflet *Cervical Screening: THE FACTS*. Although this leaflet lists three types of sexual activity as increasing cervical cancer risk, it makes no mention of HPV and how this has been linked to cervical cancer development. This is interesting as it is now widely accepted that HPV plays a significant role in cervical cancer development and information about this is available on the NHSCSP website. However, no mention of HPV is made in the information leaflet and, in the absence of any explanation, it is perhaps inevitable that women will attempt to make sense of the possible ways in which sexual activity could increase cervical cancer risk. As it is probable that this will be mediated through the knowledge that smear tests check for cervical cell abnormalities, it is perhaps not surprising that women understand the link in terms of sexual activity causing damage to the cervix.

It therefore appears that, in the absence of knowledge about the role of HPV in cervical cancer development, women attempt to make sense of the ways in which sexual activity may increase the risk of cervical abnormalities in novel ways that do not fit well with the medical perspective.

This lay focus on the potential for some form of physical damage to the cervical cells is further reinforced and developed through discussions around childbirth. For some women cervical screening was seen as being necessary after the birth of children in order to make sure that 'everything was back to normal' and that no damage had been done to the cervix during the birth. There is conflicting research evidence on the effect of parity in cervical cancer development, for example Munoz *et al.* (2002) suggest that high parity increases the risk among HPV-positive women while Mogren *et al.* (2001) found that increased parity was protective and argue that this therefore contradicts other research in which multiparity was found to be associated with higher risk. However, women's discussions are not based upon this kind of evidence. What seems more likely is that the context in which these women were offered their first smear test is influencing their perceptions.

Before the introduction of the national programme in 1988, cervical screening operated opportunistically with women being offered smear tests when they visited their GP for other reasons, frequently in the context of childbirth. Many of the older women within this research spoke of having their first smear taken after the birth of their first child, and of continuing this pattern of having a test to check for cervical abnormalities after each subsequent birth. It is therefore likely that, for many women, childbirth came to be perceived as creating the need for screening. The offer of cervical screening in this context may lead women to try and make sense of why they need a test to check for cervical abnormalities at this time and therefore how giving birth may potentially cause these abnormalities. In common with the discussions around sexual activity above, these lay ideas tend to revolve around some kind of physical damage to the cervix.

This particularly seems to be the case with Heather, for whom childbirth plays a very strong role in influencing her understandings and perceptions of screening. I had asked Heather if she could remember the context in which she had had her first smear test taken. She told me,

> *'it was after having my first child, because you had to, it was part of after having a baby, it's part of an on-going thing after, that's when it kicks in, you have your six week check-up and everything and then the first letter came so you need a cancer smear'* (Heather 50-64 AC)

The fact that she was invited to have her first smear shortly after the birth of her first child is clearly influencing how Heather thinks about cervical screening. She discusses it as simply one part of a wider package of check-ups that are necessary after having a child. For Heather having a smear test after giving birth is important in order to 'make sure everything is back and everything is fine', there is a need to make sure that the body has returned to 'normal' after the trauma of birth.

The relation of cervical screening to childbirth is so strong for Heather that, as well as influencing how she thinks about and understands screening, it also impacts on how she would advise other women. When I asked Heather to comment on the vignette about Jessica she drew strongly on the fact that she did not yet have any children and tailored her advice accordingly,

'well I would say to her, because obviously she hasn't got a child yet, I'd say wait until she has a baby and then it will all fall in to place…I would say to Jessica monitor it, if she hasn't had a child by the time she's 30 then go and have a smear test just to check everything is alright, I wouldn't necessarily say every three years if it was normal' (Heather 50-64 AC)

So here the fact that Jessica does not have children is of great significance to how Heather perceives her need to attend for screening. Whereas other women almost immediately suggested that they would try to encourage Jessica to attend, Heather suggests that it may not actually be that important for her to attend at this time. She suggests that things will just fall into place when she has a baby, again highlighting Heather's perception of the smear test as a routine check-up after birth, and so she does not need to worry about it at the moment. However, she does not dismiss the need for Jessica to be screened at some point and so suggests that if she has not had a child by the age of thirty then she should be screened, just to check that everything is alright.

It is interesting that Heather does not appear to make the same kinds of connections between the potential for cervical damage during sexual activity as she does for childbirth. This may be because she was sexually active herself before her first test and so, in her mind, it is childbirth that makes screening necessary and not becoming sexually active. This therefore suggests that the context in which women are first offered screening, and the way that this differs under the current national programme from the earlier opportunistic arrangements, may play an important role in influencing how screening is understood and thought about. The context of the individual woman's life, and what is going on around the time that cervical screening is first suggested, may therefore be important in determining how screening is made sense of in individual contexts. This then draws attention to the narrative structure of women's lay ideas and understandings, and demonstrates how women often link together life events in order to make sense of health and illness (Blaxter, 1983; Popay *et al.*, 1998). For Heather, a fundamental influence on how she understands cervical screening, and its relevance to her, is through linking her first smear test invitation to the birth of her first child.

This section began with a discussion that demonstrated how women routinely take up and validate sexual activity as a factor increasing cervical cancer risk, although this may not always be fully understood and lay women's understandings and interpretations may not fit well with the medical perspective. However, lay women do demonstrate an awareness of sexual activity as a risk factor. In comparison, the other two risk factors explicitly listed in the information leaflet, smoking and the use of immunosuppressant drugs, are not discussed as such by any of the women in this research. This is perhaps not surprising in the case of using immunosuppressant drugs as this will be a relatively rare phenomenon and not something that many women will have experience or knowledge of. The case of smoking as a risk factor for cervical cancer development is more interesting.

Of the 35 women interviewed in the course of this research, not one discussed smoking as a specific risk factor for cervical cancer. In fact the only context in which smoking was mentioned was during women's accounts of the steps they took to look after their general health. This is interesting as smoking is explicitly listed as a risk factor in the information leaflet[62].

Despite this, smoking was only ever discussed in general health terms and never as a specific risk factor for cervical cancer. In Pitts and Clarke's (2002) research, 45% of women indicated smoking as a risk factor, although again it is important to bear in mind that this was a study aimed at assessing knowledge and that, in terms of indicating risk factors, women were asked to tick all the factors they thought might increase risk from a list provided (all of which were established risk factors).

Therefore, in comparison with sexual activity, smoking is not a risk factor taken up and validated by women within my research. The failure of women to recognise smoking as a specific risk factor for cervical cancer may perhaps be due to their inability to establish a causal pathway between smoking and increased risk. In the case of sexual activity, the potential impact can be understood fairly easily, albeit not always in

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[62] Women not regarding smoking as a risk factor for cervical cancer specifically is an interesting counter to their tendency to talk of cancer in general when it comes to incidence and speed of development, which I discuss later in this chapter. It may be that women are more aware of specifics when talking about risk factors and disease causation than they are when it comes to other aspects.

accordance with the medical perspective, through the location of the cervix within the body and the site of sexual activity. However, in contrast, the effect of smoking on cervical cancer risk may be less easy to establish for the lay woman. In comparison with something such as lung cancer, in which the causal pathway can be established with little difficulty i.e. smoking causes poisons to be inhaled into the lungs, the connection between smoking and the cervix may be less apparent. The relative difficulty in establishing the reasons behind the increased risk may influence lay women's readiness to take up and validate smoking as a specific risk factor for cervical cancer. This has important implications for health promotion in a wider context in terms of how information is communicated. When informing lay individuals of risk factors for certain conditions, whether it be cervical cancer, heart disease or any other example, it is important that the ways in which these work to increase risk are explained. It would appear that the ability to establish a causal pathway to explain how a particular risk factor is involved in disease causation is important in influencing whether people regard these as valid, and whether they are likely to act on them.

In contrast to those risk factors that women do not take up and validate from the information material on cervical cancer and screening, stand those factors that women bring independently to their understandings of cervical cancer. The two main examples of this within my research are genetics and the menopause, both of which were covered in the previous chapter in the context of exploring individual women's self-positioning with regard to cervical cancer risk. I dealt with perceptions of genetic risk comprehensively previously and so do not repeat this. However, the way in which menopause is perceived to increase cervical cancer risk has not been dealt with and so I consider it briefly here.

The previous chapter dealt with the menopause as a time during which some women regarded themselves as at particular risk. I explored the case of Julia who felt unsure about the bodily changes she was experiencing, and Vanessa, who argued that declining hormone production associated with the menopause was a cause of cervical cancer. However, the coverage of the menopause as a risk factor in the previous chapter did not fully explore the range of women's ideas about how the menopause could work as a risk factor. In Julia's case, her discussion was limited to a discussion of how she personally felt uncertain about her body during the menopause and how this had made her feel

more vulnerable. It was suggested that this vulnerability was probably not limited to cervical cancer and was in fact a more general feeling. In contrast, Vanessa set out her quite specific and detailed ideas about how the menopause represented a dangerous time in the context of cervical cancer. The declining hormone production associated with this period was seen to be a cause of the disease.

