“Women with learning disabilities and carers experiences and views of cervical screening”

A research project undertaken in South Central and South West Edinburgh LHPs and in Lothian

Full Report

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July 2006

Supported by The National Lottery® through the Big Lottery Fund
BIG LOTTERY FUND

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Acknowledgements

The Healthy Woman's Project would like to thank the women and carers who agreed to participate in this research project. We would also like to extend our gratitude to the many organisations in Lothian who agreed to act as gatekeepers for the project and identified and approached possible participants on behalf of the project.

The project would like to thank the following individuals and groups:

- Michael Brown, Learning Disability Nurse Consultant and Research Fellow, Greenbank Centre, Royal Edinburgh Hospital.
- Antonia Ineson, Senior Health Policy Officer, Deaconess House.
- Joan Fletcher, Clinical Effectiveness Facilitator, Clinical Governance Team, Edenhall Hospital.
- Anne King, Clinical Governance Team, Edenhall Hospital.
- Members of Edinburgh People 1st.
- Members of Edinburgh People 1st Women's Group.
- Claire Morrison, Senior Secretary (now left), The Healthy Woman's Project.
- Gill Reid, Assistant Manager, FAiR, Edinburgh.
- Mary Siggs, Speech and Language Therapist, William Fraser Centre, Royal Edinburgh Hospital.
- Carol Turnbull, Community Learning Disability Nurse, Grange Loan, Edinburgh.
- Dr Rebecca Walton, Consultant in Public Health Medicine, Deaconess House.
- Diane Willis, Research Associate, University of Edinburgh.
- Dr Rachael Wood, Specialist Registrar in Public Health Medicine, Deaconess House.

Executive Summary

Background

The Healthy Woman's Project (HWP) undertook a one year action research project that explored the views and experiences of women with learning disabilities and carers regarding cervical screening in South Central and South West Edinburgh Local Healthcare Partnerships (LHPs) and in Lothian.

The project was initiated to address local and growing national concern that women with learning disabilities are excluded, often by default, from the cervical screening programme.

This research project builds on and contributes to a wider body of work undertaken on cervical screening and learning disability in Lothian. These findings have provided a local evidence base to develop a targeted approach to improving access to cervical screening for women with learning disabilities, within a wider context of tackling health inequalities.

Methodology

The research approach included the following steps:
- In-depth qualitative interviews were conducted with ten women with mild to moderate learning disabilities. Data was analysed thematically.
- A postal questionnaire was distributed opportunistically to 885 carers of women with a learning disability across Lothian. Data was analysed for frequencies using SPSS 13.0 for Windows.

Findings

The key findings of the research can be summarised as follows:

- The majority of women reported that they were invited for cervical screening through letters sent out as part of the routine and local practice-based call and recall system. This was also reflected in the carer's questionnaire. For some women this was problematic. The woman's literacy skills affected how she understood the invitation letter, as some women were reliant on the support others to understand the contents of the letter. None of the women received letters which were adapted to their levels of literacy or understanding.

- Some women reported that they had opportunistic discussions about screening with their health professional. It was clear that opportunistic screening had a role as this provided more personalised approaches to invitations, but care must taken how this was done. Some women reported being confused and anxious when cervical screening was introduced during a consultation about a completely unrelated health issue.

- A minority (30%) of the carers reported that the woman they cared for had ever had a smear test. A notably greater proportion of paid carers (at 44%) than family carers (at 8%) reported that the woman they cared for had ever had a smear test. 51% of the total carers respondents reported that the woman they cared for had never had a smear test, with a conversely greater proportion of family carers (at 84%) than paid carers (at 29%) reporting this.

- Women and carers reported that initial information on cervical screening was commonly gained through informal support networks, including friends, family and in women's magazines. Health professionals commonly provided further information about screening during the appointment for the smear test. How successfully the woman understood and assimilated the information given to her at the time appeared to be dependent on both the approach and gender of the health professional.

- Women commonly didn't make the link, nor were supported to make the link between risk factors for cervical cancer and their eligibility for the test. They were asked by the health professional about their sexual and smoking activities, but no explanation was given by the health professional as to why they were asking these specific questions. Carers frequently commented on their lack of knowledge in this area, and highlighted the need for information to specifically address this.

- Both women and carers reported the great variance in the extent to which women were actually involved in the decision to have or decline a smear. Whereas some women were central to the decision, others were largely excluded from it.

- Decisions were made for women by health professionals that rested in a number of cases on assumptions about the woman's sexuality. Some women interviewed were assumed to be sexually inactive on the basis of their disabilities (both physical and learning disabilities) without being involved in a discussion about their sexual histories. However, women were also assumed by their health professional to be problematically sexually active which led to inappropriate screening and some trauma.

- In some cases, women's consent to screening was not well-informed and they had a smear test with little idea of the precise risks and benefits of screening. The decision made to have a smear was also affected by a range of factors that included wider life experiences and views. Carers reported that preparation – including the woman being offered and accepting a preparatory consultation to discuss screening facilitated the decision making process.

- In general, the smear test experiences of women with learning disabilities do not differ significantly from those of non-learning disabled women. Factors reported by women and carers that facilitated the woman's experience included the approach and gender of the smear taker and familiarity with the smear taker.

- Most women interviewed reported that they went without support and stressed they did not want support to attend. During actual procedure, the majority reported that they wanted test *"over and done with."* Anxiety was common regardless of past smear experiences and women commonly experienced test to be uncomfortable and sometimes painful. Health professionals commonly advised the woman to relax but did not give any indication or explanation of how to do so.

- Those women who had had abnormal results wanted something to explain what these might mean. In particular, some women wanted information on what abnormal and unsatisfactory results were, what treatment is offered and the efficacy of the treatment. This points to the importance of making good the paucity of adapted resources in this area.

Recommendations

1. Uptake of cervical screening and relationships with carers

1.1 Health practitioners should draw on a woman's carer for knowledge of how she prefers to communicate, but not on actual decision-making.
1.2 Health practitioners should negotiate with family carers about the importance of the woman being able to have a private space during consultation, if she so chooses.
1.3 The development of a carers guide in supporting a woman with learning disabilities through cervical screening is required. This will contribute to the carer being as informed as possible on all aspects of cervical screening and service provision.

2. Being invited for cervical screening

2.1 If health practitioners are discussing screening opportunistically during a patient consultation, they must take care to explicitly separate cervical screening from the issue which initially prompted the consultation.
2.2 Should a male practitioner broach the issue of cervical screening with a woman, they should consider offering her another appointment with a female colleague for a more sustained discussion.
2.3 On receiving the Recommended Call List from SCCRS, practices may choose to cross check with the QOF Learning Disability Register to identify a woman with a known learning disability to follow-up the standard invitation letter by phone or face to face contact.
2.4 On receiving the Defaulters List from SCCRS, practices may choose to cross check with the QOF Learning Disability Register to identify a woman with a known learning disability and to use this opportunity to send supporting materials to the identified woman.
2.5 As a minimum, practices should flag the woman's general notes to allow screening to be discussed during a future consultation.
2.6 Women with learning disabilities who are on early recall and fail to attend should be proactively offered a specific consultation to discuss the issue.

3. Cervical screening: information, knowledge and eligibility

3.1 The production of pictorial leaflet in a range of formats is required for women and carers which specifically describes eligibility for cervical screening, and risk factors for cervical cancer.
3.2 This leaflet should be used in practices to support health professionals in their discussions with women about their eligibility for screening.
3.3 The production of a pictorial leaflet in a range of formats is required for women and carers which describes the smear test from invitation onwards.
3.4 When issuing supporting materials, practices should routinely use this leaflet for their learning disability patients.

4. Decision-making about cervical screening

4.1 A guide for health practitioners is required that gives advice on good practice in consent to cervical screening including checking understanding of cervical screening; how to establish eligibility for screening; consequences of screening and free choice; and within this include tips to assisting communication.
4.2 The provision of training to health practitioners is required to raise the topic of power issues between practitioner and patient.

4.3 NHS Lothian local community learning disability nurses have developed a tool for assessing the sexual health knowledge of people with learning disabilities. Practitioners should consider drawing on their advice, or directly involving them, if further input on sexual health is required.

5. Preparation for a smear test

5.1 How to best to prepare a woman for cervical screening is highly individual. A guide for health practitioners is required to prompt the practitioner to consider a range of options to facilitate preparation.

5.2 Primary care and community learning disability teams should work closely together to ensure adequate preparation. The community learning disability team can have an important role in preparing a woman in having a smear. Speech and Language Therapists have a specific role in supporting and facilitating communication.

5.3 A range of resources are required for women, carers and health practitioners to facilitate preparation including a range of health information resources and relaxation training.

6. Experiences of the smear test

6.1 How to best to carry out the smear test is highly individual. A guide for health practitioners is required to highlight the ways in which screening can be sensitively provided to meet the needs of women with learning disabilities. This can include consideration of:

6.1.1 Offering the woman the choice of whether she wants another practitioner with her for support during the procedure, or her carer, if she has one.

6.1.2 Where possible, ensuring that the smear taker is female and familiar to the woman.

6.1.3 Providing opportunities to allow sufficient time to explain to the woman how the sample is taken before taking the smear.

6.1.4 Any physical limitations with regards to the practice environment for women with a physical disability and where required, offer a viable alternative.

6.1.5 If the woman is physically disabled, practitioners should offer the woman a choice of position and in particular, lying on her side.

6.1.6 If the woman is resistant or uncooperative, stop and offer her another appointment and consider including relaxation training.

7. After the smear test. Results, abnormalities and treatment

7.1 There is a 7 day gap between SCCRS informing practices of results and issuing letter to the woman. When an alert comes to practices about an abnormality, practices should cross check with the QOF Learning Disability Register to identify a woman with a known learning disability and she should be proactively invited for a consultation to discuss the results and possible interventions.

7.2 Accessible leaflets on (1) abnormal cervical smear results and (2) colposcopy and cervical screening treatment respectively are required to be developed.

Box 1. Definition of a Learning Disability

When defining the term ‘learning disability’, the Healthy Woman’s project has used the same definition of a learning disability as The Same as You? (2000) This national policy document on learning disabilities defines a learning disability as a significant, lifelong condition that has three facets:

- reduced ability to understand new or complex information, or to learn new skills;
- reduced ability to cope independently; and
- a condition that started before adulthood (before the age of 18), with a lasting effect on the individual’s development.

Learning disability can be categorised into mild, moderate, severe or profound. However, there is little agreement on the definition of different levels of severity of learning disability and these categories can be used to generally suggest the level of disability. Nonetheless, people with learning disabilities are a heterogeneous group with different skills, strengths and support needs (NHSCSP, 2000).

Box 2. Prevalence of learning disability

Approximately 2 adults in every 100 (2%) of the population have a mild/moderate learning disability and 3-4 adults in every 1,000 have a severe learning disability (The Same as You?, 2000).

The average GP’s list will have up to 40 patients with a mild to moderate learning disability, including up to 8 with a severe learning disability (Barton et al, 2005). Only a small number of people with learning disabilities are known to specialist learning disability services. It has been estimated that in Scotland, around 25% of people with a learning disability are in regular contact with specialist health and local authority services (The Same as You? 2000).

Box 3. Principles of screening

Screening can be defined as offering a test to an apparently healthy person to ascertain if they are likely to have an early stage of a particular disease so that they can be offered further investigation and treatment to improve their eventual outcome. Screening can be provided through organised formal population wide programmes, or offered and provided opportunistically, when the person comes into contact with health services (Wood, 2004).

Integral to the nature of screening is its risk reduction. The National Screening Committee emphasises this and defines screening as, "…a public health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by a disease or its complications, are asked a question or offered a test, to identify those individuals who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications" (National Screening Committee, 2000). The ethics of screening, in that screening at a population level has its limitations, are fundamental to the process of offering and providing cervical screening. This is recognised by the National Screening Committee in that it emphasises that participation in screening must be based on informed consent.

Box 4. Risk factors for cervical cancer

The major risk factor for cervical cancer is infection with certain strains of human papilloma virus (HPV), in particular HPV 16 and 18. Women who have ever been sexually active are likely to have been exposed to HPV at some point. Persistent infection with 'high risk' forms of HPV is linked to an increased risk of an abnormal cervical smear.

Other risk factors for cervical cancer include early age at first intercourse, multiple sexual partners, having a partner who has had multiple partners, early first pregnancy, long term oral contraceptive pill use, smoking and non-attendance for cervical screening (Stuver et al, 2000; Schiffman et al, 1999).

Box 5. Scottish cervical screening programme and the cervical smear test

The Scottish cervical screening programme aims to reduce the incidence of and mortality from cervical cancer. It does this through offering women aged 20 – 60 a cervical smear once every 3 years.

The cervical smear test is used to examine a sample of cells from the cervix. This allows for abnormal cells in the cervix to be detected and treated. If left untreated, these may develop into invasive cervical cancer.

Ineligible women are defined as those with congenital absence of the cervix, or a previous total hysterectomy for benign disease.

Box 6. Uptake of and the results of cervical screening in Scotland and in Lothian

Since the inception of the Scotland-wide programme, there has been a 34% reduction in both incidences of invasive cervical cancer and mortality from the disease (NSD). This has been attributed largely to the prevention of pre-cancerous changes in the cervix and effective treatment of these as a result of cervical screening. In the year 2000, take-up of the service stood at 86.7% (Scottish Executive, 2001) in Scotland as a whole and 81% in Lothian (NHS Lothian, 2001). There is no reliable information available regarding the uptake of cervical screening by women with learning disabilities in Lothian.

The results of the cervical screening programme in Lothian are comparable to those in other areas of Scotland. In Lothian in 2003, 81% of eligible women had been screened in the previous 3.5 years and 85% in the previous 5.5 years. 87% of the smears taken were normal, 6% were unsatisfactory for the purposes of screening, and 7% showed some abnormality (NHS Lothian, 2004).

1. Introduction

This report describes the findings of a research project that aimed to explore the experiences and views on cervical screening of women in Lothian with learning disabilities, and their carers or supporters.

The project ran over a year from January 2005 and was designed to inform a three-year project, The Healthy Woman's Project (HWP). HWP, the first project of its type in Scotland, aims to pilot ways of improving the quality of, and access to, cervical screening for women with learning disabilities in South Central and South West Edinburgh Local Health Partnerships, and to document local good practice which can be adapted for use across Lothian and more widely within Scotland. The project was initiated to address local and growing national concern that women with learning disabilities are excluded, often by default, from the cervical screening programme.

The research reported on here builds on and contributes to a wider body of work undertaken on cervical screening and learning disability in Lothian by the HWP project team and others. This includes:

- an audit of existing practice in primary care regarding cervical screening for women with learning disabilities undertaken in 2004 in the same localities by Rachael Wood from the Public Health and Health Policy Directorate of Lothian NHS Board; and

- a series of consultation events held by the HWP project in 2005 with Edinburgh People 1st Women's Group on improving aspects of cervical screening, including testing a range of accessible resources on cervical screening and the smear test.