This idea of changes in hormone production was a dominant theme amongst the women who suggested that this was a risky time during which screening may be particularly important due to the perceived uncertainty and 'riskiness' of the body that the menopause brought about, although it is employed with subtle differences.

For example, when Alice was considering whether screening was more important for some women than for others, in the context of discussing the vignettes, she suggested that,

> *'well yes, a lot happens to your body between 40 and 50 and you get a lot of changes and erm, you know, hormones, you know, hormone changes kick anything in you know, only because I know people that, not cervical cancer, but all kinds of different ailments seem to happen between 40 and 50, it's just a woman's age you know'* (Alice 35-49 WB)

In this extract Alice draws on the hormonal changes associated with the menopause in order to suggest that the body is somehow more vulnerable at this time and that these hormonal changes may play a role in 'kick-starting' the development of some disease. This is not limited to the development of cervical cancer however, in Alice's view all manner of 'different ailments' could be triggered. In providing evidence for this, Alice draws on the people she knows that have developed different conditions during this time and suggests that 'it's just a woman's age'. What this extract demonstrates very nicely are, firstly, the specific way in which Alice uses the idea of hormonal changes and, secondly, the particular kind of evidence she draws upon to support her suggestion.

Deirdre also draws on the idea of bodily changes associated with menopause to suggest that this is a particularly risky time. However, as we shall see, she does this in a subtly different way to Alice and draws on a different form of evidence. Deirdre said,

> *Deirdre: 'often things can happen to you in your 40s and 50s and things*
> *can develop in, especially as you're probably approaching the menopausal*
> *age, and erm things can happen in your balance and everything is upset...'*
> *NA: 'you've just said your balance, what do you mean?*
> *Deirdre: 'well your hormone balance, and everything changes'*
> *NA: 'and that is related to approaching the menopause?'*
> *Deirdre: 'mmm...you wait until it happens to you* (laughs)*'*
> (Deirdre 50-64 WB)

So in common with Alice, Deirdre suggests that the time around the menopause is uncertain and risky, as the hormone balance of the body is upset. However, while Alice suggests that these bodily changes may trigger the development of some disease, Deirdre appears to be suggesting a more subtle process whereby the imbalances of the body may leave it vulnerable and the 'door open' for disease to enter in. It is noticeable that, unlike Alice, Deirdre does not draw on the experiences of people that she knows to support her ideas. Instead it appears that she is drawing upon her own experiences of the menopause to support her ideas. In particular her laughing 'you wait until it happens to you' response to my question suggests that she is drawing on a resource that is not available to me as a young woman but that I will come to acquire.

It is therefore apparent that the women who discuss the menopause as a potential cervical cancer risk do so in subtly different ways and to differing degrees of specificity. For example, while Alice and Deirdre talk of hormonal changes in general terms, Vanessa (in Chapter 8) talked more specifically of particular hormones not being produced in the same quantities during and after the menopause as they were previously.

It is interesting to note that, of the five women who explicitly suggested the menopause as a cervical cancer risk, four had started their menopause[63]. The fifth, Alice, was 38

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[63] These five women were 4 White British and 1 African Caribbean. No South Asian women mentioned the menopause but this was perhaps unlikely given that many, especially the older women, found it difficult enough to discuss cervical screening. It is therefore unlikely that they would independently raise the menopause and associated bodily changes.

years old and spoke in terms of '40s and 50s', an age group that she would soon be entering. These women are therefore drawing on issues that are particularly pertinent to them in making sense of cervical cancer and screening. However, it was not the case that all women of this age group felt the same way. When I told Roberta that some previous interviewees had suggested that the menopause was a time during which screening was particularly important due to the risk posed by hormonal changes, she argued strongly against this idea.

> *'Well I don't think that's necessarily true, any time is risky, I think that all times are risky. I didn't, I don't know whether the menopause is a higher risk time or not. I would tend to think that it doesn't matter what time, that you should be screened all the time'* (Roberta 50-64 WB)

Although the women that did discuss the menopause in these terms are likely to have been influenced by their own experiences, and their particular stage in the life course, not all women of this age did so. To link up with the discussion of developing causal pathways in the case of other risk factors, the most commonly employed pathway here appears to be through a hormone imbalance brought about by the menopause. In addition, while it appears in many cases that this feeling of vulnerability goes beyond the specific case of cervical cancer and represents a more general feeling of uncertainty and insecurity, the location of the cervix may again be important. Being the neck of the womb, the cervix is inextricably (if only in women's minds) linked to reproduction and it is therefore possible that women make connections between cervical changes and menopausal changes more generally.

9.4 Lay Perceptions of Cancer

How women understand and think about the prevalence or incidence of cervical cancer is likely to be an important factor in influencing how they view cervical cancer screening and whether they regard it as an important thing to do. However, during my interviews with women in the course of this research it increasingly became clear that women do not always separate off issues relating specifically to cervical cancer from perceptions of cancer in general. For example, in accounts of their personal risk of developing cervical cancer it was common for women who drew on an increased awareness or family history of cancer to make reference to cancers other than cervical.

For example, if we think back to the case of Zena, who has been discussed in previous chapters, her talk of her family's cancerous genes includes several types of cancer, including breast, stomach, lung and bowel cancers. So although Zena names the specific types of cancer that have affected her family members, she still bundles these together in her assessment of her family's 'cancerous genes' and in her positioning of herself as at increased risk of all types of cancer, including cervical. It became increasingly apparent that many women talked of cancer as if it were simply one disease that could occur in different locations around the body without fully appreciating the specifics of each cancer type[64]. The tendency of women to view cancer in very general terms perhaps inclines them to think about incidence and the speed of development in very general terms and therefore not to engage with the specifics of this particular type of cancer.

9.4.1 Cervical cancer incidence

There were 2,424 new cases of invasive cervical cancer registered in England in 2000 (National Statistics, 2003), leading Cancer Research UK to state that it is the eleventh most common cancer in UK women, accounting for about 2% of the total (Cancer Research UK, 2003). The incidence of cervical cancer has fallen markedly since the introduction of the national screening programme in 1988 and mortality has declined significantly during the last few decades. I recap only briefly on this material here in order that the following discussion can be placed into context. More detailed information can be found in Chapter 2.

Of the 35 women interviewed, only two talked specifically of cervical cancer incidence. Matilda regarded herself as well-informed on a range of health issues due to her membership of a women's group that met regularly to discuss such things, and during our interview she demonstrated a sound knowledge of cervical cancer risk factors (as discussed in the previous section). In the context of discussing women who do not attend for screening, Matilda employed the relatively low incidence of cervical cancer as an argument against encouraging all women to attend.

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[64] As I suggested earlier in the chapter, this is less the case with risk factors and disease causation than it is with incidence and speed of development.

> *'I think really that's their choice, I mean you can say they're considered high risk but even so...we now know that cervical cancer isn't as widespread as a lot of other cancers which they don't screen for...I think it's like the choices people make in terms of their lifestyle you know'* (Matilda 35-49 WB)

Here Matilda specifically discusses the incidence of cervical cancer, and throughout the interview continually maintained the distinction between cervical and other types of cancer. This was something that was rare within the women interviewed. Matilda's view that cervical cancer is relatively rare in comparison to other cancers can be seen to influence her views on attendance. As has been discussed in the previous chapter, Matilda was one of those who positioned herself as at increased risk due to her past sexual behaviour and who therefore attended regularly for screening. What is interesting about the extract above is how Matilda suggests that, because cervical cancer is relatively rare, even those considered to be at high risk of developing the disease are still not likely to become ill.

In contrast, Roberta discussed cervical cancer incidence quite differently. She suggested that cervical cancer was quite common and that it was wise for everybody to be screened as a family history was not an important factor.

> *'I think cervical cancer is quite common and I think it needs, I don't know that it's just a tendency that one, I think that one is one that altogether can just occur. So I think it's wise for everybody to have it done. You know, that one seems to be quite common from what I read about it'* (Roberta 50-64 WB)

It is clear in this extract that Roberta is specifically talking about cervical cancer incidence. She repeatedly uses the phrase 'that one' to separate cervical cancer off from other types of cancer, and contrasts 'that one' with others in terms of both incidence and the causes of its development. In contrast with Matilda, Roberta does not maintain this distinction throughout the interview. However, she and Matilda are the only two women to make such distinction between cervical cancer and cancer in general when considering incidence.

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For the vast majority of women within the research, incidence was only discussed in very general terms and only in reference to the incidence of cancer as a whole. This was commonly raised in response to questions about the relative importance of attending for screening and, perhaps not unsurprisingly, most women who suggested a high incidence of cancer were amongst those who had discussed their awareness of, or perceived vulnerability to, cancer through reference to friends or family who had had cancer of some kind. Although most women discussed the prevalence of cancer in general in fairly measured terms, whilst stressing the importance to attend for screening, a noticeably extreme response should be highlighted in the case of Amina. During the course of our interview Amina spoke in very strong terms about how important it was for women to attend for screening.

> *'I think it's good for the ladies to do that, yes it's really good because most of them you know, they get cancers...but if they do this then they will be safe and then they know that everything is fine with them'* (Amina 35-49 SA)

Here Amina suggests that most women will develop cancer of some kind and uses this perception of extremely high incidence to stress the importance of attendance. She repeatedly stressed how she went for a smear test every time she was called and that she thought that cervical screening was very good and very important. However, Amina did not keep these views to herself. She told me how she was constantly trying to persuade South Asian women that she knew to attend and suggested that a lot of non-attendance, particularly among older South Asian women, could be attributed to a combination of fear and lack of information. Amina appeared very committed to encouraging these women to attend for screening and outlined her future plans to do so.

> *NA: 'so how do you think that you could do that?'*
> *Amina: 'it's easy for me, because other ladies they love to go into mosques I'm planning to get some place for rent, I've been looking just for one room, so I'm going to gather them there and then while we do something about Islam and the Holy Koran talk about that, but after that I'm going to keep*

them for just half an hour and talk to them. I can get them (to attend)*'*
(Amina 35-49 SA)

Amina's perception that most women will get cancer of some kind, combined with her awareness of South Asian women not attending for screening, has resulted in her commitment to remove what she sees as the barriers to attendance and to her developing schemes through which to achieve this.

It is therefore the case that, in a minority of cases, the prevalence and incidence of cancer is greatly exaggerated in women's minds. What is interesting in the case of Amina is that, while she is evidently so committed to cervical screening and to encouraging other South Asian women to attend, this is a group that, given the generally accepted risk factors for cervical cancer, is at relatively low risk. However, Amina's perception of cancer incidence in general does not reflect this and she therefore makes strenuous attempts to increase attendance amongst this group.

9.4.2 Cervical cancer development

Another important theme that women drew upon, again both in relation to cancer in general and specifically to cervical cancer, was the speed of development. This in particular, as will be discussed further below, was a theme that led to criticism of the current screening arrangements.

The important factor to be borne in mind here, and that which makes cervical cancer screening an interesting case, is that smear tests are designed to detect **pre**-cancerous changes in the cells of the cervix. They are not designed as a test for invasive cervical cancer. The aim of the screening programme is to identify, and treat, pre-cancerous changes that may, if left untreated, go on to develop into cancer. Cervical cancer is widely accepted to be preceded by such benign, pre-malignant lesions, indeed the whole screening programme is based around this, but, as I discussed in Chapter 2, it is by no means certain that all cervical abnormalities will lead to cancer nor that all cases of cervical cancer will be preceded by these lesions. As such, there is a degree of uncertainty around disease progression and it is therefore difficult to provide any kind of timescale for cervical cancer development. It remains the case though that the screening programme is based upon the assumption that regular screening to identify

and treat pre-malignant abnormalities can prevent the vast majority of cancers developing, and that an interval of three or five years (depending upon age) is sufficient (Sasieni *et al.*, 2003).

While many women interviewed were aware that the purpose of screening was to identify any changes in their early stages, only relatively few used the specific term 'pre-cancerous', and fewer still demonstrated an awareness that not all abnormalities identified would go on to develop into invasive cervical cancer if left untreated. In terms of the speed of cancer development, the general view expressed by women was that cancer could develop at such a pace that cervical screening needed to be more frequent. When talking about her decision to continue attending for smear tests following her relatively recent first one, Christine linked the importance of having regular checks with the speed at which cancer could develop.

> NA: *'so do you think you'll go on having them?'*
> Christine: *'well yes if it's necessary, because I think I read that after a certain age you should really have it on a yearly basis, so I think it would be good to keep checking because, you know, with cancers they just appear on you and it's good to just check and make sure, so I will carry on yes'*
> (Christine 20-34 AC)

For Christine then cancers of all kinds can 'just appear on you' and therefore it is necessary to have regular checks to make sure that everything is as it should be. As was discussed in the previous chapter, Christine's awareness of cancer had been raised by her father's death and so it is likely that this experience is influencing her views here to some degree. In addition Christine says she has read somewhere that cervical screening should be performed yearly after a certain age. These two factors combine to mean that Christine is committed to continuing attendance in order to keep a check on her health.

Samira echoes this view but takes it further by exploring the potentially asymptomatic development of cervical cancer. The idea that something can be developing inside the body without the individual being aware of it was raised by a number of women and Samira represents the views expressed,

'so many things can be happening inside your body that way, and sometimes you can have no symptoms but a lot of things are going wrong inside so at least this way you get to find out a bit about your body, you know, what's happening in there' (Samira 35-49 SA)

Another dimension is therefore present in this type of discussion, that the individual woman may not be aware of the changes going on in her body. In this way cervical screening is viewed as something to be valued for the way in which it can give women information on their bodies that they themselves do not have access to. Samira discusses how things can be happening inside the body but, because of the lack of symptoms, women are likely to be unaware of this and so need the smear test to provide them with the information. For Samira this information does not appear to be threatening, instead it is valued for the knowledge it can give the individual woman about what is happening inside her own body.

Perhaps the most extreme views on the potential speed at which cervical cancer could develop are those expressed by Doreen. When I asked her if she attended for screening every time she received the invitation letter she assured me that she did and went on to explain why it was important to do so,

'I think it is important yes because you never know when things develop, especially at my age, you don't know what's going to develop within a week, a month, never mind a year because things develop by themselves so I think it is important yeah' (Doreen 50-64 AC)

Here Doreen really stresses the speed at which 'things' can develop. Again, she does not appear to be considering cervical cancer in particular, rather she is discussing health problems more generally. Nevertheless, Doreen employs these general arguments when asked about cervical screening and smear tests in particular and uses them to stress the importance of regular attendance. As I will go on to show in the next section, the perception of the rapid pace at which cervical cancer can develop is one of the themes women draw upon when challenging the organisation of the screening programme.

9.5 Using Lay Ideas as a Challenge

In the majority of instances involving women talking about risk factors and disease causation discussed above, women did not use their understandings of these, and the ways in which they interpret them within the context of creating a rational framework, to explicitly challenge the official discourse. It appears as if women made sense of such matters in ways which were meaningful to them and did not seek verification for these, thereby decreasing the likelihood that they would become aware of the discrepancies between their ways of thinking about risk factors and disease causation and those medically recognised. Instead, the only contradictions they perceived were between their understandings and those of other lay women. In the discussions above we saw cases of this, for example when Davina and Zena challenged suggestions that cervical cancer risk may be lower for women in long-term monogamous relationships. In these cases lay women can, and do, challenge what they perceive to be the misguided understandings of other women. In this way they only indirectly challenge the official discourse, through challenging medically correct lay ideas, and seemingly remain unaware that they are doing so. In this context then resistance is located at the level at which women interpret and understand risk factors and disease causation, thereby engaging more actively with the official discourse rather than simply accepting it, and not in using these as an explicit challenge.

One notable exception to this is Selma, who shows an awareness that the official discourse states that cervical cancer risk increases with more sexual partners and the earlier women become sexually active, but ultimately favours alternative explanations.

> *'I think that the chances increase the more sexual partners you've had and the earlier you're sexually active, so I suppose there are certain types, but it all seems to be fairly sort of random...nobody really knows why it hits or what type of person, so I suppose that there is a certain type of person who is more at risk but I don't know, I just think that it's just like all of these types of things, sometimes you're lucky and sometimes you're not'* (Selma 20-34 WB)

Selma is therefore aware of the official discourse on potentially risky forms of sexual activity, but is unsure about the validity of such claims. Therefore, while she 'supposes'

that there are certain types who are more at risk, she ultimately rejects these as adequate explanations for why some women develop cervical cancer and others do not. Instead, Selma ultimately favours explanations based on randomness and luck, 'sometimes you're lucky and sometimes you're not'. Indeed she goes so far as to suggest that nobody really knows why some women develop cervical cancer instead of others, therefore explicitly challenging the medically recognised risk factors and cervical cancer epidemiology.

However, these explicit challenges were rare in terms of lay ideas on cervical cancer risk factors and disease causation. Instead the vast majority of explicit challenges occurred in the context of the current screening arrangements, both in terms of how frequently women are screened and the age group that is routinely invited for screening.

Many of these challenges can be seen as rooted in women's perceptions of the speed of cancer development, as discussed above. At the time of the research, NHSCSP guidance was that women should be screened at least every five years, and many Primary Care Trusts screened women every three years. However, the majority of the women in this research felt that three years was still too long between smear tests and suggested that yearly screening would be better. As was shown in an earlier section, women's perceptions of the speed at which cervical cancer could develop has already been identified as an important factor influencing how screening is thought about. However, these lay understandings on speed of development can be taken further and many women used them as a basis on which to challenge current screening arrangements and argue for more frequent smear tests. For Davina, three years was simply too long between tests and the programme was wrong to have adopted this as an adequate screening interval.

> *'I think it should be once a year, or even eighteen months, I don't think they should leave things like that so long'* (Davina 50-64 WB)

Here Davina goes beyond simply setting out her ideas on the speed at which cervical cancer can develop and explicitly uses these to challenge the organisation of the programme. She quite clearly states that she doesn't think 'they' should have such a long interval between cervical smears.