The two pilot LHPs in which the HWP is based are in inner-city Edinburgh. Together, they contain 26 GP practices and cover approximately 20% of the population of Lothian (Wood, 2004). There are some differences in their respective populations: SCELHP serves a relatively affluent population with a slightly older population profile than the Lothian average, while SWELHP serves a more deprived population.

The research project, while developed to inform subsequent phases of the HWP, has wider significance. It is unusual in eliciting the views of women with learning disabilities themselves, who are more commonly 'spoken for' by proxies in health-related research. This report reflects on the methodological challenges posed by making women with learning disabilities central to the research process, and adds women's voices, as well as those in their wider networks, to the growing research literature on cervical screening and learning disability.

2. Background: Existing services: Learning Disability services in SC/SW LHPs

There are two community learning disability teams covering South Central and South West Edinburgh LHPs respectively that include a range of professionals, for example Community Learning Disability Nurses, Speech and Language Therapists, Occupational Therapists, Physiotherapists and Psychiatrists. Practitioners provide support and input to people with learning disabilities regarding aspects of their health on a one to one basis, and offer and facilitate support to groups.

2.1. Background: Policy and Practice in relation to Learning Disability

Over the last two decades there has been a considerable shift in the way services and support for people with learning disabilities have been provided. This has been reflected in the closure of long-stay institutions nationally and the provision of community based services and supports designed around people's needs and wishes, and the increased emphasis on Primary Care and general hospital services in providing care for people with learning disabilities.

These moves have been supported by successive waves of policy and legislation designed to bring about the rights of people with learning disabilities to social inclusion and participation and to protection from abuse. *The Adults with Incapacity (Scotland) Act 2000* provides a legal mechanism for gaining consent or acting on a person's behalf when they do not have capacity to give or withhold consent. The *Disability Discrimination Act 1995* makes it illegal to discriminate against people with disabilities in employment, access to goods, services, transport and education. DDA 2005 amends the 1995 Act, putting a positive duty on public bodies to promote equality of opportunity and of provision. Health-related policy and recommendations for action have been developed within the framework provided by these acts.

In Scotland, the publication of *The Same as You? (2000)* set the national policy for health and social care services for people with learning disabilities and emphasised the rights of access to employment, public life, lifelong learning and to active participation in the community. The contribution of nurses and midwives to the care and support of people with learning disabilities is described in the National Nursing Review *Promoting Health, Supporting Inclusion (2002).* The *NHS Health Scotland Learning Disability Needs Assessment (2004)* report identified actions and recommendations to ensure the health needs of people with learning disabilities are effectively addressed.

Further changes in healthcare provision are currently underway to encourage care of the optimum quality in Primary Care for people with learning disabilities. The revised General Medical Services 2006-2008 contract offers considerable potential in this area. Its associated Quality and Outcomes Framework includes incentives (for the first time) for GP practices to encourage the establishment of learning disability registers. This forms the first step in ensuring better clinical management of learning disabled patients. There is the potential to build on this with the introduction in Scotland of Direct Enhanced Services for adults with learning disabilities. This should encourage GP practices to identify and address any barriers to access for people with learning disabilities to treatment and appropriate screening.

2.2. Background: review of relevant research literature and guidance

The literature relevant to this project includes that on:

- uptake of cervical screening amongst women with learning disabilities;
- the factors influencing this; and
- the more general literature on the factors influencing access to Primary Care for people with learning disabilities. This is important because cervical screening is provided largely within Primary Care, and Primary Care will continue to be pivotal to the call and recall system following the roll-out of SCRRS in Lothian in December 2006.

In summarising findings from the relevant bodies of literature, the project team has drawn closely on a systematic review carried out by Rachael Wood prior to her local audit of Primary Care practice, and on a review carried out to support the original application to the Big Lottery Fund for the project's funding. These reviews on Primary Care, cervical screening and learning disability have been updated regularly by the project team as new literature has become available. Project staff also carried out a search on appropriate methodologies for carrying out research with people with learning disabilities; made contact with local and national researchers in learning disability with tacit knowledge of the field; and have drawn on the experience of those involved in other local health-related initiatives in relation to people with learning disabilities - for example the Better Health Through Better Communication project (Hartley, 2003).

Finally, the project has also drawn on a comprehensive review of the literature on barriers and facilitators to cervical screening amongst the general female population carried out within Lothian's Directorate of Public Health and Health Policy (Regnauld, 2003) and findings from a study on experiences of cervical screening amongst the general population of Lothian female patients in Harthill (Milne et al, 2004). This more general literature, whilst not summarised in this section, has informed the discussion of findings from the current project, enabling the project team to tease out in the analysis those issues which are likely to be specific to women with learning disabilities from those which arise as themes in the more general literature on experiences of cervical screening.

Research on access to both primary care and cervical screening has been almost exclusively Primary Care-based and reflects the practices and opinions of health professionals. Whereas this small body of work has produced some valuable data on the possible and probable barriers inhibiting access of women with learning disabilities to cervical screening, the paucity of information on the views and experiences of women with learning disabilities themselves represents a major gap in this field of research.

2.2.1 Access to primary health care for people with learning disabilities

Evidence shows that people with learning disabilities have greater health needs, and a different pattern of health problems compared to the general population (Cumella et al, 1991). With the closure of the institutions which previously formed the focus for the organisation of their health care, mainstream services, and particularly Primary Care, have become increasingly pivotal to meeting the health needs of people with learning disabilities. Estimates of Primary Care consultation rates amongst people with learning disabilities vary, with studies of GP case notes suggesting a consultation rate higher or comparable in frequency to those amongst the general population and carer-based reports suggesting a rate lower or comparable (Stein and Ball, 1999; Langan et al, 1994). Evidence further suggests that consultation rates are higher for those living in care homes compared to those living alone or with their families (Lennox et al, 2003; Howells, 1986).

There is, however, evidence of significant levels of unmet health need, as manifest in the significant reported prevalence of undiagnosed or inadequately-managed health problems (Rogers, 1994; Singh, 1997; Kerr et al, 1996; Lennox and Kerr, 1997). Furthermore, patients with learning disabilities have also been found consistently to be less likely than the general population to receive health promotion and disease prevention interventions (Langan et al 1994; Kerr, 1996; Whitfield, 1996; Beange, 1995). Problems of access to health care may also be compounded by the fact that people with learning disabilities are more likely than the general population to experience socio-economic disadvantage (Durvasula, 2001; Beange, 2001). In sum, research findings suggest that people with learning disabilities are generally disadvantaged in their access to health services.

Evidence suggests a number of factors in the way Primary Care is provided which may underpin this disadvantage. Patients with a learning disability do not necessarily fit well into the predominantly reactive model of care, which relies on people coming forward to ask for help and that short consultations with insufficient time do not allow people to communicate in ways in which they are most comfortable (RCGP, 1990; Rogers, 1994; Beange and Bauman, 1990).

Knowledge, attitude and experience of health care professionals towards people with learning disabilities have been examined by several postal survey studies of primary care professionals. In general, these studies have identified that GPs seem willing to accept responsibility for the co-ordination and provision of primary care to people with learning disabilities (Stein, 2000; Dovey and Webb, 2000; Bond et al, 1997; Kerr et al, 1996). However, they appear less willing to accept responsibility for co-ordinating health promotion and disease prevention programmes for people with learning disabilities, and in particular to offer and provide the annual health screening increasingly recommended (for example in NHS Health Scotland, 2004 and changing recommendations for practice described above) for people with learning disabilities, principally due to the fact that they feel there is no evidence to support them (Stein, 2000; Dovey and Webb, 2000; Bond et al, 1997; Kerr et al, 1996; Plant 1997). However, one study found that GPs were able to see the value of the health checks once they had direct experience of them (McConkey et al, 2002).

A local survey of the attitudes of Primary Care providers in relation to people with learning disabilities found a generally positive approach to the capacity of Primary Care to meet their needs, and the ability of people with learning disabilities to participate in their own healthcare (Hartley, 2003). Interestingly, however, respondents who had most contact with people with learning disabilities were generally less confident than others that their needs could be adequately met within Primary Care, which the author attributes to their more realistic assessment of the current system's ability to meet their needs.

Lack of experience and training on the part of Primary Care staff in providing care for people with learning disabilities has been identified in a number of studies. Practice nurses have expressed a lack of confidence in dealing with people with learning disabilities and requested a desire for further training (Plant, 1997; Powrie, 2003). In one study, they specifically identified the provision of cervical screening for women with learning disabilities as an issue in which they require guidance (Powrie, 2003). By contrast, GPs expressed a reluctance to undertake further training on caring for patients with a learning disability, or improving communication skills (Stein, 2000; Carlson et al, 2003).

Evidence suggests that joint working with specialists in learning disability, whilst recommended in policy and guidance, is not necessarily optimised in practice. Several studies highlighted the minimal contact with and lack of understanding of the role of the Community Learning Disability Teams within primary care teams (Thornton, 1999; Stein, 2000; Powrie, 2003; Carlson, 2003).

Communication has emerged as an issue pivotal to providing care in a number of pieces of research. The problems experienced by people with learning disabilities when having to communicate about complex subjective health issues, give medical histories, and absorb and remember treatment details have been highlighted Insufficient sensitivity to and training in the range of ways in which people with learning disabilities most effectively communicate, including people who have little access to written or spoken language, creates barriers for people with learning disabilities in primary health care access (Barker and Howells, 1990; Beange, 1996; Cumella et al, 1992). Langan et al (1994) found that carers could be the barrier to raising issues to do with health promotion and screening. Howells (1986) relates this to the fact that carers' regarded such issues as 'relatively trivial' in the context of the major disabilities many people with learning disabilities live with.

Finally, appropriate services can only be targeted at patients with learning disabilities if they are known to service providers. Wood's (2004) exploration of current practice within two Edinburgh localities suggests that whereas patients with severe learning disabilities are formally identified through a recording of their diagnosis within their records, Primary Care staff are more reluctant to record a formal diagnosis where patients have milder learning disabilities, and rely on informal identification within practices. The reluctance to formally diagnose stems from a fear that formal diagnosis may serve to stigmatise patients. This fear of reinforcing stigma is echoed in the wider literature, where staff expressed wariness about returning to outdated and overly medicalised models of care and support for people with learning disabilities (Beange and Bauman, 1990; Stein and Ball, 1999).

2.2.2 Uptake of cervical screening in women with learning disabilities

Three cross-sectional studies UK have identified a significantly lower than average uptake of cervical screening amongst women with learning disabilities. (Pearson et al 1999; Djuretic et al, 1999; Stein and Allen, 1999). They identified that uptake in the previous five years of women with learning disabilities eligible for screening ranged between 13% and 24%. This compares with between 77% and 88% of the eligible female population in the respective areas. Published initiatives to improve services in general or cervical screening uptake amongst women with learning disabilities have also identified similarly low rates of uptake from baseline information (Whitmore, 1999; Biswas et al, 2005; Langan et al, 1994).

Interestingly, these findings contrast with those on uptake of breast screening, where uptake amongst women with learning disabilities is more comparable to that of the general eligible population. Biswas et al (2005) found that 77% of women with moderate to severe learning disabilities had had breast screening, an uptake rate comparable to the general population, as opposed to 16% women having regular cervical screening. Djuretic et al (1999) found an uptake of 43% amongst eligible women with learning disabilities compared with 14% for cervical screening. This suggests the importance of recognising specific issues which frame the low uptake of cervical screening amongst women with learning disabilities. More general issues (of communication and informed consent, for example) appear not to inhibit uptake of breast screening to the same extent that they do for cervical screening.

There is no information available in Lothian on uptake of cervical screening amongst women with learning disabilities.

2.2.3 Factors influencing access to cervical screening for women with learning disabilities

Two studies used postal surveys to ascertain the views of GPs about women with learning disabilities who had not had a smear test in the recommended period (Djuretic, 1999; Pearson et al, 1998). A major reason given for not having had a smear was lack of sexual activity. Other reasons given included the smear test being ‘not required’, the presence of the learning disability per se and the woman not responding to the invitation, perceived technical difficulties in performing a smear test, for example due to physical disabilities or challenging behaviours and lastly, the perceived difficulty from practitioners in obtaining informed consent. Low levels of risk due to the assumption that the woman with learning disability is not sexually active were common. Concern about consent issues are echoed in a number of other studies (Haire et al, 1992; Djuretic et al, 1999). Langan et al (1994) found that an assumption of sexual inactivity is the most common finding, although refusal by women and carers was also there.

One qualitative study used semi-structured interviews with primary care staff to examine their attitudes to cervical screening and the sexuality of women with learning disabilities (Nightingale, 2000). In general, GPs appeared sceptical of the worth of cervical screening, viewing it as clinically and cost ineffective, whereas practice nurses were more positive. Women with learning disabilities were viewed as being a difficult group who were excluded from invite to cervical screening if the practice had met its target payment.

Attitudes towards the sexuality of women with learning disabilities varied considerably in this study, ranging from ‘asexual’ to ‘promiscuous’, but also included recognition of the increasing evidence of above-average levels of experience of sexual abuse amongst women with learning disabilities. Hall and Ward (1999) found during a focused initiative to optimise screening that it was impossible to predict which women had had sexual experience.

A further reason which may inhibit the take-up of cervical screening amongst women with learning disabilities in some areas is the existence of policies suggesting that women are moved from call/recall lists on the basis of learning disability *per se* (Broughton, 2002; Broughton and Thomson, 2000).

One rare qualitative study used semi-structured interviews to explore the experiences of women with learning disabilities regarding cervical screening and their perceptions and those of their carers of the factors facilitating and inhibiting access to screening (Broughton and Thomson, 2000). Facilitating factors included adequate preparation to increase understanding of the procedure, including the use of visual aids, the approach of the smear taker and having a supporter present. Barriers included a lack of knowledge about cervical screening on the part of both women with learning disabilities and their carers, anxiety about cervical screening, and low priority afforded to cervical screening by carers. Further barriers included the difficulties women with learning disabilities reported in using appointment systems and waiting rooms. Invitations to and information about screening that is not easily understood were further inhibiting factors of access to screening. The latter is echoed in findings from other work (Djuertic et al, 1999).