In addition to these criticisms based upon screening frequency, women also employed their lay understandings on the speed of cervical cancer development in order to challenge the 20 to 64 year old age group that was routinely invited for screening at the time of the research. This worked in two ways: suggestions that cervical screening should start before the age of twenty, and that it should continue past the age of sixty-four.

The idea of starting to have cervical screening when becoming sexually active was an important factor in arguments for starting screening before the age of twenty. As several women pointed out, women and girls are becoming sexually active at younger and younger ages and therefore screening may need to be started earlier. This was tied in with ideas about the speed of development as these women suggest that even starting screening at twenty may be too late, again raising questions about their understandings of the nature of the pre-cancerous changes that smear tests are designed to identify.

Julia was one of the women who suggested that screening needed to start much earlier.

> *'I think maybe 20 is a bit old nowadays, I think maybe we should reduce it and I think maybe if a doctor...knew that a young girl was sexually active, be it from 12 or whatever, you hear some horrible stories...but if they are then maybe it should be a matter of fact that they go on the register to be screened'* (Julia 35-49 WB)

So here Julia explicitly suggests that girls should be put on the cervical screening register as soon as it becomes known that they are sexually active. However, this goes against specific NHSCSP guidance advising that, as teenagers' bodies are still developing and changing, smear results for those under twenty may show abnormalities when nothing is wrong and so screening could do more harm than good in such cases.

Women's arguments for screening continuing past the age of sixty-four operated along similar lines. Women aged sixty-five and over who have had consecutive normal smears in the preceding years are routinely taken out of the programme as the natural history and progression of the disease means it is highly unlikely that they will go on to

develop cervical cancer within their lifetime. However, it seems that, once again, lay women's understandings of the speed of cervical cancer development may influence how they interpret this routine withdrawal of women from the system. Many suggested that cervical screening should continue past the age of sixty-four and some went as far as to suggest that it should be life-long. A common theme drawn upon was that women can still be sexually active past this age and that they therefore still need screening. Abigail explicitly challenged what she saw as the assumption that older women no longer have sex when asked to consider the vignette of Sheila, a 62 year old woman,

> *'there shouldn't really be an age limit on it…she's just as prone to it as a young person…I know that she's been through the menopause but probably she's got a regular partner or something, just because she's 62 doesn't mean to say that she's not going to have a regular, or regular different partners at 62'* (Abigail 20-34 WB)

The idea of women still being sexually active past the age of 64 years, combined with exaggerated perceptions of the speed of cervical cancer development, led many women to argue that those aged 65 years and over are still at risk and therefore still need screening. However, as I have already made clear, women aged 65 and over are only removed from the screening register if they have had consecutive normal smears in the preceding years, this will not be the case for those with previous abnormal results or who have never been screened. Women with a history of normal smear test results are regarded as at very low risk and, given that a normal smear test shows no signs of pre-cancerous cervical abnormalities, it is very unlikely that they would go on to develop these abnormalities, and then that these would go on to develop into cervical cancer, within the women's lifetime.

However, within the information leaflet, women are simply told that the screening programme offers smear tests to all women aged 20-64 years and that women still need to be checked if they have passed the menopause. They are told to ask their doctor for advice if they: have had a hysterectomy, are over 65 years, have never had sex or are not sure if they still need to be tested. Therefore no explanation is offered as to why the particular age range has been chosen, nor is it made clear that women aged 65 and over will only be routinely withdrawn from the programme if they have had consecutive

negative tests in the preceding years. In the absence of such an explanation it is perhaps inevitable that women attempt to make sense of why those aged under 20 and over 64 are not screened. As demonstrated above, the focus on sexual activity as a risk factor within the leaflet leads women to understand that all those sexually active need to be screened, leading to calls for screening for those above and below this age group.

In trying to understand why these women should be excluded, particularly those above the upper age limit, many women constructed alternative explanations that fitted in with the other understandings they held and with their view of society more widely. Given the focus on sexual behaviour as a main risk, coupled with their assertions that those over the age of 64 are still likely to be sexually active, these women could not identify any reason why the risk of cervical cancer should suddenly decrease after this age. Therefore, in order to make sense of why this was the policy, alternative reasons were suggested, sometimes quite forcefully. These centred around older women being excluded from screening due to the negative views that society holds about them. Women talked about those over the upper age limit being 'written off' and 'thrown on the scrap heap', it was 'hard luck' if they developed anything after this age. Vanessa felt this particularly strongly and argued that,

> *'…doctors say that you get to 65 and you're redundant and unfunctional and you have no other function in life, you get thrown on the scrap heap,* (they think) *'we're not going to spend money and waste time on you'…'*
> (Vanessa 50-64 AC)

Therefore, in the absence of any other suitable explanation Vanessa, and others like her, draw on ideas of older people being seen as no longer of any use to society and as a drain on resources. While many suggested that this was how older women were viewed, this did not mean that they went along with these views by any means. Those that suggested this may be the reason for excluding these women from the screening programme were adamant that this was unfair and could not be justified. Many of these drew attention to the fact that, in the context of an ageing population, 64 could not possibly be seen as old and that women of this age could still play a very active role within society and indeed many were still working and paying taxes. A smaller number

drew specifically on the contribution through taxes to suggest that older women should be entitled to screening as they have paid for it in this way.

In constructing these alternative explanations for why older women are withdrawn from screening, and particularly in arguing for the perceived unfairness and discrimination they suggest, a discourse of rights and entitlements is drawn upon that stands in interesting contrast to the idea of women feeling a moral obligation or responsibility to attend. Arguments for screening continuing past the age of 64 were framed in terms of these women having the opportunity to attend and being entitled to screening if they wanted it. In this way, the elements of responsibility and obligation were shifted onto those providing the screening. Through the construction of these alternative explanations, and the strong arguments against them, these women are explicitly challenging the current screening arguments and resisting the notion that they are in any way adequate.

9.6 Conclusion

This chapter has been concerned with exploring how lay women make sense of the official discourse on cervical cancer and screening, taken primarily as the information contained within the *Cervical Screening: THE FACTS* leaflet that all women invited for screening should receive. This process was framed in terms of how women attempt to fit all the information that they receive together into some kind of rational framework in which everything makes sense in relation to everything else. In order to achieve this bridges are built to link pieces of information together and particular pieces that do not fit, or that cannot be made sense of, are omitted or rejected.

I began with a consideration of how lay and professional perspectives on health are differently constructed, and therefore accept very different kinds of evidence. However, it was also made clear that these two forms of knowledge cannot be treated as two distinct entities that are entirely separate from each other. Instead, the two can often be seen to overlap and intertwine at times, but also to diverge at others. Indeed it is these potentially complex inter-plays that are of interest in the context of this chapter. An awareness of these issues was important in order to fully appreciate the different ways in which lay and professional perspectives are constructed.

The empirical exploration of these ideas began through exploring how lay women understand the risk factors for cervical cancer. Lay ideas on specific risk factors were compared with those medically recognised and particular attention was paid to how these are interpreted in order that lay women can understand how they work to increase risk and how particular risk factors, such as smoking, are omitted on the basis that they cannot be made sense of. A key focus here was on how sexual activity, which many women discussed as a risk factor, was understood and how links were drawn between sexual activity and cervical abnormalities. In the absence of any information on the role of the HPV virus within this process, women drew on the notion of some kind of physical damage to the cervix being the means through which risk was increased. This notion of physical damage was further extended to childbirth, in which the same potential was perceived.

I also explored lay understandings on the incidence and speed of development of cervical cancer, and how these can differ from the medical perspective. I demonstrated how largely overestimated ideas of both incidence and the speed at which cervical cancer develops led many women to challenge the adequacy of current screening provision. I suggested that, although elements of challenge could be identified in the context of risk factors, the strongest and most coherent challenges come through in this latter context. Lay women's arguments centre around calls for more frequent screening, typically every year or eighteen months, and for the extension of screening beyond the current age range routinely invited. Challenges to the target age group for screening, particularly in terms of the routine withdrawal of women at age 64, were particularly interesting and involved the production and advancement of alternative discourses. This was because, in the absence of any apparent reason why risk should suddenly decline at this age, coupled with no awareness of the criteria through which only low risk women are routinely withdrawn, alternative explanations were constructed. These centred around the idea that women over the age of 64 were perceived as contributing little to society and that it was therefore not worth screening them. In some cases an economic element was incorporated that suggested there was a reluctance to 'waste' scarce resources on women over this age. In challenging this, a discourse of rights and entitlements, earned through the payment of taxes for example, was employed, which stands in interesting contrast to the perceived discourse of obligation and responsibility that surrounds cervical screening.

The key argument that I have put forward throughout this chapter is that resistance, in this context, comes through women's active engagement with the official discourse on screening and the ways in which they understand and make sense of it through attempts to fit all of the information presented to them into some kind of rational framework. Through this active engagement and imagination a space is opened up between discourse and the individual through which the potential for a more flexible relationship is created. Instead of a process of straightforward imposition, the individual can engage more critically with the discourse, or particular elements of it, and come to understand it in potentially divergent ways.