2.2.4 Interventions and recommended good practice

There is little published material on interventions relevant to cervical screening. Biswas et al (2005) describe an intervention to improve the uptake of breast and cervical screening through one-to-one counselling. This resulted in a small (6%) increase in uptake of cervical screening, and confirmation that in the majority of women with learning disabilities counselled, screening was inappropriate because they were unable to consent, because it was not agreed as being in their best interests, or because they were otherwise ineligible for screening. A further initiative described support offered to one GP practice aiming to improve access to cervical screening for women with learning disabilities by a multi-disciplinary group, but reports poor response (Whitmore 1999). A final recent intervention focused primarily on the development of tools for assessing eligibility and risk amongst women with learning disabilities (Sharples, 2006). This appeared to be more orientated to helping the health professional to assess risk than involving women in this.

The NHS Cancer Screening Programmes (CSP) (2000, 2006) produced good practice guides on breast and cervical screening for women with learning disabilities. This is based on the consensus opinion of experts, on existing policy on the provision of healthcare for women with learning disabilities and based on the principle that women with learning disabilities should have the same right of access to the cervical screening programme as other women. Women should not be excluded from the programme on the basis of their disability, or the assumptions about their sexual activity. Whilst participation to cervical screening should be ideally based on informed consent, screening should still be offered if it is considered necessary and in the best interests of women unable to give consent.

The guide supports existing policy regarding the provision of general health care for people with learning disabilities and pays particular attention to the following areas to reduce existing barriers and enhance good practice: staff attitudes and communication skills, physical barriers to access, flexibility of services in providing cervical screening, accessible information and guidance on consent. Specific guidance on good practice in providing cervical screening to women with learning disabilities is outlined in Box 7.

Box 7: Recommended Good Practice in cervical screening

- To support the woman to begin to understand if cervical screening is important to her, before the topic of cervical smears is discussed, women may need information about the human body, relationships and sexuality.
- Extensive preparation may be required and provided by a range of professionals, including the primary care team and the Community Learning Disability Team as well as the woman's carer or supporter.
- Preparation should be facilitated through the use of an accessible leaflet/book and be consolidated by a visit to the surgery to meet the smear taker and see the premises, if necessary.
- Assumptions about the sexuality of the woman should not be made by professionals or carers. Be aware that the presence of a carer or supporter may be an inhibiting factor for some women to talk openly about their sexuality.
- Practices should have the flexibility to offer pre-appointments and/or double appointments to those women who require and/or request them.
- Women should be able to be accompanied by a carer or supporter at all stages of their cervical screening.
- Emphasise the woman's right to choose to have a female smear taker.
- Taking a smear test at the woman's home should be considered.
- A flexible, patient and gentle approach by the smear taker, using appropriate language can facilitate the woman's experience of the smear test.
- Both individual and group practices should consider supporting one or more practice nurses to specialise in providing care for patients with learning disabilities.

3. Methodology

The research project was conducted in two distinct phases: in-depth qualitative interviews conducted with a sample of ten women with learning disabilities and a postal questionnaire distributed to 885 carers of women with a learning disability in Lothian. These will be examined in turn. Parallel ethical permission was sought from Lothian Regional Ethics Committee (LREC) and the City of Edinburgh Council's (CEC) Social Work Department in December 2004 and approval was given, subject to minor amendments in January 2005.

The study protocol included, as a methodology, a focus group discussion with a naturally occurring group of women with learning disabilities in Lothian who met for educational, social or support reasons. This aimed to elicit women's experiences and views of screening, whilst allowing for wider investigation of the themes arising from individual interviews. However, the few naturally occurring women's groups that exist in Lothian were approached and chose not to participate in a focus group discussion.

The original intention was to interview 10 carers of women with learning disabilities in Lothian and to hold a focus group based on a naturally occurring carers' group. Despite the fact that 40 agencies and organisations, including Lothian-wide and local carers organisations agreed to act as gatekeepers to approach individual carers for the research project, no carers came forward as possible participants to interview.

Feed back from gatekeepers suggested that carers of women with learning disabilities have been saturated with requests for participation in service provider user-led consultations. Moreover, carers directly expressed frustration to the two researchers at their experience of not being kept informed of service changes as a result of their input in previous user involvement. The sensitivity of the research topic appeared to have discouraged carers of women with learning disabilities from possible participation. Lastly, gatekeepers suggested anecdotally that carers might have difficulty in finding time in their day to be interviewed, given their many other commitments.

Against this background, an amended proposal was submitted to LREC and the CEC Social Work Department in June 2005 suggesting the use of a carer's questionnaire, to replace the 10 individual carer's interviews and the focus group based on a naturally occurring carers group as a research method. Given the multifarious demands of being a carer of a woman with a learning disability, in this situation, the use of the carers questionnaire was justified as a research method, as it placed fewer demands on the participant to complete and return the questionnaire, compared to individual interviews and focus group discussion. This is a general issue of which future research can learn from. Nonetheless, as a caveat, it was recognised that the use of the carer's questionnaire could not assure increased participation of carers in the research project. Approval was given by LREC and CEC for this amendment in July 2005.

A flowchart has been used to summarise the methodological approaches used in the research (Appendix 1).

3.1 Interviews

3.1.1 Purpose

Interviews aimed to elicit women's individual experiences and views of screening. The interview schedule was semi-structured to reflect issues and areas of concern arising from previous research on the topic, including barriers to cervical screening, whilst allowing plenty of scope for women to give of their experiences and tell their stories in their own way (Appendix 2).

The interview schedule was developed following consultation with both local specialists in the learning disability field and experts in qualitative research, the small body of equivalent research on cervical screening and learning disability (Pearson et al, 1998; Djuretic et al, 1999; Broughton and Thomson, 2000), and emerging good practice in researching the experiences of those with learning disabilities (McCarthy, 1998). Language was kept as straightforward as possible given the complex nature of the topic being discussed and further, integrated appropriate stimuli including pictures, symbols and photographs to augment and support communication.

A prompt box of resources relating to the cervical screening process was used during the individual interviews, to stimulate discussion and elicit the woman's views on how the cervical screening process could be improved to meet their needs. Smear taking equipment, including a plastic speculum and brush and pot were also included as prompts to stimulate discussion. The interview schedule was piloted with several women from People 1st Edinburgh, a national advocacy organisation for people with learning difficulties and changes were made accordingly to some of the questions and the range of stimuli used.

3.1.2 Sample and Recruitment: Individual Interviews

The study individually interviewed 10 women with learning disabilities. As there is no central database of people with learning disabilities in Lothian, women eligible for participation in individual interviews were opportunistically identified and approached through a range of local teams, agencies and groups. These included primary care-based Community Learning Disability Teams in SC and SW LHPs, Social Work and Voluntary agencies working with women with learning disabilities across Edinburgh. Teams and agencies were provided with a letter and information sheet about the research and the project as a whole.

As the primary aim of the interviews was to assess and gather the views of women with learning disabilities in relation to cervical screening, the sample was therefore composed of women with a learning disability aged 20 and over. Women who were too young to be invited for screening (under the ages of 20) were not included in the sample. Further inclusion criteria included women with learning disabilities who currently resided in SC and SW LHP areas or who worked or attended day placements or educational activities in those areas, with experience of primary care and had experience of being offered a cervical smear test. As the interview process is reliant on the participants ability to call and recall information and tell of their own experiences through discussion, the sample group were women with mild to moderate learning disability, who had the verbal ability to generate discussion on their views and the cognitive ability to call and recall their experiences of the cervical screening process to inform the research. Capacity to consent was an explicit criterion for inclusion.

As participants were recruited from the learning disability population, comprehensive extra steps, described below, were taken to assure their protection and to provide necessary safeguards to establish meaningful choice by agreeing, or not, to participate whilst critically ensuring that participants were free from coercion. Furthermore, given the sensitive nature of the topic and the fact that issues of sex and sexuality are intrinsic to cervical screening, there was a possibility that participants could disclose incidents of alleged abuse. Against this background, in order to maintain their safety, it was included in the information to the gatekeeper and participant and explained to the woman with learning disabilities before consent was sought, that if disclosures were made the researchers would follow existing guidance, The Lothian Interagency Guidance on Protecting Vulnerable Adults (2003).

The process of approaching and recruiting women with learning disability for individual interview took place in three stages**.** Initially the teams, groups and agencies who agreed to act as gatekeepers to identify potential and individual participants were provided with an information sheet about the research and what it entailed with which to initially approach potential participants. This consisted of a letter and an information sheet in simplified language in font size 16 and with appropriate symbols and graphics. Prior to arranging to meet the woman, the researchers had requested in the information sheet that gatekeepers could assure them that the participant did not come into the category of Adults with Incapacity.

At this point, the researcher arranged to meet the woman in the environment where she felt most comfortable and with a staff member or supporter present who was versed in the woman's usual and preferred mode of communication, unless stressed otherwise by the participant. This provided an opportunity for further discussion of the research and for the woman's concerns and questions to be addressed by the researcher. A visual map of the UK was used to indicate to the participant those likely to read the findings, thus explaining the parameters of the research. The researcher clarified the timescale of the research with the participant, advising that the woman had 14 days to decide whether or not she wanted to participate. The researcher stressed to each participant that they were happy to be contacted in the interim to address any remaining concerns. A copy of the information sheet was left with the woman and her worker, or supporter as a point of reference for discussion between them about her participation. The woman was given the opportunity to meet the researcher up to two times to discuss the research project and any issues or concerns, as necessary.

The third stage comprised a further meeting to obtain fully informed consent from the woman before agreeing with the woman the details of the interview. It was written into the consent form and stated to each potential participant before signing the consent form that participation in the study was voluntary and they could refuse to participate without having to explain their reasons to the researcher. The researcher then requested written consent from the individual to participate in the research. However, it was important to note that written consent did not have to be the person's full name. In the case of this research, for a woman with learning disability, written consent was classified as where the woman put pen to paper and marked it (McCarthy, 1998). Consent was witnessed by the researcher present and the woman's carer, supporter or friend, if requested by the woman herself. Participants were given the choice to meet the researcher in their own home, or at another venue where they chose to sign consent.

It seems important to note that recruitment of women with learning disabilities for the study was more difficult than anticipated. This appeared to be in part, due to the sensitive nature of the topic and the tension between meeting the needs of the possible learning disabled participant and fulfilling the ethical parameters of researching a vulnerable population (Goodey, 1999), as information to both gatekeepers and possible participants was reported to be complex.

3.1.3 The Interview Process

Individual interviews were conducted by one of the two female researchers either at the person's home or at another venue of their choice, for their convenience and further to address any issues of confidentiality and anonymity. Before the interview, the participant was given the choice to be interviewed by herself, or with a staff member, carer or supporter present. Interviews were digitally recorded. Individual interviews were on average 35 minutes long, although a couple lasted between 45 minutes to one hour. At the end of the interview, participants were asked if they wanted a copy of the transcript, in either written or taped format to check its contents before the material went forward to analysis.

As it is recognised that the research process 'takes' from people, and to value the input of participants, participants have been kept informed of the research findings and outcomes. As such, all participants were asked if they would like a copy of the finalised research findings, to be sent on completion of the research report. The findings are available as a report, a simplified summary including graphics and a taped summary building on the Norah Fry Research Centre's 'Plain Facts' development of good practice in disseminating research findings to people with learning disabilities.

3.1.4 Interview Analysis

Interviews were transcribed by the project secretary after ensuring no names or identifying material was on the tapes. This was done by removing participant details from the voice files of each interview. Each voice file was assigned a unique identifying number (UIN) and held under password on the researchers' computers. Participant details were stored at a separate NHS site.

Interviews were analysed both deductively and inductively. Deductive analysis was carried out through the analysis of transcripts in terms of how they reflected and suggested scope for building on and developing previous research findings in the field of learning disability in relation to cervical screening and primary care. Interviews were analysed inductively using QSR N6 computer software to generate in vivo analytic categories that reflected the experiences and views of the women interviewed.

Initial generation of analytic categories took place through discussions between the two researchers and Judith Sim, Chief Investigator (CI) for the research project, based on close reading of the transcripts. Coding categories were then developed. The three personnel independently coded the interview transcripts using N6 qualitative data analysis computer software. N6 was also used to compare coding between researchers, and discrepancies were discussed. Several meetings between the researchers and CI were held during the coding process to discuss progress, and to allow for the possibility that the close attention to transcripts entailed by coding may generate fresh analytic insights for discussion. Hypotheses and conclusions drawn from this phase of analysis were tested against counter-examples in the data, and revised accordingly.

3.2 Questionnaire

3.2.1 Purpose

The questionnaire design was structured in a tick-box format, including multiple-choice questions to reflect issues and areas of concern arising from previous research on the topic, whilst providing space in the format for carers to write their experiences and give their views (Appendix 3). However, given that the research project was now delayed, a decision was made by the Principal Investigator of the research project, Merinda Levi to pilot the draft questionnaire only with local experts in the fields of research and audit in NHS Lothian, instead of including carers of a woman with a learning disability in the piloting of the questionnaire. Moreover, this approach was further justified given the difficulties the project had encountered thus far in approaching and recruiting carers for interview. Professionals were asked to comment on content, including understanding, answering and gaps and design, including lay out, length and format. Once piloted, amendments to the draft questionnaire were made to both content and design accordingly.

3.2.2 Sample and Recruitment: Postal Questionnaires

Carers were again identified through the range of local teams, agencies and groups in Lothian who previously agreed to act as gatekeepers for the research project. These included primary care-based Community Learning Disability Teams in SC and SW LHPs, Social Work, voluntary agencies, local and Lothian-wide organisations representing carers. Teams and agencies were provided with a revised letter about the research project, for their information.

As the researchers did not have access to a database or records of carers of a woman with a learning disability, sampling was opportunistic as we were reliant on the gatekeepers to identify and approach carers on our behalf. The inclusion criteria included carers who were recognised as partners, familial, unpaid and paid, aged 18 years old and over and lived in Lothian.

If they agreed to act as a gatekeeper, via existing records and databases, gatekeepers were asked to identify carers following the inclusion criteria stated above. After two to four weeks, the researchers contacted the gatekeeper to confirm if they agreed to act as a gatekeeper and to ascertain the number of carers who fitted the inclusion criteria. Once this was ascertained, the researchers hand delivered the relevant number of stamped envelopes to the gatekeeper, containing a letter, information sheet, and the NHS Lothian Cervical Smear Test leaflet to provide additional information about cervical screening for carers and a carer's questionnaire in a free-post envelope. Gatekeepers then approached carers by sending them an individual stamped envelope containing the questionnaire pack described above.

In the information sheet, carers were offered the opportunity to discuss the project with the researcher, if they wished. On receipt of the envelope, carers were asked to complete and return the anonymised questionnaire within 28 days in a freepost envelope to NHS Lothian's Clinical Governance Support Team (CGST). Consent to participation was implied by the fact that carers had completed and returned the questionnaire within the allocated timescale.

As with the interviews, in terms of good practice in keeping participants informed of the research findings, the project team will issue a letter to all gatekeepers requesting that they inform carers they are invited to contact the project to request a copy of the completed research report.

3.2.3 Analysis

Each returned questionnaire was assigned a number on arrival by Joan Fletcher, CGST facilitator at NHS Lothian. Data was manually entered using SPSS 13.0 for Windows and analysed for frequencies. By analysing the data for frequencies, the number of respondents who identified with issues as relevant to their experiences and/or views of supporting a woman through cervical screening emerged. A sub-analysis of written responses was conducted by the two researchers following coding of central themes.

Further analysis was performed to test the hypothesis that there would be a difference between the views and experiences of carers who could be classed as 'family' and those of paid carers. The data file was therefore split into those who were a parent, partner or sister of the woman with a learning disability and all other categories. Frequencies were then calculated on the split file and the results from the two groups were compared. All analysis was carried out on fully anonymised data. As the data contained no fields in which to identify a participant, it was not necessary to register the data with NHS Lothian's Data Protection Officer.

4. Results

4.1 Response rate

4.1.2 Individual Interviews

As the project was reliant on gatekeepers to identify and approach women with learning disabilities, and very few organisations returned the Refusal Form, we had no clear measure of how many women were approached and refused to participate in the interviews. 10 women agreed to take part and were interviewed. 8 of the 10 participants had had a smear test. Interviewees had a variety of age ranges. This information is summarised in Table 1. 4 of the 10 women also had a physical disability. 2 of the 10 women were married and had children. 9 of the 10 women lived either independently or in supported living accommodation.

Table 1: Age ranges and smear test history of interviewees

Age	Screened	Not screened
20-29	3	1
30-39	2	0
40-49	2	1
50-59	0	0
60+	1	0

Although the sample size was small, the interview data's strength is its rich and in-depth qualitative nature. However, when considering the following results, it should be borne in mind that they represent the experience and views of 10 women with learning disabilities who chose to participate. As such, the findings cannot be generalised, nor is the sample representative of women with learning disabilities as a whole.

4.1.3 Questionnaire

885 questionnaires were hand-delivered to gatekeepers to issue to carers, on behalf of the project. Although the researchers included in the methodology a process to record the number of questionnaires issued to gatekeepers, given the dependence on gatekeepers to issue the questionnaires, we were not in position to control the sample size or calculate the response rate.

A total of 126 questionnaires were returned. Again, caution is advised when considering the following results, as they represent the views of only the 126 carers who chose to complete and return the questionnaire. This sample is not representative of carers or supporters of a woman with learning disability as a whole.

5. Interview Findings

5.1 Being invited to screening

In receiving their most recent invitation for a smear test, 7 of the 10 women recalled being invited through receiving a letter from their GP practice. One woman, whose last test was some years ago, was unable to recall when she had had her last smear test and how she was invited. Whilst attending their practice or health clinic for other health issues, the GP and nurse invited 2 of the 10 women opportunistically for a smear test. One woman had been invited opportunistically for her first smear test and had since received invitation letters.

Although the researchers did not see the letters of invitation sent to the women, it is likely that in all but one case they were routine letters sent by the respective practices to all women eligible for screening, rather than letters adapted to the needs of women with learning disabilities. One woman, however, described being invited in a way that recognised her particular needs

> "I had a letter and it was from a different doctor … and the nurse must of wrote something in my notes because she actually had a leaflet and it was just like an appointment to see her."

For one woman, the invitation letter she received was unproblematic. It was less straightforward for others, however. One woman described that on receiving the letter, "I put it in the cupboard…the print itself was just a wee bit too small."

Although no others spontaneously attributed the inaccessibility of the letters to print size, when asked by the researchers to comment on sample letters, almost all women opted for those in larger font.

The woman's literacy skills affected how she understood the invitation letter, as some women were reliant on the support of others to explain the contents of the letter. Support to read, and understand the letter's content, was provided through informal networks, including family, friends and paid support workers.

One woman described her experience of receiving an invitation letter and two reminder letters from her doctor [1] as a warning, stating

> "I just kept ripping up the letter. I got warnings, warnings from my doctor. He just sent me letters saying it was quite important to have a smear test. I got two or three and then after that, I just made an appointment."

Responses to opportunistic discussion of screening varied. For some women it provided an opportunity for a fuller discussion than just getting an invitation.

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[1] Guidance in Lothian at the time the research was carried out suggests that women be sent two reminder letters if they fail to attend in response to their initial invitation for cervical screening.

> "She (the doctor) was very good and she talked to me about other issues not just about smear tests, other women's issues as well like checking your breasts and things like that so I thought that was really good and that I got the opportunity and she showed me how to do it."

For others, however, the way in which screening was raised as part of a discussion about other health issues caused confusion and anxiety. One woman interpreted it to mean that an urgent investigation of 'something wrong' was necessary

> "I went to the doctor about something else and he said that I should get a smear test done. I felt that it was just like, for some strange reason I thought there must be something wrong with me if they are in a hurry to get it done, as well like the scientist thinking there was something wrong."

One woman hypothesised that cervical screening may be related to her blood pressure.

> "Em, the doctor has (offered to arrange a cervical smear) once or twice when my blood pressure has been pretty high. I don't know if that was anything to do with that but he said 'I'll put you in for another smear test just to make sure everything is okay.'"

At least one woman was offered the test itself alongside a discussion about cervical screening when she attended a Family Planning Clinic. Whereas this is not normally recommended, it suited this woman because it meant that she would not have to visit the Clinic twice with a child in tow

> "I hadn't had one for about five years and we had moved address so the family planning clinic asked me if I wanted to have it. I couldn't really remember when I had had it because we had changed *(from areas of Scotland)*, so they asked if it was okay. (They) just asked if I wanted it there and then, or I could leave it until another day. I had the child with me, but I just said to do it because I was there and one trip is enough when you are getting that done."

5.2 Information on cervical screening and the smear test

None of the women interviewed recalled receiving any written information from health professionals in their most recent invitation for a smear test, although several women recalled receiving written information from health professionals in their previous smear invitations as their main source of information regarding cervical screening.

Although one woman felt that the leaflet information she had been sent previously by her general practice supported her in making an autonomous decision about whether or not to go for a smear test, for the majority, the leaflets – at least in the form they are currently available - appeared not to be significant as a source of information about screening. Rather, the invitation seemed to trigger an 'information journey' in which women access information on cervical screening at different stages of the cervical screening process. The majority of women first discussed screening within their informal networks, often triggered by the fact that they depended on others for help in understanding the invitation letter.

The nature of the relationships women had within these networks influenced how able they were to discuss screening. For some, it was relatively easy. One woman, for example, who found it difficult to read the information leaflet that had arrived with her letter of invitation described seeking out the help of a friend and commented

> "I just felt more relaxed with my good friend. We are really close."

Conversely, one woman spoke of her difficulties in being understood by her paid carer, which in turn affected how able she was to discuss screening. She commented, "I did ask her like some questions but sometimes she doesn't understand me." One woman advised that she did not want to discuss cervical screening with her friends or family, noting "…it's not one of those things that you bring up in conversation."

Several women drew on the researchers as a source of information about screening and asked specific questions. Comments during the interviews also made clear that the women remained confused after having gone through the screening process. One woman remarked

> "…It is just not knowing a lot about why we have to have it in the first place. I thought every so often you have to get a screen of the breasts or something, I don't know. I am not sure what the difference is."

Another woman commented, whilst questioning one of the researchers about colposcopy, that although she hadn't needed it herself, it was good to know about such things because "… you can say to friends and stuff," highlighting the ways in which women with learning disabilities can see themselves as sources of information and advice, rather than simply as passive recipients of information.

Only one woman described being offered a specific preparatory appointment to discuss screening, which covered the purpose of screening and her eligibility for the test, although others had an opportunity to discuss the smear test with a health professional beforehand when it was raised opportunistically as part of a consultation on something else. Where women discussed it with the health professional for the first time when they actually went for the smear, most were committed to having the test. These discussions therefore did not serve as the basis for deciding whether or not to have the test. Women's descriptions of these encounters were framed by both the approach and the gender of the health professional. The woman describing her preparatory appointment contrasted it to an earlier, and somewhat traumatic, experience of having a smear from a male doctor.

> "Generally she went into more detail telling me why you should get it done. She is a woman so maybe that's why it worked better maybe men are not supposed to deal with women's problems so well. I never felt good about talking about women's problems to a man doctor. I don't think you get the same type of treatment you know maybe sympathetically."

She also valued the GPs' overall approach, commenting

> "…I thought at least she is not treating me like I am stupid or something like that because that is what my worry is. That people think the worst of you."

She contrasted this with an earlier GPs' attempt to describe the test to her

> "He tried to explain it by drawing pictures of the womb and it didn't exactly go down well. I think he tried to explain it but it didn't mean anything to me. 'This is the womb' and didn't say this is what is going to be going on."

Familiarity with, and confidence in, a GP could, however, over-ride the importance of gender. One woman whose most recent smear was carried out by a male GP whom she knew well commented

> "If you trust the trust the doctor that is fine by me...I know the doctor quite well now and I have had a lot of illnesses and things like that so I have had regular check-ups. So it wasn't a problem. I think if it was the first time I met him that might be a problem for me, then."

All the women interviewed believed that the cervical screening process could be improved through the provision of a range of accessible resources on cervical screening. This included information being provided in leaflet, audio-tape, DVD or video format. The individual women each had a preferred resource, although a couple of felt strongly against the use of a video. A choice of information resources was felt to be fundamental in enabling informed choice about whether or not to have a smear test. One woman commented, "A lot of ways to get the information over has got to be a good thing." Moreover, the way the information is presented was of importance, and particularly, how accessible information resources were perceived by its readers, as principally being information for women, as opposed to information for learning disabled women.

All the women wanted information on the smear test procedure, although how this was best represented remained equivocal. Some of the women felt that showing the actual procedure and smear taking equipment was too graphic and would increase women's anxieties about the smear test. Conversely, several women thought that showing the procedure, including the equipment would allay women's anxieties about the test. Honest and informed information about the smear test procedure was also suggested as important in enabling the woman to better understand screening. One woman noted

> "If you are going to the dentist you want to know what is going on inside your mouth, you know. It is about knowing what does what and I know it looks quite scary seeing it (the speculum) but I think it will explain why it is not a comfortable thing to get done either."

Women expressed a preference for contextual information about cervical screening. Information on the purpose of cervical screening and the risk factors for cervical cancer was suggested.

> "I think it should be clear why you have to get the test done. I think that you have got to say to people the reason why they are getting it. Because if you are in a sexual relationship and that's why you should get the test done because there is a chance of getting cancer and you need the test done to find out if you are safe. If the person is not having sex, I find that it would be a waste of time getting it done, unless they are in a sex relationship then that is when it is really important."

In particular, some women wanted information on what abnormal and unsatisfactory results were, what treatment is offered and the efficacy of the treatment.

> "It should be backed up by another one saying something like if you get your test back and it comes back with an abnormality then it doesn't mean cancer, it means that you have to have a test to find out what is going on."

Another woman commented

> "Maybe in the information leaflet you should have that in the worst case scenario, you could have something that it is treatable. May be a story of somebody that has had an abnormal result. Put that in the leaflet. The worst case scenario. Somebody did have abnormal cells and it got treated."

5.3 Knowledge of cervical screening: purpose and process

There was a variety of ways in which women described the purpose of cervical screening, with women who had not had a smear test appearing slightly less knowledgeable about the purpose of the test and those who had further investigation or treatment appearing particularly well-informed.

Commonly, the test was linked to the detection of cancerous cells. When asked by the researcher why they thought women are invited to have a smear test, similar responses included, "To make sure nothing is cancerous below" and "To check to see if they have got cancer."

A minority linked screening with prevention. For example, one woman commented

> "To save them from getting cancer."

Another linked screening with reduction in incidence.

> "I think there is a very small figure of people that do have cervical cancer nowadays because it is caught."

The two women who had had further investigations as the result of their smear test and for another cancer respectively provided almost text book definitions of the purpose of cervical screening. One described it as

> "…to check for abnormal cells that could lead to cancer and if they catch it early, it can prevent cancer."

Another made the distinction between screening identifying pre-cancerous cells, that may or may not progress into cancer, and cancerous cells, stating screening can identify "…slight changes in cells that can be sorted out."

Both these women are likely to have accumulated this knowledge during the course of their journeys through screening and treatment, rather than starting with such knowledge as the basis for making a decision about whether or not to have screening.

There was some confusion as to how cervical abnormalities manifest themselves in the body. One woman spoke of her experiences of examining herself to try to identify changes in her cervix, "…feeling for the odd bump when there wasn't anything there." This may reflect the fact that cancer is popularly represented in terms of 'lumps' and 'bumps'. Moreover, an aspect of a learning disability is the difficulty in conceptualising abstract concepts, or thoughts. Therefore, given the location of the cervix within the body, it is not surprising that this uncertainty was held.

However, although overall women had reasonable knowledge of the purpose of the smear test, they were far less aware of the general risk factors for cervical abnormality including the fact that women need start having smears only once they became sexually active, nor were they able to describe how they are able to protect their sexual health. Whereas most women described being asked about their sexual and smoking activities by their health professional, in few cases did they describe the professional making explicit the relevance of the questions or how they linked to risk of cervical abnormality.

A further aspect of information about cervical screening is the process: exactly what does taking a smear involve? Most women described discussing this with the health professional who had done their smears, and a number had been shown the speculum beforehand. Occasionally, however, women had not been prepared, and the consequences of this are discussed below.

One woman suggested that detailed information about the process would be valuable

> "...you know what is going to be done and what position you might be in and things like that."

5.4 Factors that influenced the woman to have a smear test, or not have a smear test

The involvement of individual women in the decision about whether or not to have a smear varied considerably. Whereas some women were central to the decision, others were largely excluded from it. One woman made an autonomous decision to have a smear test. Several of the women described that they were supported by either their carer or health professional and in some cases by both in deciding whether or not to have a smear test.

Other women, by contrast, were marginal to discussions and decisions about whether or not they should have a smear. One woman described how she listened, without being involved in, a discussion between her carer and her GP about her eligibility for screening. Although she was hugely relieved to learn that she was not eligible for a smear test, she was curious about what it was and (because of her 'onlooker' status) did not have the opportunity to ask questions. She would also have preferred the encounter to have been otherwise, commenting

> "I would have preferred the doctor to speak to me…well, you know yourself better."

Two women described how they were effectively excluded from decisions by assumptions made by the GP which, in both cases, rested on contrasting stereotypes of the sexual lives of women with disabilities. One woman described how, some years ago, she had responded to an invitation for cervical screening before she was sexually active

> "…he sort of accused me of having lots of sex, in a strange way, 'cos he presumed that I must be sexually active. He thought because of my age that I would be sexually active and he said that."