Chapter 10

The Power of Resistance

10.1 Introduction

The objective driving this research has been to develop a sociological understanding of how women demonstrate resistance to the official discourse on cervical cancer screening. As such it seeks to balance a tendency for much empirical work employing Foucauldian theory to focus upon his earlier works, therefore emphasising the power of disciplinary practices and techniques of domination to control and govern individuals. I have argued that this runs the risk of portraying individuals as little more than passive victims who are simply ensnared within such power relations and are powerless to resist them. My research adopted a different perspective and employed Foucault's later works (see for example 1984b&c, 1988), which detail his ideas on how a more flexible relationship between discourse and the individual can be suggested, in order to explore resistance and, as I will develop in the course of this concluding chapter, the power that such resistance can have.

I used these ideas to explore the case of cervical cancer screening and considered the contribution of studies drawing attention to the 'moral obligation' that many women can feel to attend for screening (Howson, 1998b, 1999) through their application of Foucauldian ideas on power and governmentality to this area. While recognising the importance of exploring how power can be exercised in such forms, I have argued that this needs to be balanced with a consideration of how individual women respond to such discourses and how they may resist and refuse them. Through this it was possible to explore the relationship(s) that women have with the official discourse on screening but to avoid portraying them as powerless in the face of this. However, although my analysis focused on identifying and exploring instances of resistance, this was in relation to the form(s) of power being resisted.

In order to establish the forms of power that are exercised in this area the documentary analysis set out in Chapter 6 characterised the official discourse on screening. This therefore ensured that the other side of the power/resistance relationship was not ignored and that the context in which individual women are resisting was taken into

account. Indeed context, and the kind of power that any resistance is in response to, is likely to play an important role in the forms this may take and the resources that may be drawn upon. Without such a balance between the exercise of power and the potential for resistance, this study would have been guilty of similar shortcomings to those critiqued. Such an approach echoes the feminist arguments explored in Chapter 3, highlighting the problems associated with focusing solely on either power or resistance. In this way a focus on power/structure is critiqued for neglecting the potential for resistance and portraying individuals as passive victims, while a focus on resistance/agency can fail to consider context and blame individuals for unsuccessful resistance (Davis and Fisher, 1993). In order to overcome such problems the focus shifts away from exploring either power or resistance in isolation towards an exploration of the ways in which they impact on each other. Such a focus also offers a means through which to overcome some of the problems that Abu-Lughod (1990) identifies in terms of how to deal analytically with resistance. Abu-Lughod has suggested that we should not be so concerned with the status of resistance itself, but rather with what particular forms of resistance can tell us about the forms of power that they are competing with, again emphasising the need to think in terms of the relationship between power and resistance rather than attempting to deal with either in isolation.

Initially, this final chapter draws together the new material set out in the analysis chapters. This encompasses the documentary analysis that characterised the official discourse on screening and the three subsequent chapters that set out how women have resisted this in different ways. In exploring the kinds of resistance that have been identified I relate back to both the theoretical and empirical discussions of resistance, the forms it may take, from Chapters 3 and 4. This brings together for the first time the different instances of resistance identified in the thesis and explores how they vary, the kinds of resources they draw upon and the extent to which they are pursued. Context is also of importance here for the ways in which it may impact upon the kinds of resistance identified.

Building upon this, the particular relationship between power and resistance in the case of cervical screening is considered. I consider the kind of power that is exercised through the official discourse and develop the idea that this encourages women to engage with screening in a particular way, thereby presenting them with a general

subject position to adopt in relation to the discourse. Following this I explore what this means for women's resistance, and the potential and power of such resistance. I also relate back to wider theoretical debates around the relationship between power and resistance and consider what research in this particular area can bring to these. I suggest that it is possible to think of power and resistance in terms of a complex network of possibilities within which things could always have been other. This leads back to Foucault's idea of the more flexible relationship between discourse and the individual. Through the particular example of cervical screening, I demonstrate that this process need not be one of straightforward imposition or linear progression, instead I argue for the existence of a network containing multiple points of potential difference or divergence, at which a slight variation in interpretation or understanding can lead to a very different outcome. In specific relation to individual women and the official discourse on cervical screening, there exist many points at which this discourse, or more importantly particular aspects of it, may be simply accepted or may be interpreted, understood or negotiated in such a way as to lead individual women to refuse or resist. This research has demonstrated how such resistance is primarily located at the thought or talk level, with relatively few examples of it being translated through into behaviour. In this final chapter I explain how and why this type of resistance is important.

10.2 Power and Resistance in Cervical Screening

Chapters 3 and 4 of this thesis included a running discussion of what could, or indeed should, be regarded as resistance and the forms that this may take, both in terms of theoretical ideas and examples from past empirical studies. This drew attention to the ways in which resistance can be thought about and how it may manifest itself. I considered the importance of not being too quick to regard something as resistance, and running the risk of ascribing to it a quality that was never intended (Abel and Browner, 1998), and the need to avoid 'romanticizing' women's resistance (Abu-Lughod, 1990). The need to produce some form of criteria for identifying resistance within this study was therefore central and Chapter 3 in particular dealt with some of the relevant theoretical issues.

At the forefront of these was the question of whether intentionality is vital in determining whether or not the label of resistance should be applied. Contrasting

perspectives were considered with Kielmann (1998) arguing that intentionality is indeed necessary, while Riessman (2000) employs the concept of 'transformative effects' rather than focusing on intention. However, there must still be an element of agency present within Riessman's criterion and she ultimately concludes by arguing that resistance be thought of in terms of individuals pressing their own claims in opposition to others. Throughout this thesis I have aligned myself more with the argument or definition put forward by Riessman as I regard this as more useful than Kielmann's overly restrictive criterion of intentionality.

Having established the kind of theoretical criteria that I would employ, I turned to consider the ways in which resistance may manifest itself in order to both sensitise myself to these and also to further reinforce my criteria. Through the empirical studies in both Chapters 3 and 4, I explored ideas of resistance as transformative thoughts and actions (Riessman, 2000), the production of oppositional, alternative or counter discourses (Kaufert, 1998; Ramazanoglu, 1993; Weedon, 1987), the reinterpretation or conceptualisation of particular issues (Markens *et al.*, 1999; Potts *et al.*, 2004), the reappropriation or relocation of expertise (Browner and Press, 1996; Murphy, 2003; Rogers and Pilgrim, 1995) and a refusal to think in biomedical terms (Gold and Ridge, 2001).

These different forms of resistance also reinforce the need to consider context, as the potential for resistance, and the different forms that this may take, are likely to be heavily influenced by this. This leads back to the discussion above about the need to consider both power and resistance, and the relationship between the two, in such work. This is because the form of power, and the means or channels through which this operates, will almost inevitably influence the kinds of resistance possible.

I ultimately adopted a deliberately open definition and regarded resistance as any thought, talk or action that diverged from the official discourse on screening. More aligned with Riessman (2000) than Kielmann (1998), the focus is on the alternative conceptualisations or counter discourses that women produce on cervical screening and the cancer itself. As argued in Chapter 4, this wider definition of resistance moves away from the limited focus on a simple dichotomy between attendance and non-attendance in order to capture the diverse range of positions or stances that women may adopt.

Before turning to the kinds of resistance demonstrated, this thesis characterised the official discourse on cervical screening in order to explore the kinds of power operating in this context and to establish what it was that women were resisting. The documentary analysis presented in Chapter 6 set out this characterisation and the way in which the NHS Cervical Screening Programme communicates with women and presents screening to them. This represented a deliberate juxtaposition of the official, state level discourse and individual women.

Through this characterisation power was seen to operate in a range of ways. The information contained within this material is presented as fact, therefore implying objectivity, scientificity, and 'truth'. This serves to invalidate any other forms of knowledge or information that women may hold and consequently constructs official bodies as the only, or at least the most appropriate, people who can or should speak on such a subject. The material goes beyond merely providing information and instructs women on how to view screening and how they should engage with it. The categories of attendance and non-attendance are powerfully constructed within this discourse and sociological work has problematized attendance because of this, linking it to wider debates about the exercise of power within society and arguing that it is embedded within a moral framework of responsibility and obligation (Howson, 1998b, 1999). Women who do not attend run the risk of being seen as irresponsible and deviant by both health professionals and wider society.

Within this official discourse power can be seen to operate in different ways. The relative constructions of attendance and non-attendance are relatively straightforward and have been considered by both research in this area and others. In addition to this though, the information set out in this material encourages women to approach cervical screening from a particular perspective and to understand and think about it, and the cancer itself, in certain ways. Information on issues such as risk factors, the experience of having a smear test taken and who should be screened and how often is framed in certain ways. As the thesis went on to demonstrate, individual women often resisted these ways of thinking and understanding, and the creation of a general subject position, sometimes leading them to carry this level of resistance through into behaviour.