This woman was overridden by her GP and recalled that she had made a decision that was not in her best interests. She commented

> "I said that I wasn't in a relationship with anyone and I have not had sex. And he asked me if I wanted to take a urine sample to see if I was pregnant but I refused on the grounds that I didn't have to have that test done, but I did say that I would have the smear test. But I got it done but I felt like I was bullied into it a bit."

Another woman who is a wheelchair-user described her experience, some years ago, on visiting her GP after receiving an invitation for a smear test.

> "As soon as the doctor saw me, he was sort of 'Oh no, no, no you don't need one because you are disabled'. And he was sort of 'don't be ridiculous'. He actually refused to do it because of the disabilities that I have."

Effectively, she felt that the decision had been made for her. She recalled, "…when I brought it up again, I left it for a bit and then, dunno then I approached him from a different direction and it was still the same like, oh no, don't be ridiculous."

Although this interaction occurred twenty years ago, and at the time the woman was excluded from the cervical screening programme without her knowledge or discussion, it appears that no one has since spoken to her about whether her circumstances have changed.

For others, their perception of the 'high' status of their GP contributed to shaping their decision. One woman, for example, commented

> "It was like well, at that point in time, I thought okay because he is the sort of big cheese, he will know what's best."

A woman's decision whether or not to have the smear test was affected by her relationship with others. Paid carers were central to this and several women advised that their paid carer had supported them in making their decision to go for a smear test. One woman also recalled that her key worker had given her time to think and consider the information she had given her about the smear test, before communicating her decision about whether or not she wanted to attend.

For some women, their decision to attend for screening was motivated by more general factors than their immediate contacts with health professionals or others about cervical screening. General attitudes towards health, for example, affected one woman's decision making process, and she described going for a smear test to reassure herself that nothing was wrong.

Wider health experiences and histories also shaped decisions about screening. One woman noted

> "I had a scare with my head and that is why I am totally for any sort of test. No matter how frightened I am. I had a melanoma on my head, it's away, but if I hadn't paid attention to it. You hear the word cancer and you're like, ooh but stuff like that is treatable but it is horrendous. My head was stitched up for two weeks but the fact was it was away and that's the only way I can look at it. End of, you know. That's why I think it is important to be checked."

Another described feeling that it was important to have a smear because she had known others in her circle who had had cancer.

An opportunity to discuss the test – to ask questions and to address any issues or concerns with a nurse or doctor was seen as important to enable the woman to prepare for the test. Women could see the benefits of being offered a discrete preparation visit, as this could help to facilitate the assimilation of information on cervical screening and the smear test. One woman, due to heightened levels of anxiety, recognised the difficulties of absorbing information on the day of an actual examination.

> "You are not really concentrating on any questions or anything so I think you know the questions would be better before there was any sort of examination or whatever."

Some women could clearly see the benefits of being offered the opportunity to discuss the smear test with a practitioner before the procedure commenced, however, noted that this would be of benefit to other women and not themselves. It was felt that this would delay the actual procedure, which they wanted over and done with, as one woman noted, "It can make it worse though. It just delays it." One woman commented that the opportunity for dialogue had reassured her, as she perceived the health professional to be acting in her best interests. A further woman suggested that the gender of the health professional would be an issue, preferring to talk only to a female nurse or doctor.

An opportunity to see the treatment room before the smear test was met with mixed feelings amongst the women interviewed. In general, women felt that this could be beneficial to other women, but they themselves would prefer not to see the treatment room. However, participants stressed that this should be offered to women.

The opportunity to see the smear taking equipment, including the speculum before the procedure was found to be disagreeable to those women who had not had a smear test, principally because the equipment frightened them. However, the majority of women were of the opinion that opportunities to see the speculum would help to conceptualise and better understand the procedure. One woman noted

> "I think it is jut knowing what is going to be in you, or you know what is going on around you, but you cannot see it because your brain goes into thinking the worst."

5.5 Having the smear test

Different factors influenced how the woman experienced the smear test. These are addressed in detail below. The majority of the women interviewed went for their smear test without support and further, when prompted, stressed that they did not want support to attend. Those who requested support to attend went with their respective carers.

The health professionals approach to the woman whilst conducting the smear test was critical to the woman's experience of screening. Confidence and trust in the professional themselves, and in their ability to undertake the test competently were contributory factors to how the woman experienced the smear test. One woman spoke of her trust in the health professional to undertake the procedure, noted

> "I mean at the end of the day, the person has got to trust the doctor and feel comfortable about what is going on."

One woman who had previously experienced a painful smear test noted

> "It was when I had the test before the bairn, before it was agony. And I was bleeding after that, but this one was actually over in two minutes. I suppose it depends who is doing it, a professional, and how many they have done before."

An important factor in facilitating the woman's experience of the smear test was the flexibility of the health professional in their approach towards the woman. One woman, who is physically disabled, commented on the positioning her GP had placed her during the procedure

> "With smear tests, I thought there was only one way but my doctor, because I have arthritis in my hip, told me I had to lie sideways to get it done and I didn't know that you could do it that way as well."

A superseding issue for many of the women interviewed was the ability of the smear taker to make them feel at ease for alleviating feelings of anxiety. One woman explained that she had found it helpful when a nurse had held her hand during the procedure and talked to her about everyday events, which helped her to take her mind off any negative feelings.

> "It's (the test) not very nice. You need someone to take your hand and calm you down. We were just talking about general stuff, to get it over."

Familiarity with the smear taker was believed to be a factor that contributed positively to the woman's experience of the smear test. Familiarity with the smear taker, and with other health professionals based at her local practice, enabled one woman to be more autonomous in her ability to access her health practice effectively.

Familiarity with the smear taker also contributed to the woman feeling at ease during the procedure. One woman noted that she found this helpful.

> "Because it is like they are not like total strangers to you, so you have a conversation but it is nothing to do with the actual thing. So while the doctor is doing the smear, I am too busy talking (to the nurses)."

Only one woman felt that familiarity with the smear taker was not a factor that affected her experience of the smear test. When asked by the researcher if she thought the experience could have been improved if she had known the smear taker, she commented

> "Not really, because all of the doctors and nurses they have there are usually there for a while and you get used to having a different one all the time."

Most of the women interviewed preferred to have, and had a female smear taker. Embarrassment can be a causal factor that shapes a woman's experience of cervical screening. This was reflected in the some of the women's views and experiences. One woman spoke of her preference at having a female taker, commenting

> "Yeah, a female I dinnae get embarrassed, but a male, like a male, that's when I get embarrassed cos there is nothing worse than getting a smear test done."

A few women seemed unaware of their rights to request a female smear taker. This is reflected in one woman's experience, as it transpired that her male GP had undertaken her smear test without a chaperone present. Although this woman did not appear unduly concerned by this, NHS Lothian has clear local guidelines on chaperoning and the smear test for practitioners to follow.

The gender of the woman's carer affected how she experienced her smear test. One woman recalled that she had been accompanied to her doctor's surgery for a previous smear test by a male carer who waited in the waiting area whilst she had the test. Whilst acknowledging the intimate nature of the test, she identified that the presence and support of female carer would have facilitated her experience.

Physical barriers of access both facilitated and inhibited access to screening. Of the former, one woman spoke of the approach of her doctor and practice nurse who facilitated her access to cervical screening, despite the fact that her practice surgery is not wheelchair accessible. She noted

> "I can't go to the surgery so they came to me. The building is not, well there is stairs and I can't get in with the wheelchair, so they come to me and they bring extra torches and lights, so it turns into quite a laugh."

Conversely, one woman spoke of her difficulty in attempting to get on to the treatment couch. Despite her being a wheelchair user, no attempts were considered by her practice to adapt the equipment to suit her needs, or offer her a viable alternative. As such, she recalled her experience noting, "Well, it was hard because it was high, it was too high."

The perceptions of the setting of cervical screening - including the physical layout of the place influenced one woman's screening experience. She suggested improving the physical environment by "…may be just colour around the room to make it kind of warm, something to look at."

It was common for the majority of women interviewed to express that their main focus was a desire to get the smear test over and done with. One woman equated her experience of wanting the test over and done with to the actual embarrassment of the test. She noted

> "I just wanted it over and done with because I thought it would be embarrassing. To be honest, I just wanted to get it done and out of the door. That is how I felt. I just felt like em, well I can't explain it, I just felt like get it done and over with and that is the end of it rather than ask any questions."

A contributory factor that helped put the woman at ease was when the smear taker talked them through the procedure during the smear test. All the women interviewed felt that during the actual procedure, the smear taker had provided them with adequate support, by talking to them through what was happening, which in turn had enabled them to better understand what was happening.

Nonetheless, some of the women reported that prior to the actual smear test, the smear taker had not prepared them sufficiently as to what would be happening. In most cases, these women had had previous experience of the smear test. However, this should not preclude them from this opportunity. One woman stressed that she would have preferred for the nurse to talk to her about the test before it was carried out, even though she had a smear test previously.

Some women who did not want to ask questions during the test were given the opportunity to do so by the smear taker. One woman noted

> "He (the doctor) asked me if I wanted more information and I said no, I've had the test done before and em, I said is there anything new

> being done and he said no, it's just in case you want the information and I said no, it's fine. But he said stop me at any time to ask questions. He said he would tell me what he was doing while he was down there kind of thing."

However, some women commented that they felt unable to ask questions. One woman explained her reticence to ask questions as, "...I have always been a quiet person when it comes to asking questions."

Anxiety was a common feeling described by some of the women when describing their experiences of the smear test. This was regardless of their past smear test experiences. During the procedure itself, their anxiety could be pinpointed to just before the smear was taken, and in particular as the speculum is being inserted. One woman noted, "I was anxious when he started putting it in, the yeah, that speculum." Another woman commented on her anxieties, "…just lying there before the metal thing is going into me."

Another common experience raised by some women interviewed was that they found the procedure uncomfortable and sometimes painful. A smear taker was unable to complete the test for one woman as she bled heavily. As a result of this, she has since consented to sign a disclaimer form to remove her name from the cervical screening call and recall list, although was advised by her GP that this could be reviewed should her circumstances change.

In terms of reducing the perceived and actual feelings of pain and discomfort, it was common for women to prepare themselves by attempting to relax into the procedure. One woman noted that she, "…just laid back and tried to relax as much as possible." Similarly, another woman commented, "I just tried to get comfortable and relaxed." One woman was advised by the health professional to draw on her experience of childbirth to reduce her anxiety about the procedure. She commented, "One or two of them, they say open your legs slightly as if you were having your baby and it relaxed me a wee bit."

There appeared to be a difference in the (dis)comfort experienced by women between a metal and plastic speculum, as one woman noted that she found the plastic speculum more comfortable. Moreover, to reduce the discomfort of the metal speculum during the procedure, several women suggested that the metal speculum should be warmed with warm water.

In attempting to allay the woman's anxieties about the test, and also to reduce her discomfort during the procedure, it was common for the smear taker to advise the woman to relax. However, none of the smear takers who advised their patient to relax gave any indication, or explanation of how to do so. Without prior preparation to explain and practice relaxation techniques, for example regulating breathing, these well-meaning comments were effectively futile. This is encapsulated in the narrative below:

> R. Did you want to ask them questions?
> "No, only if it hurts me that much. The nurse said relax, but I couldnae, I couldnae relax."
>
> R. How did you actually feel when you had the test?

"That hurt. It hurts my bum."
R. Did you say that to the nurse?
"Uh huh."
R. What did she say?
"Just relax but I couldnae."
R. Did she say how to relax?
"No."

The opportunity to be offered relaxation techniques – to prepare the individual before and during the procedure was viewed as a positive contribution by all the women interviewed. Women felt that the primary aim of relaxation techniques would be used to relax them. However, one woman felt they could be used to distract her from the procedure.

5.6 Smear test results

Those women who had been for a smear test had all received their results; one woman had contacted her GP surgery by telephone for the receptionist to issue her results, whereas the remainder received their results by letter. One woman had some difficulty recalling how she had received her result and further, a couple of women could not remember what their last smear test result was. One woman recalled that she had told her doctor that she didn't understand the difference between a positive and negative result.

> "He wrote down like what negative and what positive meant so I pinned it on my board. It was very simple cos I sometimes get confused with the negative and positive."

Anxiety was a feeling that was attributed to the cervical screening process – "what if" the procedure identifies possible deleterious changes? One woman commented on the experience of waiting for the test result, "…sometimes you have got that little doubt in your head, the what ifs." Moreover, there was some confusion as to how long the test results took to be issued to the recipient.

Abnormal results can provoke heightened levels of anxieties in women. Such a result can cause considerable concern for the woman as she may link the term 'abnormal' to the development of cancer and the requirement to undergo further investigatory tests. One woman recalled her experience of such a result.

> "The letter came back and I didn't know what it was. It just said there is some abnormality and you need to have another test and I was like, why another test? And it must mean that I have cancer! That just stuck in my head."

Again, the approach of the GP and/or practice nurse is pivotal in how the woman experiences an abnormal result. The above woman was supported by her GP to understand what the result meant, whilst providing her with information to allay her anxieties.

> "My doctor phoned me back and explained it. He just reassured me that when it says abnormality, don't think the worst yet because it sometimes comes back meaning that there is something there to confuse the issue.
>
> I think if you talk to your doctor you get reassurement. To read a letter, it just gets you terrified by what you read and you read it again and it doesn't change what you have read. But you talk to your doctor and the doctor brings you back down to earth, like he said it can be something and it can be nothing. Don't do the panicking yet. I'll do it for you. He was very good."

This woman's GP also supported her to undergo further investigatory tests, which were negative for the development of pre-cancerous cervical cells. She commented, "The reason why it was abnormal was because I had two little cysts on the neck of my womb and it confused the actual test." Despite the fact that her GPs approach had positively contributed to the woman's experience of an abnormal result, she nevertheless found the experience distressing.

> "May be they could rush the results through for you and then put your mind at ease instead of another five days waiting around. I was a nervous wreck."

When prompted by the researcher how she thought this process could be made easier, this woman commented

> "May be they could write 'Your test was inconclusive', or something like that. They should make it sound like, well not make it sound like there is nothing wrong but not make you turn into a terrified clown. A lot of the tests do come back with abnormalities it is just that it is something really simple to sort out and it doesn't mean the worst and I think, I don't mean tone it down and make it sound like nothing is going to be wrong but just try and get a balance."

Due to her literacy levels, one woman requested and was given support by her paid carer to read the letter and understand her results. The majority of the women interviewed understood their results without requiring support to do so. When prompted, women advised that they would have contacted their GP or nurse should they have required support to understand their results. In general, women stated a preference to receive their results by letter. In part, confidentiality was a key factor. One woman explained this, "I prefer the letter, yeah, because your call could maybe like out on hold over the phone or you are busy and the nurse is not available."