Chapter 7, the first of the analysis chapters dealing with resistance, explored the way many women interpreted and made sense of the official discourse on screening and resisted particular aspects of it through engagement in a process of individualisation. Resistance in this way comes through the reluctance and refusal of these women to adopt the general subject position suggested, or to think about and understand screening in such terms. Instead, women pursued their own understandings and interpretations of screening, and produced alternative discourses on its nature, meaning and significance.

The resources that women drew upon in resisting in this way varied and the availability of different resources to different women was of interest in considering the kinds of resistance that were open to them. A common resource upon which such alternative conceptualisations were based was the physical and emotional experience of having a smear test taken and the significance attached to this. Through the deployment of problematic experiences, women were able to reframe and reinterpret screening in ways that differed significantly from that presented within the official discourse. This was also the case when women incorporated the impact of the bodily changes they were experiencing. Again this led to them thinking about and understanding screening in ways that diverged from the official presentation, but which appeared significant and meaningful to them as individuals.

The employment of emotional and/or physical experiences and the impact of bodily changes are inherently individually and experientially based. In contrast, the women who drew upon their cultural and/or religious identities in order to resist the official discourse on screening were employing a very different resource. The use of this kind of resource, for example Muslim women's understanding of screening as compromising an unmarried girl's virginity, appeals to something more than purely individual experience. Instead, it draws on a more widely held identity and religious and/or cultural discourses. The appeal to such a group identity can open up the potential for other forms of resistance than those that are more individually based. The kind of knowledge or experience that comes through physical or emotional experiences for example is necessarily specific and particularistic in nature. This form of knowledge differs markedly from the pursuit of objective and generalizable knowledge with which biomedicine is concerned. Religious or culturally based knowledge relies less on such an experiential and particularistic base and can draw on more widely held discourses

that are perhaps seen to lend them more validity and authority. This was demonstrated by individual respondents being more sympathetic towards women who, they suggested, may have problems with screening due to religious or cultural barriers than those who found the procedure problematic because of embarrassment or pain.

The extent to which individual women pursued these alternative discourses or conceptualisations varied and, in Chapter 7, I explored the range observed, which ran from deference to medical authority through to the maintenance and pursuit of such individual, non-medical knowledges. At this end of the spectrum women drew on resources such as personal experience or religious and cultural perspectives in order to challenge the way in which screening is presented within the official discourse. This clearly fits with Riessman's (2000) argument that resistance be thought of in terms of individuals pressing their own claims in opposition to those of others.

Chapter 8 continued the theme of resistance as individualisation, and the pursuit of personal claims in the face of opposition, through an exploration of how individual women engaged in a process of self-positioning with regard to their perceived cervical cancer risk. Rather than adopting the general 'at risk' position suggested by the universal approach to screening taken by the programme, there was a tendency for women to work out their individual relationship to screening based on perceptions of their own risk or vulnerability to the disease. In this way, resistance comes through these women's refusal to adopt a general 'at risk' position, and the negotiation of their own personal and individual ones. This involved women drawing on particular kinds of risk factors, both medically correct and incorrect, that they regarded as important in determining who was most likely to develop cervical cancer. However, as discussed in the chapter, this could also extend beyond the level of risk factors to the highlighting of personal characteristics or identities which meant that they would never be affected by such risks. Once again, these women were negotiating their individual position within the very general.

I demonstrated how women employed a range of different risk factors when working out their individual risk positions, and that these did not always match those risks highlighted within the official discourse. While the risk associated with having several different sexual partners was generally acknowledged, some women also talked in terms

of a genetic risk or family history, something that is not found within the official discourse and is not thought to play a role in cervical cancer development. However, it is clear that there is a growing awareness of genetic influences in other conditions and therefore, while women bring these risk themes from outside the specific context of cervical screening, they are suggested to them through other medical and health promotion discourses. As Foucault (1984c) has argued, the means through which individuals work out their relationships with wider societal discourses are not simply invented by them, instead they are models already found within society that are used creatively.

The different ways in which these risk factors, both medically correct and otherwise, are employed by women when working out their individual risk positions was also of interest. Within Chapter 8 I argued that these could be grouped according to whether or not they are perceived to be under the control of the particular individual and, therefore, whether that individual could be construed as responsible for such a risk. As such, risks associated with sexual behaviour and general health status were regarded and treated differently from those which are not under individual control, for example a genetic influence or bodily changes. I noted that, with only one exception, an individual's sexual behaviour was only ever discussed as a factor that reduced their risk. The exception discussed only her past sexual behaviour as having increased her risk, therefore meaning that none of the women interviewed discussed their current sexual behaviour in these terms. In contrast, the idea of a genetic influence was employed by different women to both increase and decrease their risk. I argued that the degree to which the individual can be construed as responsible for a particular risk factor, and therefore its social acceptability, may influence how different risk themes are employed and talked about by women within this self-positioning process.

Within the more general individualisation process discussed in Chapter 7 (and above) resistance was mainly discussed in terms of women advancing alternative conceptualisations of, and discourses on, cervical screening. In the context of self-positioning in relation to risk however, this was followed through into behaviour and the impact on screening attendance explored. I argued that, because the screening programme is opt-out in nature, the routine call and recall and the assumption of attendance meant that the majority of women I interviewed who considered themselves

as at low risk continued to be screened. However, there were notable exceptions to this and examples of women in this position either reducing their attendance in accordance with their perceived low risk, or ceasing to attend altogether. In this way, resistance was pursued beyond the thought or talk level and was translated into action as women resisted the regular calls to attend that they received and pursued their own paths. What is important here is that these were not women who had any other problems with screening. They had attended in the past but their current circumstances had led them to position themselves as at low risk of developing cervical cancer and they maintained this in opposition to the regular invitations to attend that they received.

Chapter 9 moved away from such an individual perspective and considered how lay women engage with the material on cervical cancer and screening within the official discourse. Ultimately it argued that the differences between lay and medical ways of knowing influenced how women understood and made sense of this information and that this could lead them to resist the medical perspective through alternative interpretations and understandings. This was not to suggest that all women's views formed a single coherent whole. Instead, there was a plurality of views and understandings, again reinforcing my argument for thinking in terms of a network with a multitude of points for potential divergence and resistance.

Lay interpretations and understandings of the risk factors set out within the information leaflet could lead women to very different end points. For example, I discussed the different ways in which sexual activity was understood as a risk factor for cervical cancer. In the official discourse risk focuses on becoming sexually active at an early age, having had several partners, or a partner who has, and not using condoms. However, what is not made explicit is that these risks relate to the role played by certain types of the sexually-transmitted human papillomavirus (HPV) in cervical cancer development. In the absence of such additional information and explanation some women, through their attempts to make sense of this and create a causal pathway that would lead from risk factor to cancer development, understood the influence of sexual activity in very different ways. Alternative conceptualisations included the risk coming through the amount of sex a woman has, regardless of who or how many people it is with, or having sex in different or unusual positions. In these cases the risk is seen as coming through the potential for some kind of physical damage to the cervix. Having

been told that something represents a cervical cancer risk, but in the absence of more detailed information on how this works, women attempted to 'fill in the gaps' and to create a causal pathway in order to make sense of the incomplete information.

In contrast, the failure to be able to establish a causal pathway could lead to women failing to 'take up' a particular risk factor and accept it as such, even though it is clearly set out within the information material. I explored this through the example of smoking. Despite its presence on a list of risks within the leaflet, women demonstrated a resistance towards accepting it as such. I suggested that this may perhaps be due to an inability to understand how smoking would work as a risk for cervical cancer, in contrast to other diseases such as lung cancer in which the causal pathway is well established.

However, despite the interesting instances of resistance around different risk factors, it was how women thought about the incidence and speed of development of cervical cancer that led to the strongest resistance to, and criticisms of, screening provision. I discussed within the chapter the tendency for women to think and talk in a general way about cancer incidence and that this often led to them overestimating the incidence of cervical cancer. Cervical cancer was therefore seen as relatively common[65] and screening was perceived as very important. In addition to this, the general view expressed by women was that cervical cancer could develop at such a pace[66] that cervical screening needed to be much more frequent than the present three to five yearly interval. Contributing to this were concerns about the lack of symptoms and, as a result, many women argued that screening was important due to their own inability to tell if anything was wrong. This raises important issues about whether such things as levels of screening provision should be led by 'consumer' want or should be determined on the basis of medically established need. In this instance resistance comes through women employing their understandings of both the incidence and development of cervical cancer in order to challenge the current screening interval and to resist the message that this is sufficient. Criticisms were also made of the target age range routinely invited for

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[65] This may also be influenced by some women understanding an abnormal smear test, and any further investigation and treatment, as indicating the discovery of cervical cancer rather than simply cervical abnormalities which may, if untreated, have gone on to develop into cancer.
[66] Again the above point may be of relevance here.

screening with arguments put forward for extending this in both directions. The argument for routinely screening women over the age of 64 years was a particularly interesting case as this frequently drew on a discourse of rights and entitlements to screening for women of this age. This kind of discourse stands in contrast to those that have focused upon women's responsibility to attend and shifts the onus of responsibility onto those providing screening. This focus upon rights goes further than the idea of need discussed above as the assertion is that, not only do women over 64 years still need screening, they are being denied a service to which they should be entitled.