Box 8. A summary of women's additional suggestions on how cervical screening could be made easier or improved[2]

- A preference was expressed by the majority of women for the adapted letter[3] shown to them. Reasons given for this included; the print was clearer to read in type size 16 and font type Arial, the length of the letter was shorter and the contents of the letter were perceived to be less technical and more welcoming.
- Additional comments in terms of improving the adapted letter was the need to include contact details not only to signpost the service to the reader but also to provide a direct link to the health professional, should the reader want to discuss the letter, or any issues or concerns regarding the letter's contents.
- A tension emerged between practices providing enough and accurate information in the invitation letter on the risks for cervical cancer and benefits of cervical screening, to enable the reader to make an informed choice and including information that could potentially motivate a woman to attend out of fear. The local invitation letter included the sentence, "This is an important test for a preventable disease, which kills many women each year." This sentence was said by one woman to be "…a bit scary."
- The invitation letter should be supplemented with an information leaflet.
- When asked if only women with a learning disability should get an adapted leaflet with their invitation, or every woman, in general women suggested that every woman should get one with their invitation letter.
- Preparation was viewed positively by the women consulted with. Carers and people who provide direct support were identified as having a key role in providing support to foster decision making. This endorses the findings of this research. Other aspects of preparation that could facilitate the woman's access to cervical screening included visiting the treatment room before having the smear and visiting the doctor or nurse before hand to discuss the test.
- Women should be offered the choice of either a metal or plastic speculum.
- The provision of health education was suggested as an area that could contribute to improving the woman's experience of the smear test. One woman commented, "They could have one of those models like they do with pregnancy and things like that. I don't know, they could do a lot more to let people see what the GP is going to do down at that end."
- If the general practice was aware of an individual patient's communication difficulties, the practice should offer to provide their results by telephone. One woman felt that if the patient required support to understand their results, their practice should inform them in a letter of the opportunity to make an appointment with their health practitioner to discuss the results.

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[2] Findings from the consultation session on good practice in cervical screening undertaken by the project with Edinburgh People 1st Women's Group have also been included in the summary. Participants were asked to give of their opinions and views on the process of cervical screening from invitation letters through to getting results.

[3] Samples of a local invitation letter and an invitation letter that had been adapted from the NHS CSP (2000) Good Practice in Breast and Cervical Screening for Women with Learning Disabilities were shown to participants during both the interviews and consultation session.

6. Carers' Postal Questionnaire results

This section presents:

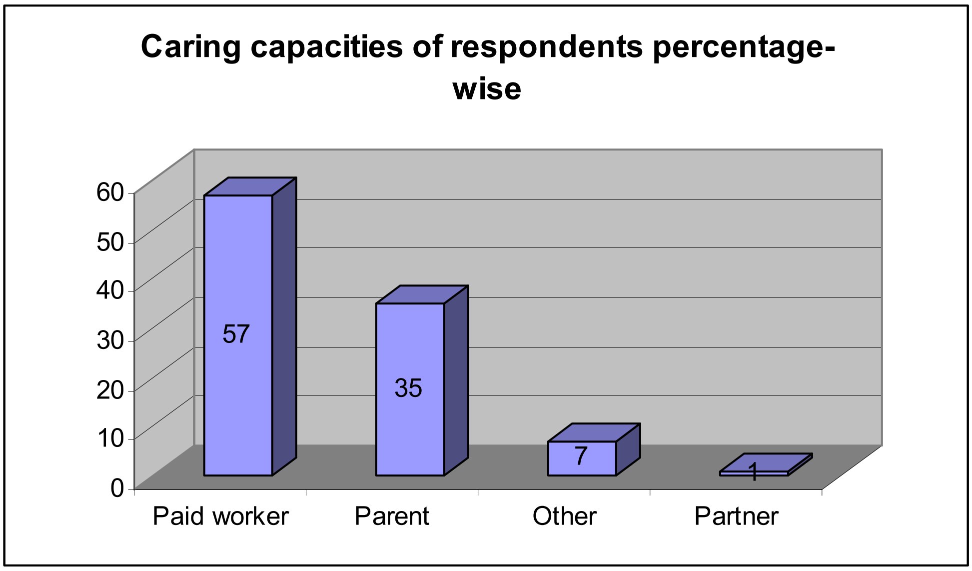
1. Demographic information about respondents, including the capacity in which the respondents cared for the woman with learning disabilities.[4]
2. The cervical screening histories of those for whom respondents cared.
3. Themes from carers' written responses about how to make the cervical screening process easier for women with learning disabilities and carers.

126 questionnaires were returned. Results in each area are presented as valid percentages of those who responded, and are rounded to the nearest whole number. Because we were not able to monitor the number of questionnaires distributed to carers, we have been unable to calculate the response rate. As the questionnaires were designed to replace focus groups, we were particularly interested in the qualitative, written information returned by respondents. However, analysis of the quantitative data returned suggests interesting trends worthy of further investigation.

6.1 Demographic information

Respondents supported women in the following capacities:

Graph 1. Caring capacities of respondents percentage-wise



'Other' here included the woman's sister (5%), a Community Learning Disability Nurse (1%) and a supporter (1%). Results henceforth are divided into 'family carers', comprising parents and sisters and 'paid carers' comprising paid workers, including CLDN.

A significant majority of both family and paid carers (respectively 98% and 84%) supported women in accessing Primary Care. They did so in the following ways.

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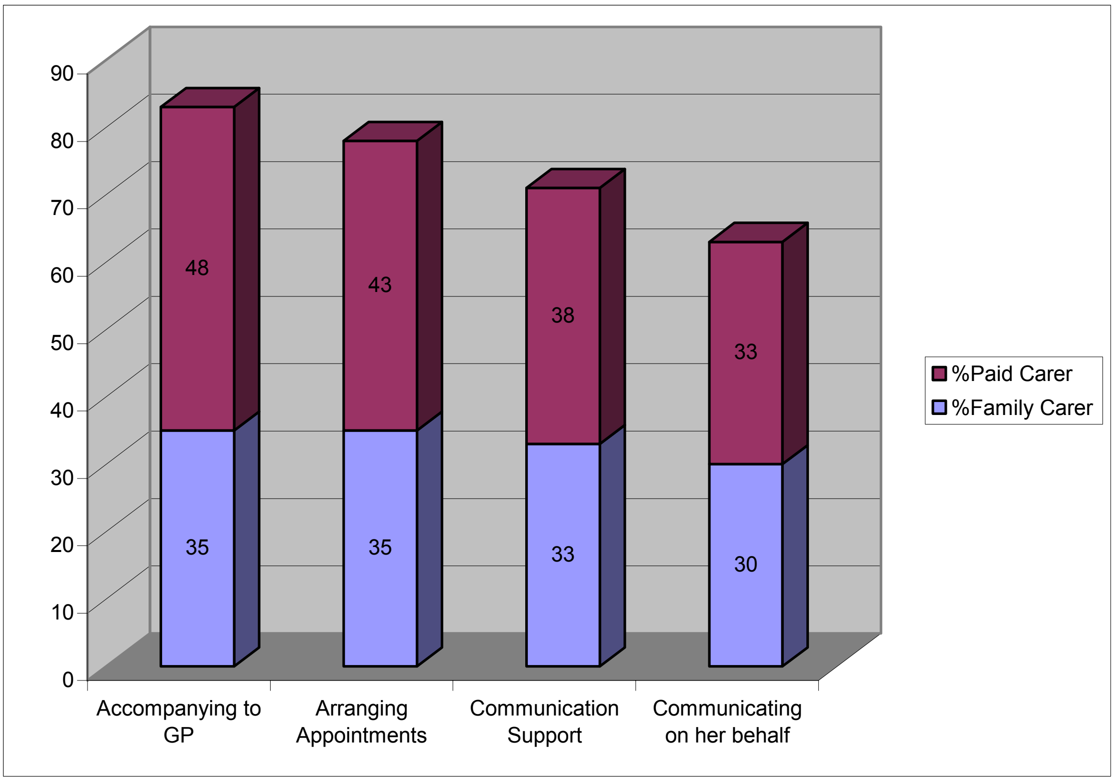
[4] Henceforth, 'carer' is taken as shorthand for those both caring and supporting a woman with disabilities .

Graph 2. Types of support provided in accessing Primary Care percentage-wise



It is clear in the descriptions of how women were supported to access Primary Care that there was a wide spectrum of abilities in the women cared for. [5] Where some women were able to organise their own appointments and attend the GP on their own, for example, in other cases carers undertook all aspects of organising visits, and acted as proxies for the women in encounters with health professionals.

Paid carers were significantly less likely to know the details of a woman's screening history. A higher proportion of paid carers did not know if the woman they cared for had ever had a smear test (27% paid carer and 8% family), for example, and were similarly less likely to know whether she had been invited for a smear, or whether she had received any information about cervical screening.

6.2 Carers' views on women's experiences of cervical screening

The questionnaire addressed 4 distinct areas in supporting a woman with a learning disability about cervical screening, and these are addressed in turn:

- cervical smears, smear history and being invited for a smear test;
- explanation and decision making;
- going for a smear test; and
- after the smear test.

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[5] Data on women's functional abilities were not sought in the questionnaire. The spectrum of abilities in this sample was, however, clearly wider than that in the sample of women interviewed.

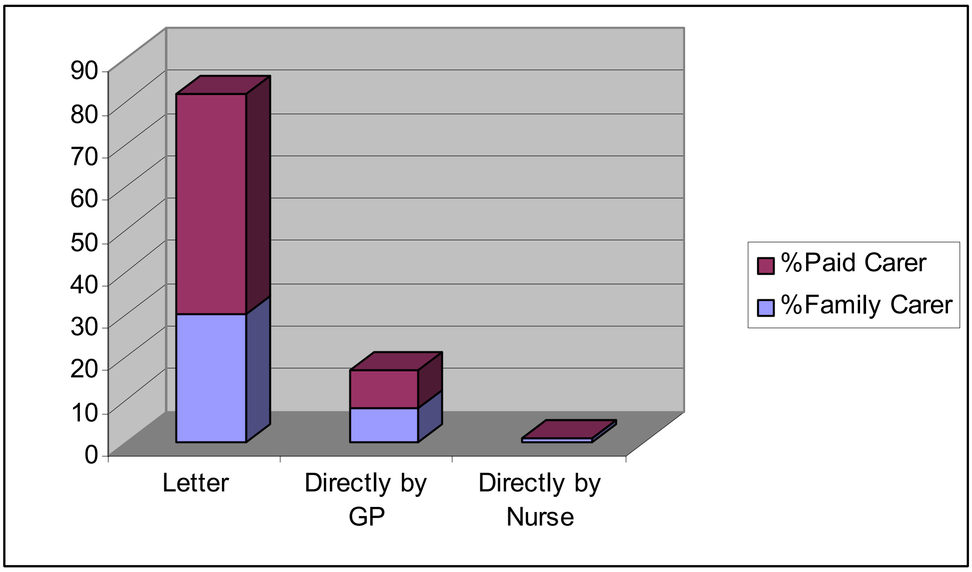
6.2.1 Cervical smears, smear history and being invited for a smear test

A minority (30%) of respondents reported that the women they cared for had ever had a smear test. A notably greater proportion of paid carers (at 44%) than family carers (at 8%), however, reported that the women they cared for had ever had a smear test. 51% of the total respondents reported that the woman they cared for had never had a smear test, with a conversely greater proportion of family carers (at 84%) than paid carers (at 29%) reporting this. Differences in responses between family and paid carers are reflected below systematically in responses to other areas of the questionnaire.

58% of the total respondents reported that the woman they cared for had ever been **invited** for a smear test. Again, a greater proportion (65%) of paid carers reported that women had been invited against 48% of family carers. A correspondingly higher proportion of family carers (46%) noted that the woman had never been invited for a smear test against 19% paid carers.

Women were invited for screening through the following routes:

Graph 3. Types of screening invitation percentage-wise



A number of carers felt that written invitations coming 'out of the blue' were unhelpful, and should be replaced or supplemented by more personal approaches, which rested on those sending out the invitations being aware of a woman's particular needs. One family carer commented

> "Instead of the letter from the GP coming out of the blue, time should be taken before the letter is sent out to look at the individual and how best to explain it."

Another paid carer similarly felt that the letter should be supplemented by a more personal approach.

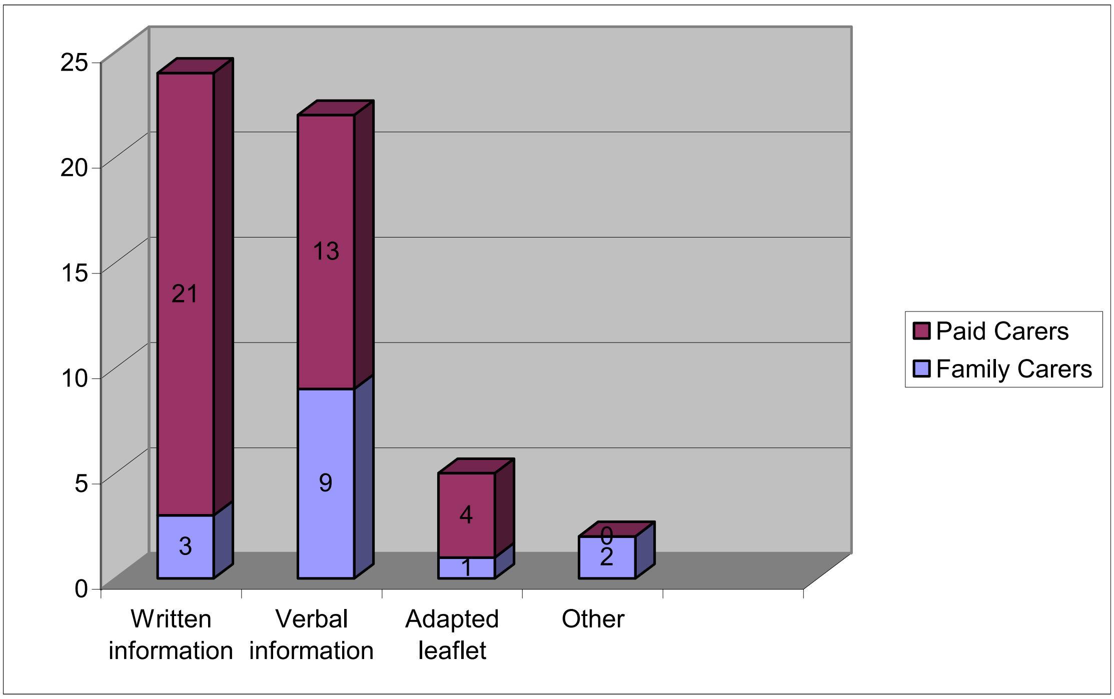
> "She does not read well, a letter followed by a phone call would work better. When she has a date, she would be able to attend herself."