In drawing the new material presented within this thesis together we can gain an overview of the resistance found within the context of cervical cancer screening and how this is influenced by the kind(s) of power being exercised through the official discourse and by the particular context and circumstances. I have discussed how power is exercised through the official discourse in terms of its implicit claims to objectivity, scientificity and 'truth' and the way in which it encourages women to think about and understand screening in particular ways. It is possible to see two main forms of resistance to this emerging within the research. The first comes through the clear process of individualisation that women engage in, in order to work out their own personal and individual positions in relation to the very general official discourse. Throughout the thesis I have discussed this type of resistance in two particular forms: the individualisation of the experience and meaning of screening found in Chapter 7, and the self-positioning in relation to cervical cancer risk found in Chapter 8. Both of these essentially come down to women resisting the general subject position suggested to them through the official discourse, drawing instead on their personal experiences, beliefs, characteristics and circumstances in order to work out and negotiate a space for themselves as individuals.

The second main form of resistance identified is less individual in nature, although women's individual understandings and perspectives do play a role in how the resistance is pursued, and was discussed in Chapter 9. Here resistance comes through women's reluctance and refusal to think about cervical screening, and the cancer itself, in medically 'correct' terms, instead creating and employing their own understandings to produce very different conceptualisations, and making arguments for changes to screening provision on the basis of some of these. Therefore, although there are aspects

of individuality within this second type of resistance, the focus is not on individualisation in quite the same way. Women are producing alternative conceptualisations of, and discourses on, such things as cervical cancer risk factors, causal pathways for these, and the incidence and development of the disease. These are not produced in terms of applying to them as individuals and playing a role in the working out of a particular subject position, instead they can be applied to women more generally. Therefore, in contrast to the focus upon themselves as individuals within the previous type of resistance, in the second the emphasis is on cervical screening, cervical cancer and women more widely.

As I have emphasised throughout the thesis, the types of resistance identified within cervical screening are mainly located at the thought or talk level and constitute women producing alternative conceptualisations of, and discourses on, screening through the employment and incorporation of a range of resources. While there are notable and interesting exceptions to this in which women pursue their resistance through into behaviour, for example by reducing or ceasing their attendance for screening, these represent a minority. In considering the types of resistance shown it is vital to take into account the context in order to fully understand both the potential for resistance and the limitations that may be placed upon it.

Within the official discourse power is exercised through the way in which women are encouraged to think about and understand screening. There is no overt coercion to attend within this material; instead screening is presented in such a way as to encourage women to attend through their apparent choice. This reflects the ideas on neo-liberal forms of government discussed in earlier chapters. Indeed, as I have continually argued, searching for resistance solely at the level of attendance is misguided as this simple dichotomy cannot adequately represent the diverse range of positions that women adopt nor the complex interplay of factors that influence these. Further, an assumption that attendance for screening represents a full and unquestioning acceptance of the official discourse, and therefore the lack of any resistance, is problematic as it inevitably leads to the conclusion that the vast majority of women occupy such a position. My research has clearly demonstrated that this is unlikely to be the case. Instead, in the following section, I return to my argument for thinking in terms of the existence of a complex network which contains multiple points of potential difference or divergence. Within

this, slight variations in interpretation or understanding can potentially lead to a diverse range of outcomes. As I suggested in the introduction to this chapter, in the context of cervical cancer screening, there exist many points at which women may simply accept the official discourse, or more commonly particular aspects of it, or they may interpret, understand or negotiate these in such a way as to lead them to refuse or resist. I wish to suggest that, not only does such resistance exist in response to the power exercised through the official discourse on screening, it also has a power of its own.

10.3 The Power of Resistance

This research has been framed theoretically in terms of Foucault's work on power and resistance and, in particular, has sought to explore and further develop his later writings on 'technologies of the self' as the means through which resistance can be demonstrated. This locates the potential for resistance at the level of everyday life and, through this, large scale cultural patterns need not be perfectly reproduced at the individual level. Instead, a more flexible relationship between discourse and the individual is suggested, with individuals seen as having the potential for interpretation rather than the process being one of straightforward imposition. However, Foucault argues that the practices used in such resistance are not simply invented by the individual but are suggested through their culture and society. It is through the individual's creative use of these that resistance is possible (Foucault 1984c).

Through the application of these theoretical ideas to the case of cervical cancer screening, I have sought to explore women's resistance to the official, state level discourse that surrounds this. It has consistently been shown that women do not unquestioningly and passively adopt this discourse, and the assumptions, understandings and meanings within it, in terms of a straightforward imposition. Instead, this thesis has demonstrated a much more dynamic process with numerous points for potential difference, divergence and resistance. This leads me to argue that, rather than a one-dimensional conceptualisation, we need to conceive of this process in terms of a complex web of potential points of resistance which may ultimately result in individual women adopting very different stances or positions. As such, it is important to recognise that resisting is not a homogenous process. I have shown in some detail that women resist in different ways, employing different resources and pursuing their resistance to differing degrees using a range of strategies. This approach to

conceptualising resistance mirrors Foucault's ideas on how power should be thought about. In the same way that power is seen as being diffuse and dispersed, present within all social interactions, I would argue that resistance can also be thought of in such terms. Therefore, the conceptualisations of resistance produced in this study fit well with feminist arguments that resistance cannot be reduced to a single locus and that attention needs to be focused on how women can be 'negotiating at the margins of power' (Davis and Fisher, 1993:6).

During the process of working out a definition of resistance to be used throughout this thesis, I engaged with a range of existing empirical studies of resistance in order to explore the potential forms that it may take. It is useful here to look back on these and to compare the kinds of resistance ultimately found within this study to these. This also allows a consideration of the importance of context in influencing the potential for resistance in different circumstances.

In the case of cervical screening, this study has demonstrated that resistance is concentrated mainly at the level of thought and talk, and involves the production of alternative conceptualisations of, and discourses on, screening. As such, the kinds of resistance identified stand in contrast to studies in which resistance has manifested itself clearly at the behavioural level, for example Rogers and Pilgrim's (1995) study of parents refusing to immunise their children and Gold and Ridge's (2001) research on HIV-positive gay men's refusal of antiretroviral therapy. These examples involve some degree of confrontation with health professionals as these interventions or treatments are offered and, especially in the case of childhood immunisation in the UK, the expectation is that they will be accepted. From the outset I recognised that, given that coverage rates routinely exceed 80%, it was unlikely that this kind of resistance would be widespread in the context of cervical screening. Indeed, I have continually argued that such a focus on attendance/non-attendance would have been misguided.

However, refusal is not the only form of behavioural resistance that was identified within the studies and that is possible. There may be different possibilities for behaviour-based resistance in response to a discourse that advocates an ongoing practice, for example in the case of infant feeding (Murphy, 1999, 2003) or childrearing (Bloor and McIntosh, 1990). These contexts involve discourses encouraging individuals

to behave in particular ways over an extended period of time, the vast majority of which cannot be subject to close scrutiny or surveillance as it takes place outside a medical setting. In these cases there exists the potential for behaviour which runs counter to that prescribed, for example formula feeding or early weaning, which need not come to the relevant health professionals' attention. As discussed in Chapter 4, Bloor and McIntosh (1990) have suggested that this is likely to be the most common form of resistance precisely because it can be concealed and therefore any possible confrontation avoided. Cervical screening though does not fit into this kind of model and, consequently, women do not have the opportunity for this kind of resistance. This is because, even though screening is ongoing in the sense that it routinely continues for approximately forty years of a woman's adult life, she is not being screened continually throughout this period. Instead, screening takes place once every three or five years, representing a series of separate instances rather than a continual process. This removes the potential for ongoing resistant behaviour that can be concealed, as women are required to present themselves for regular smear tests that only health professionals can perform, interpret and report the results of.

Resistance in the case of cervical screening is therefore limited by context and in attempting to conceptualise and explore this we need to look beyond the simple dichotomy between attendance and non-attendance. Instead, we should focus upon the level at which discourses are negotiated, interpreted and made sense of, as it is at this level that women are most active. Past empirical studies have focused on this level and have explored how lay individuals have produced alternative conceptualisations and discourses in different cases, for example the understanding and employment of the concept of risk in prenatal testing (Markens *et al.*, 1999), the privileging of experiential knowledge in prenatal care (Browner and Press, 1996), the pursuit of non-medical understandings of erectile dysfunction (Potts *et al.*, 2004) and challenging the stigma of childlessness in South India (Riessman, 2000). This is very much the level at which the majority of resistance to the official discourse on screening is located, with only relatively few examples being pursued into behavioural resistance. However, this does not mean that such resistance is meaningless or is not worthy of sociological attention. On the contrary, I argue that such resistance, aside from being intrinsically interesting in its own right, is important for the potential and power that it has, and for what it can

contribute to a Foucauldian understanding of the relationship between power and resistance.

The resistance documented here has demonstrated that women do not passively and uncritically accept the official discourse on screening, and the general subject position it presents to them, as a focus on coverage levels and attendance rates might suggest. This thesis has argued that such an assumption is both misleading and dangerous as it suggests attenders have accepted the official discourse while non-attenders have not. In contrast, I have shown that the situation is considerably more complex and that women's engagement with this discourse is a much more varied and dynamic process in which screening, and the cancer itself, are made sense of and understood in ways that are meaningful to individual women. This can lead to women resisting the general subject position and adopting a diverse range of positions in relation to the official discourse. This thought and talk level of resistance, based on interpretation, negotiation and transformation, is important, and powerful, precisely because of its ability to influence how women understand and think about screening. It provides the means through which the general subject position, presented through the official discourse on screening, can be resisted and a diverse range of alternative positions created and explored. This resistance is therefore creative and productive in nature, potentially leading to further and different forms of resistance.

This thesis has demonstrated how it is possible for women to develop alternative conceptualisations and discourses on screening, that run counter to the official, on the basis of such thought and talk based resistance, and to translate these through into behavioural resistance. I have shown that it can, albeit in a minority of cases, influence women's level or frequency of attendance, for example the non-attendance of Muslim women before marriage or the intermittent or non-attendance of those who perceive themselves to be at little or no risk. Such resistance is therefore powerful enough to challenge the official discourse and to gain a dominant position in determining behaviour, not just for individual women but also for whole social, cultural or religious groups. I do not suggest that resistance at the level of thought and talk necessarily leads on to behavioural resistance, indeed the data presented in this thesis cannot support such an assertion. What I do wish to argue is that such thought and talk based resistance be seen as a necessary precondition for behavioural resistance. It does not necessarily lead

to it, but is a necessary precondition for it. As I have made clear throughout, there is at present relatively little behaviour based resistance to cervical screening in the UK context, although it may be more pronounced within some groups than others. It is interesting to consider what may be needed to prompt an increased move from the kind of thought and talk resistance discussed in this thesis to behavioural resistance. Say that there was a national cervical screening scare, perhaps comparable to the recent case of MMR vaccination, in which the intervention itself was seen to be potentially harmful, hypothetically, that the process of scraping cells from the cervix in order to check them for abnormalities somehow weakened or damaged the cervix and therefore made HPV infection more likely. Without the preceding thought and talk level resistance, in which alternative conceptualisations and discourses can be produced and explored, and need not be linked to such a scare, behavioural resistance is unlikely. If we imagine, in this hypothetical example, that the official discourse on screening maintains that the procedure is safe and does no harm, then women who have not practised such thought and talk resistance will have nothing upon which to base behavioural resistance.

In conclusion, this thesis has demonstrated that women can be active in resisting the power exercised through the official discourse on cervical screening and the general subject position that this presents. The relationship between discourse and the individual is therefore more flexible than one of straightforward imposition. I have argued for this to be conceptualised as a complex web of potential points of resistance, with women's engagement a more dynamic process in which screening is understood and made sense of in ways that are meaningful to them as individuals. The resistance identified has predominantly been located at the thought and talk level, but in this concluding chapter I have argued why this is still of sociological interest and significance. Firstly, such resistance represents the means through which women can challenge the official discourse on screening and the general subject position it suggests to them, thereby acting as a positive and productive force through which alternative possibilities and positions can be developed and explored. Secondly, resistance at such a level constitutes a necessary prerequisite for the development of behavioural resistance. It is for these two key reasons that the kind of thought and talk level resistance demonstrated throughout this thesis, which is relatively invisible and missed if the focus is solely upon attendance/non-attendance, is important and powerful.

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Appendices

Appendix 1: Information Sheet

WOMEN'S VIEWS OF CERVICAL SCREENING

A study to explore how women understand cervical screening and how they feel about it

PhD RESEARCH PROJECT

Natalie Armstrong
School of Sociology and Social Policy
University of Nottingham

If you decide that you would like to be involved in my research then this would entail an interview with me that will last approximately 1 hour.

This interview will cover issues such as your understandings of screening, your experiences of screening and your thoughts about cervical screening in general.

Everything that you say in the interview will remain <u>strictly confidential</u> and will not be shared with anybody else.

3. How to Get Involved
If you are interested in taking part in my research then I would be delighted to hear from you. My contact details are printed on the back of this leaflet, along with some common questions. When you contact me I will provide you with more information and will be happy to answer any questions.

1. Reasons for the Research
My aim in conducting this research is to explore the ideas women have about cervical screening and how they feel about it. Your views are important as cervical screening is offered to the vast majority of women in England. I feel that a more complete understanding of women's feelings and understandings of it will be very useful and may have an impact on future cervical screening provision.

2. What Participation Will Involve
I am keen to talk to women from all backgrounds and with all experiences of cervical screening. The only thing I would ask is that you are between 20 and 64 years of age. This is because cervical screening is only currently offered to women between these ages.

4. Some Questions You Might Have
Q. Who is being asked to participate?
A. Women from all backgrounds, as long as they are aged 20-64 years
Q. What if I don't know much about cervical screening?
A. I want to talk to women with all levels of knowledge. Don't worry about giving the 'wrong' answers, there aren't any!
Q. What if I don't go for screening?
A. I am particularly interested in talking to you as your views and opinions are of relevance to my research
Q. Will you tell my GP what I say?
A. No. All discussions will be strictly confidential.

FOR FURTHER DETAILS PLEASE CONTACT

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(to minimise your costs I am happy to call you back)

Appendix 2: Interview Schedule

<u>Introduction</u>

- I'd like to start by thanking you for your time and for agreeing to be interviewed, it's very much appreciated

- I'd also like to assure you once again that anything you say will be treated in the strictest confidence and that any material used in the writing up of the research will be anonymous

- The interview will probably last about an hour and I'll be asking you some specific questions and also asking you to talk about some scenarios that I've come up with

- Although I'll be asking the questions, do please feel free to suggest something that you would like to talk about if you think there is an issue I've overlooked or that you feel is particularly important to you and we haven't covered so far

- Do you have any questions before we make a start?

<u>Cervical screening history</u>

- I'd like to start by asking you to tell me a little bit about your experiences of the cervical screening programme and your history within it

- It's probably easiest if you start in the present, telling me about your last smear test, and work backwards

- Don't feel that you have to tell me your specific test results if you don't want to, I'm probably more interested in your feelings, opinions and attitudes

- Pick up on any immediately interesting things, such as attendance/non-attendance, strong views/opinions or particular experiences

- Ask them if they can say a bit more about that and try to draw out reasons

<u>Understandings of screening</u>

- If we could move on now to talking about cervical screening itself and maybe I could ask you to tell me what you see as its purpose and what it aims to do

- Pick up on any immediately relevant/interesting aspects of their response

- If they have mentioned preventive role of screening then ask what they think about the idea of prevention, both in the specific case and more generally

Information about screening

- Can I ask you where and/or who you get your information about screening from?

- Do you read the information that you receive for example? (show them the leaflet)

- Do you get information from any other people or places?

- Do these different forms of information ever contradict each other?

- Do you consider any source of information as more reliable than others?

- If so, which and why?

- Does the information that you have received match your own experiences?

Importance of screening

- Do you feel that cervical screening is particularly important to you?

- Explore any answer given

- Is cervical screening equally important for all women? What I mean by that is do you think there are some women that definitely should go for screening, while for others it isn't so important?

- If so, who and why?

- Can you tell me why you think that?

Cervical cancer

- Would you consider cervical cancer to be one of your main health concerns?

- Ask them to consider why/why not

- Does this have an effect on how you think about screening and whether you attend?

- Ask them if they can say a bit more about this

Effectiveness of screening

- I'd like to know whether you think cervical screening is effective?

- Can I ask you to say a bit more about that and tell me why you think that?

- Have you ever heard or experienced anything that might have changed your mind?

Vignettes

- I'd now like you to consider some scenarios that I've made up

- Just have a think about them for a couple of minutes and then tell me what you think about each

- Hand them the vignette sheet and give them a couple of minutes to think about them

- Go through them one at a time and explore responses

Anything else

- We've now covered all the areas that I specifically wanted to talk about, is there anything else that you would like to cover?
- Please feel free to suggest something as it's unlikely I've thought of everything!

End

- I'd like to thank you once again for your time and for an interesting discussion
- You've been very helpful and if you have any questions or concerns after I've left then do please contact me

Appendix 3: Vignettes Used During Interviews

Jessica is 23 years old and has a long-term boyfriend. Her first smear test was normal and she has been told that her second smear test is now due. She is not sure whether to attend as she finds it embarrassing and painful.

Lucy is a 34 year old mother of two young children and works part-time. She has been married to David for eight years. She is very busy and doesn't consider screening to be a high priority.

Angela is 48 years old and has one grown up son. She is divorced and has had a couple of short-term relationships in recent years. She is now single and attends regularly for screening.

Sheila is 62 years old and has been through the menopause. She used to attend regularly for screening when she was younger but doesn't think she needs it any more.