One paid carer noted the distressing consequences of repeated invitations being sent out with no apparent recognition of her client's special needs (reflecting the experience of repeated letters as 'threats' described by one of the women interviewed), and contrasted this with a situation where her clients needs were recognised.

> "My client felt threatened by repeated letters from her GP and surgery inviting her to have a smear test. Her personal circumstances and mental health condition were not taken into account. However, a totally different situation was at the family planning clinic with a nurse specialised in disabilities."

Women received information in the following forms along with their invitations to screening:

Graph 4. Types of information received percentage-wise



It is notable that only a minority of carers reported that women had received written information alongside their invitations to screening (reflecting the experiences reported by the women interviewed), and that paid carers were notably more likely to report this than family carers. A very small proportion of women (5%) were reported to have received written information in an adapted format. Although adapted leaflets had been locally produced and widely distributed prior to the distribution of the questionnaire, but may not have been available at the time the women cared for by respondents had been invited for their smears. The fact that none had received information in alternative formats such as videos or CD-ROMs is unsurprising, as such material has neither been produced nor distributed locally.

A majority of carers (71%) reported that they had supported the woman to understand the information she had been given about having a smear test. A slightly higher proportion of family carers (at 76%) than paid carers (at 69%) supported the women they cared for in this way.

Written comments from respondents repeatedly suggested the need for improved information for women on cervical screening, suggesting that many saw this as pivotal to informing decisions about screening. A number of comments focused on the format of information, and the need for information to be available in a range of accessible formats, including larger print size and easy to read information in both leaflets and letters, Video or CD-Rom. One carer specifically suggested that an invitation letter should be supplemented by the locally-produced accessible leaflet on screening, "Keep Yourself Healthy: a guide to having a smear test." Further suggestions included information being made available to women in groups as well as individually, and that women's knowledge could be improved through the provision of health education on cervical screening in schools.

A number of comments focused on the specifics of content and messages which would tailor information to the needs of women with learning disabilities. For several respondents it was felt crucial that information explained not only the smear test procedure, but the purpose of the test, eligibility and risk factors for cervical cancer and information on women's health. One paid carer commented, for example, on the need for

> "…more accessible information on the **importance** of having a smear test and not just what happens during the test."

Information on whether a woman is eligible for cervical screening is reflected in the suggestion of two family carers that information and advice should be available.

> "…on whether it (the test) is truly needed if the individual has not had sexual intercourse."

And that family carer

> "(information) could be made clearer that there is little risk of cervical cancer if the woman has never had sex."

One paid carer further noted

> "I would imagine it would be a very difficult or traumatic procedure for a woman who had no knowledge of sex, or sexual health matters and who was not aware of her own female anatomy. Perhaps some kind of booklet which explained the female body in diagrams and simple text would lay the path to an understanding of what was going to happen."

One family carer highlighted the importance of building, in presenting information, on what women were already likely to be familiar with.

> "Most people with learning disabilities do know about cancer. Therefore, it should be explained that it is a way of preventing disease, cancer."

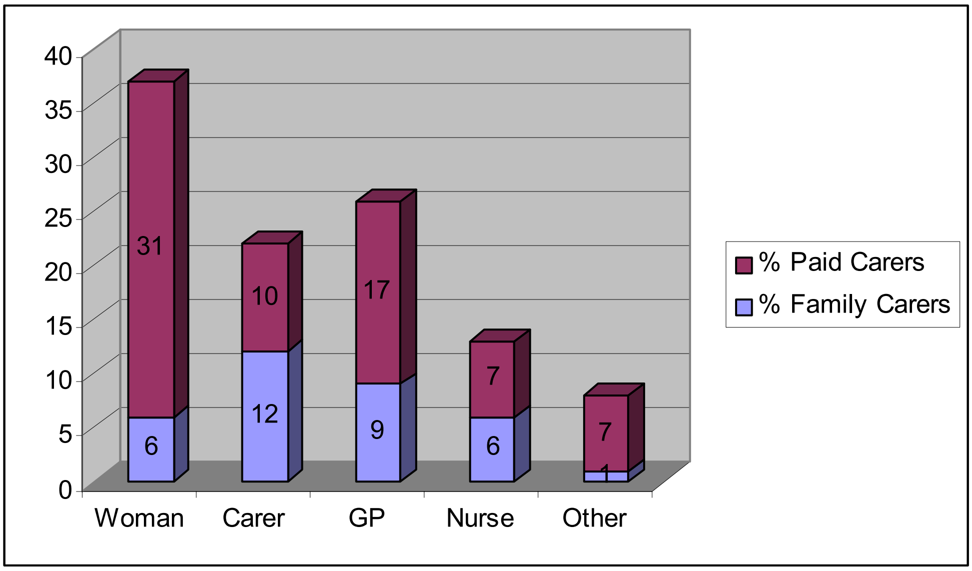
In the absence of any information accompanying the smear invitation, some carers noted how they were thrown back on their own resources in explaining the test to the woman. Some felt inadequately prepared for this, and a number identified the need for themselves to be better informed about cervical screening, in order to support the woman to make sense of the cervical screening process. Several comments on the questionnaires suggested that some carers were hazy about the criteria for eligibility for screening.

Overall, 43% respondents overall felt that the information the woman had received had helped her to decide whether or not to have a smear test and 31% felt that it had not been. Interestingly, 67% of respondents overall felt that the woman did have sufficient support in relation to the information provided, as opposed to the 19% who did not.

6.2.2 Explanation and Decision Making

The nature of decision-making about having a smear and the people and processes contributing to it are likely to be complex, as the interviews with women suggest, and not easily captured through pre-set survey questions. With the proviso that these may be somewhat crude categories, the following were involved in the decision about whether or not a woman had a smear:

Graph 5. Range of people involved in the decision-making process percentage-wise



As with the women interviewed, it is clear that some women were more likely than others to be central to the process. Interestingly, whilst 37% of respondents to this question reported that the woman herself was central to the decision about whether or not to go for a smear test, she was notably more likely to be part of the decision-making process when supported by a paid carer, 53% of whom reported this in contrast to only 14% family carers.

In some cases, the women cared for clearly refused to engage with the process meaning that a balanced discussion of eligibility, risk and benefit would have been impossible. One family carer for example commented

> "…it is very difficult when the person involved does not want to discuss anything about the smear test. The only way to have it done would be to put her out for it."

Another family carer noted that

> "My daughter refused to have anything to do with having a smear test although our doctor explained things to her."

A number of carers made clear that they had had to act as a proxy decision-maker for the women they cared for because the severity of her disability meant that she didn't have the capacity to consent. One family carer for example noted

> "My daughter is 27 years old but mentally like 2 years old. She would not understand the concept of a smear test."

Two family carers reported that they had been completely uninvolved in the procedure, and that the woman they cared for had been given the test without their knowledge. In both cases, they felt that this was wrong, and that they had had to pick up the pieces of what had clearly been a traumatic procedure for their daughters. One family carer for example wrote

> "I was not happy about the way they went about it. I did not know she was getting a smear test and she was very upset about it. They should have asked my advice first."

71% of respondents overall were satisfied with the discussions that had taken place about smears, and 20% disagreed, with a slightly higher proportion of paid carers (at 20%) than family carers (at 13%) unhappy with the ways in which it was discussed. The contexts in which decisions were made clearly varied, supporting informed decisions significantly more in some cases than in others. One paid carer made clear that the woman's decision not to have a smear was well-informed.

> "The person went to a family planning clinic but after a long talk, all information given also on many previous occasions, she decided not to have a smear test."

Another carer, on the other hand, commented that the woman she supported, or cared for was given, "…a very quick chat about a smear test."

One of the most common reasons reported by respondents for why women did not have a smear test was that the woman as not sexually active, although it was not always clear from responses whether this was elicited through discussion with the woman or based on assumptions. One family carer commented

> "The GP said that as she was not sexually active, she did not need the test just yet."

Another paid carer similarly noted

> "She is not sexually active therefore the test is not required or necessary."

Although details of women's ages were not elicited, the influence of generation on approaches to sex and sexuality was recognised by several respondents, with one paid worker commenting

> "…a lot of women with a disability have been told when they were younger that you don't have sex [they have] no understanding of relationships. The whole idea of a smear is 'no way!"

Another common reason was refusal (sometimes behavioural) on the part of women. One family carer reported for example that

> "She would not co-operate and would probably require sedation. This would be an unnecessary procedure in this instance."

Several carers reported that refusal of a smear, or its inappropriateness, stemmed from the fact that it was too invasive and would precipitate intolerable anxiety. One family carer noted

> "She would not allow anyone to touch her in that area."

Another paid carer made the point that this could reflect a more general feeling amongst women, commenting that

> "Most women are very scared of the idea of taking off her underwear and being examined."

Further reasons for women not having the smear test included the fact that they had never been invited, or that they were ineligible as a result of hysterectomy, for example.

6.2.3 Going for a smear test

This section is based on the responses of the 30% of carers (n=37) who cared for women who had had a smear test, or where a smear test had been attempted.

The GPs' surgery was the most common venue for the smear test, reported by 76% respondents. Interestingly, whilst all those cared for by family carers had their smear tests at GPs' surgeries, venues were more varied when they were supported by paid carers, with 9% of paid carers reporting that the woman had been for a smear at the Family Planning Clinic and 13% at a hospital.

The test was most commonly carried out by a nurse, reflecting common practice in Lothian. 23% of the respondents reported that a doctor carried out the procedure. 11% of the respondents, all of whom were paid carers, did not know who carried out the procedure.

A small majority of women (at 57%) who had had a smear had been accompanied during their smear. Family carers (at 56%) were more likely than paid carers (at 40%) to have accompanied the woman. 17% of paid carers but no family carers reported that someone other than themselves had accompanied the woman. Reflecting the experiences of the women interviewed, going alone could clearly be a positive choice for some women. One paid carer, for example, wrote

> "… she was only supported by staff to the surgery. She chose to have the smear test alone."

Several carers reported that the test was attempted but the smear taker was unable to go ahead with the test. One paid carer reported that the woman

> "…could not relax to have the procedure done."

Another reported that the doctor did not proceed with the test when he found that the woman's hymen was intact, suggesting that a preliminary discussion about her eligibility had not taken place.

Although overall 79% of respondents in this area reported that they were happy with the attitude and approach of the staff involved in discussing and carrying out smears, carers reported encounters as most positive where staff were sensitive to the needs of women in communicating, explaining and carrying out the smear. One family carer reported how the nurse

> "…was unsuccessfully in her attempt but was very kind and slowly explained everything."

And another paid carer commented

> "It is a very worrying and unpleasant procedure for women to go through. As long as the nurse explains what is happening and remains calm with clients, then the procedure should go well."

Such positive encounters often rested on staff being experienced or specialists in working with people with learning disabilities. One paid carer commented

> "Due to communication between myself and the practice nurse, the procedure was stress free. This was because the nurse was prepared for someone with learning disabilities and knew about communication needs."

Another paid described a positive experience when the woman she supported

> "…went to a clinic at Sighthill Health Centre specifically for women with a learning disability after various attempts at her own health centre."

Developing sensitivity to the needs of people with disabilities or bringing in those with specific expertise in this was a major theme when respondents suggested factors that would enhance the quality of cervical screening for women with learning disabilities. One paid carer commented on the need for

> "…more training for GP's and Practice Nurses on clients with learning disability."

Another paid carer echoed this in her comment that

> "…there should be more specialist information and specially trained nursing staff to explain these issues to clients."

This was also reflected in the more detailed comments of a paid carer.

> "If persons with learning disabilities/mental health conditions are visited regularly by their psychiatrists/psychiatric nurses, it would be in my opinion the best way for a disabled person to be visited/explained/accompanied to a smear test by them. They have a good insight onto that person's condition and know what is possible and what not to do."

The suggestion of being visited at home was taken up by several other respondents, as one way of helping the woman to feel comfortable and alleviate her anxiety. Several respondents reported that the smear had been carried out at home, and one family carer commented

> "For my daughter personally, if the nurse could carry out the smear test in our home, it would eliminate some of the worry for her."

The preference for a female smear-taker broadly expressed by the women interviewed was echoed by carer respondents. One family carer, commenting on what could improve the process for women with learning disabilities, commented

> "To have a female doctor do the smear test. Also, to have her female carer in the room with her and to keep in mind that you understand the feeling of a person with learning disabilities."

Again reflecting the views of the women interviewed, familiarity with the smear-taker was highlighted as a factor likely to help put a woman at ease. One paid carer suggested that one way of improving the process would be

> "To make sure if they are used to a nurse then this should be the person who does the smear test, as the woman would be comfortable with this person."

Another suggested that setting up a meeting beforehand with all those involved in the care of the woman would improve the experience for her.

Only a minority of respondents overall (43%) were satisfied with the opportunity the women they cared for had been given beforehand to see the equipment to be used and the room where the smear was to be carried out, with a greater proportion of family carers (67%) than paid carers (at 36%) dissatisfied with this. Several carers suggested that being given an opportunity for the woman to see equipment beforehand and would reduce the woman's anxiety, and also suggested that the use of smaller equipment, or equipment in different sizes would allay anxiety and maximise comfort.

Only a minority of respondents were satisfied with the encouragement to relax provided for the women they care for, although here family carers (at 63%) were more likely to be satisfied with this than paid carers (at 35%). Suggestions for helping a woman to relax included playing music during the smear test, and offering her a cup of tea before or after the examination.

65% of respondents overall in this area agreed that sufficient time for the test to take place, with paid carers (at 35%) generally more dissatisfied with this than family carers, all of whom were satisfied. Suggestions for improvement included the provision of long appointments, making sure that the woman has privacy and that the treatment room door is shut during consultations and procedures, ensuring that the woman doesn't feel rushed at any point in the procedure, and ensuring that she has an opportunity to discuss the test beforehand with the nurse, using a range of accessible information. One paid carer noted that she had appreciated the opportunity her client had had to attend a pre-test clinic with a nurse who specialised in learning disability.

Experiences of the test, however, and needs in relation to it, clearly depended in part on the individual woman. This was noted by one paid carer, who commented

> "There are two ladies that I have supported to attend a smear. One was very relaxed and the other terrified. There is no real rehearsed way to deal with this."

Several carers noted that the woman they cared for had not been given any support before or during the smear test.

6.2.4 After the smear test

Of the 30% who had had a smear test, it was most common for the woman to receive her smear result by letter (73% of the respondents). 3% of the total respondents reported that the woman had received her results directly from the GP, although only family carers reported this. The 9% of 'other' means by which the woman had received results included the woman herself having to phone, or the carer having to phone the GP on her woman's behalf. One carer reported that the woman she cared for had not received a result. Only one woman was reported as having received an abnormal result.

77% of the respondents in this area supported the woman to understand her results, with all family carers and 74% paid carers taking on this role. This may suggest either that women supported by paid carers may not have required support to understand her results letter, or that support to understand the smear result was provided elsewhere. 25% of the respondents (all paid carers) reported that support in this area had come from the Community Learning Disability Nurses, and paid carers also reported that the GP helped the woman to understand their results.

Box 9. Summary of carers' suggested ways to improve access to cervical screening

- Personalise invitations, so that standard unadapted invitations for cervical screening do not arrive 'out of the blue' and are accompanied by the offer of a wider discussion about cervical screening.
- Provide information materials adapted to the needs of women with learning disabilities.
- Make clear in the information why cervical screening is important, and risk factors and eligibility.
- Ensure that carers receive adequate information about cervical screening.
- Ensure female smear-takers.
- Allow for flexibility in where smears are taken, including the option for them to be taken at home.
- Allow plenty of time for the smear test to be carried out.
- Involve specialists in learning disability in the process.
- Enhance training in learning disability and communicating with learning disabled people for relevant health professionals.

7. Discussion of Findings and Recommendations

7.1 Preamble

Two notable features emerged from and must contextualise discussion of these findings of experiences of cervical screening amongst women with learning disabilities and their carers. Firstly, women with learning disabilities have to be seen as a group of highly diverse individuals with varied views and life experiences. Secondly, and linked to this, there are many parallels between their experiences (particularly as they emerged from interviews with individuals) and those of women in the general population whose experiences of cervical screening have been researched in Lothian (Milne, 2004) and elsewhere (Regnauld, 2003). However, it is also clear that many women with learning disabilities have particular needs which must be addressed if the cervical screening programme is to be fully accessible to them.

The discussion that follows situates findings from both arms of the research within the wider literature on cervical screening and learning disability. Findings have also been brought together with those from Rachael Wood's (2004) audit of General Practices in SC/SW Edinburgh to highlight both consensus across and tensions between those with a stake in cervical screening locally, including women with learning disabilities, their carers and those administering the programme and carrying out smears in Primary Care. Finally in the discussion we draw out where we can the wider implications of findings both for the ways in which Primary Care is provided for people with learning disabilities and general issues of access to cervical screening for the wider eligible population.

The discussion is structured by following the cervical screening process through, and highlighting recommendations in each area for improving local access to cervical screening for women in this target group. These are intended to be carried forward within the Advisory Group for the Healthy Women's project and its sub-groups on training, guidelines and health information development.

Experiences of cervical screening for women with learning disabilities are shaped by the following over-arching themes running through the discussion:

- the general ways in which Primary Care is adapted to meet their needs;
- the extent to which communication and information is adapted to meet their needs;
- the relationship between women and their carers and how this influences access to cervical screening; and
- the significance of the gender of the health professional and carer.

7.2. Uptake of cervical screening and relationships with carers

The research did not aim to assess levels of uptake of cervical screening amongst women with learning disability, and consequently, we can draw no conclusions about whether women with learning disability are more or less likely than women in the general population to have had smears. Findings from the carers' questionnaires returned suggest that uptake may be lower than average in accord with findings elsewhere. However the research did not elicit details of eligibility for screening and unlike research elsewhere (for example, Broughton and Thomson, 2000) cannot assess the extent to which levels of uptake are *appropriately* low.

Findings from the carers' questionnaire do however suggest that women may be less likely to have had a cervical smear test if they are cared for by a family carer, rather than a paid carer. This highlights important issues in terms of providing cervical screening for this group. There is no way of exploring, through the data collected, whether these relative differences in uptake reflect overall differences in:

- the nature of women cared for respectively by family and paid carers, which may in turn correspond to differences in whether or not smears are appropriate; and
- in contrasting approaches to caring for a woman with learning disabilities between family and paid carers. Paid carers may, for example, be more likely to promote autonomy, and foster independence. They may also have contrasting approaches to the sexuality of women with learning disabilities, being more likely, for example, to allow, admit or encourage the possibility of women with learning disabilities as sexual beings. Findings from previous research suggest that paid carers are both more likely to have had training in meeting the health care needs of people with learning disabilities than unpaid carers and to perceive a need for such training (Langan et al, 1994).

Findings from the carers' questionnaire do suggest that family carers had a generally more protective approach to caring which manifested itself in a more active mediation between the women they cared for and health professionals. They were more likely, for example to accompany a woman to the GP, to communicate issues on her behalf, and to generally assert their knowledge of what was best for her. Although most women with learning disabilities in the sample interviewed lived independently of their birth families, some frustration was expressed by those who lived with parents at being 'spoken for' because as one young woman put it "you are the person who knows yourself best."

Rachael Wood's (2004) audit suggests that Primary Care staff were more likely to be aware of those patients living independently of parents – particularly when disabilities were mild – and that where Adults with Incapacity treatment plans were prepared they were generally only done so for women living in formalised supported accommodation rather than in family homes. This suggests tentatively that differences in experience between women cared for respectively by family carers and others may be reinforced by current systems in Primary Care, in that adapted forms of communication and provision aimed at fostering autonomous decision-making are less likely, by default, to be targeted at women with learning disabilities living at home with their families.

Findings elsewhere have suggested that carers can act as barriers to access (Langan, 1994), but current findings clearly suggest the importance of looking at the influence of the **type** of carer as well as carers *per se*. In considering practical recommendations for action to improve access, findings in respect of the relationship between carers and women do highlight real tensions which have been noted elsewhere, for example in the NHSCSP Good Practice Guide (2000) in providing breast and cervical screening for women with learning disabilities.

On the one hand, guidance on care of people with learning disabilities generally and in relation to cervical screening stressed the importance of involving carers as a matter of routine good practice (NHS Health Scotland, 2004), and Rachael Wood's audit found Primary Care keen to involve carers. Carers can, for example, provide advice on ways of communicating, and interpreting subtle signs of distress and other aspects of language and behaviour which can help support optimum health care, including cervical screening (Langan et al, 1996). Not involving them can precipitate distressing episodes for women with learning disabilities, as suggested by the two cases produced by the carers' questionnaire where carers had not been involved in attempts to screen women, and had, in their view, been left to deal with distressed women in the aftermath.

On the other hand, this support from trusted carers has to be balanced against the rights of a woman with learning disabilities to be given the same opportunities as other women for privacy in relation to decisions about cervical screening – decisions to which discussions of sex and sexuality are intrinsic. The cases where carers had been angry at not being involved in decisions about screening raise further problematic issues of conflicting perspectives on the same situation: the health professionals' perspective on what is in the woman's best interests may be different from that of the carer, and the woman may feel able to disclose different aspects of her feelings, views and experiences to carers and health professionals respectively.

Recommended guidance and action

- Health practitioners should draw on a woman's carer for knowledge of how she prefers to communicate, but not on actual decision-making.
- Health practitioners should negotiate with family carers about the importance of the woman being able to have a private space during consultation, if she so chooses.
- The development of a carers guide in supporting a woman with learning disabilities through cervical screening is required. This will contribute to the carer being as informed as possible on all aspects of cervical screening and service provision.

7.3 Being invited for screening

Most women were invited for screening through letters sent out as part of the routine and currently local practice-based call and recall system. For some this was supplemented by more personalised approaches – for example telephone calls or opportunistic discussions or invitations for screening when they visited a GP or Practice Nurse about another health issue.

None of the women received letters which were adapted to their levels of literacy or understanding. This is consistent with findings from Rachael Wood's (2004) Primary Care audit, which found that routine, unadapted letters were sent even to those women known to have a learning disability for fear that adapted letters or leaflets would be perceived as stigmatising. Primary Care staff preferred to focus on follow-up of non-responders. This was part of a wider finding during the audit that patients with learning disabilities were not generally viewed as needing a different, proactive model of care, although staff recognised that people could fall through the net.

From the perspective of women and their carers, however, unadapted letters arriving without prior warning were considered at best unhelpful and at worst a source of distress or anxiety. This was one of the major areas where respondents identified the need for current practice to change. Both women and their carers lent instead towards preferring a more personalised approach to being invited for screening which recognised their particular needs. Almost all women who received unadapted letters depended on others for help in understanding them, which compromised their autonomy. Repeat letters sent to non-responders could be perceived as 'warnings' or 'threats', and in this sense were reported to have triggered anxiety and distress.

The views of women and carers in this area therefore appeared to conflict with the approach taken by Primary Care staff in the audit. The preference for 'treating everyone the same' in Primary Care in order to avoid stigma may be underpinned by confusion between equal access to services on the one hand and equal treatment on the other. In this case, promoting equal access to services requires adaptation to particular needs, rather than treating everyone equally. It also rests crucially on the identification of women as having particular needs associated with their learning disability. Whilst recording diagnoses is perceived as being in the interests for women with severe learning disabilities, it is resisted in Primary Care for women with mild to moderate learning disabilities on the basis that it could serve to stigmatise them.

Consultation with women with learning disabilities separately carried out by the Healthy Women's project, on the other hand, suggests that women do not perceive being identified as having learning disabilities as stigmatising as long as they are confident that it is being done in their interests and will result in their easier access to services (Levi et al, 2005). This entails not just coding of diagnoses, but specifying communication needs and preferences. It suggests the need to set Primary Care at ease about stigma, and also highlights the need for the development of materials similar to those which have been developed in relation to the monitoring of ethnicity to explain to people with learning disabilities and staff the purpose of recording diagnoses or communication needs in medical notes.

Prospective new developments in Primary Care and cervical screening have potentially contradictory implications for access to cervical screening for women with learning disabilities. The new General Medical Services Quality and Outcomes Framework (QOF) and the associated Directed Enhanced Service for adults with learning disabilities in Scotland (as described on page 2) provide incentives to GP Practices to establish registers of adults with learning disabilities and to identify, in liaison with external agencies, barriers to access. The introduction of the Scottish Cervical Call-Recall System (SCCRS) in Lothian in October 2006, on the other hand, will pull in the direction of greater standardisation and offer less potential for tailored, personalised approaches. Findings highlight the need to reconcile the tensions between these two new developments.

More personalised approaches to invitation came through opportunistic discussions and offers of screening. These are therefore to be welcomed, but with some guidance and caveats. Firstly, it is clear from interviews with women that confusion or anxiety can arise if cervical screening is introduced during a consultation about a completely unrelated health issue unless the health professional takes care to make very explicit that they are separate. Opportunistic discussions about screening left one woman thinking that cervical screening was something to do with her blood pressure, for example. This has parallels elsewhere: some South Asian women in Bradford, for example, who were regularly given smears opportunistically following childbirth, believed that cervical screening was in some way to do with childbirth. In initiating opportunistic discussions, therefore, the health professional must take care to explicitly separate from the issue which initially prompted the consultation.

Secondly, health professionals considering initiating opportunistic discussions about cervical screening should be sensitive to the preferences of women for female practitioners with whom to discuss the issue. Although interviews with women suggested that familiarity with and trust in a male practitioner built up over time can outweigh the preference for a female practitioner, this was exceptional, and findings from both arms of the research clearly suggest that most women felt more comfortable discussing screening with a woman (in the same way that women in the general population appear to). Male practitioners may well therefore 'seize the moment' in broaching cervical screening, but in doing so should offer women the opportunity for an appointment with a female colleague for a more sustained discussion.

Recommended guidance and action

- If health practitioners are discussing screening opportunistically during a patient consultation, they must take care to explicitly separate cervical screening from the issue which initially prompted the consultation.
- Should a male practitioner broach the issue of cervical screening with a woman, they should consider offering her another appointment with a female colleague for a more sustained discussion.
- On receiving the Recommended Call List (RCL) from SCCRS, practices may choose to cross check with the QOF Learning Disability Register to identify a woman with a known learning disability to follow-up the standard invitation letter by phone or face to face contact.
- On receiving the Defaulters List from SCCRS, practices may choose to cross check with the QOF Learning Disability Register to identify a woman with a known learning disability and to use this opportunity to send supporting materials to the identified woman.
- As a minimum, practices should flag the woman's general notes to allow screening to be discussed during a future consultation.
- Women with learning disabilities who are on early recall and fail to attend should be proactively offered a specific consultation to discuss the issue.

7.4 Screening: information, knowledge and eligibility

The wider research literature suggests confusion about the purpose of cervical screening amongst women with learning disability, although this has to be set in the context of the wider literature suggesting widely varying understandings of this amongst the general female population. Whilst only a small sample of women were interviewed, they were generally well-informed about the purpose of screening. It was not possible to determine through the carers' questionnaire levels of knowledge of screening amongst the women cared for. Those women interviewed who were well-informed had had to actively become so – harnessing a wide range of informal and informal sources. Furthermore, they may not have been particularly well-informed before they had had a smear. It was notable that of the two women who were best-informed, one had been recalled for further investigation and treatment, and therefore may have accumulated this knowledge during their journey through the cervical screening process rather than using this knowledge as the basis for their decision on whether or not to be screened. It was also clear that ‘knowledge’ and ‘information’ in relation to screening needs to be disaggregated: knowledge of the overall purpose of cervical screening is separate from knowledge of personal eligibility for screening and distinct again from the issue of the procedures screening involves. Being well-informed in one area did not necessarily mean that women were well-informed in all areas. Finally, there was a striking lack of written information made available to women, although this was sometimes made good by this being sought or provided within Primary Care. It was not only that women did not receive adapted information leaflets, but that only a small number of women in either arm of the research appear to have received any written information at all.

In relation to uneven knowledge, it was clear that even where the broader purposes of screening were understood, eligibility criteria for screening and risk factors were not necessarily clearly not understood by women with learning disabilities (or by some carers). It is striking that, although most women interviewed were questioned by health professionals about whether they were sexually active or whether they smoked, the link between these issues and cervical screening was not made explicit. It is therefore hardly surprising that women did not easily make the link. This has several implications. Firstly, it highlights the need for health professionals working with this group to make explicit links between the questions they are asking and cervical screening, rather than taking for granted that women understand the logic behind the questions. The extent to which the wider female population also fail to make these links remains an open question. Secondly, this highlights the need to disaggregate information resources for women with learning disabilities within the wider context of providing adapted information. The current leaflet for the general population contains a substantial amount of information, and important issues such as eligibility criteria for screening can easily get lost. A pre-smear leaflet, focusing solely on eligibility would have a clear place. This leaflet could in itself prompt health professionals to be explicit in their discussions about eligibility with women.

Results from both arms of the research also suggest that women with learning disabilities are particularly dependent on their carers for information. Carers themselves wanted to be better informed about cervical screening in order to support women. Attempts should therefore be made to inform carers as well as women about cervical screening, and even where adapted leaflets can be targeted at women with learning disabilities, the more detailed leaflets for the general population should also be enclosed.

The research elicited detailed views on the ways information should be provided, highlighting the need for detailed piloting of information resources if they are to be properly understood. This pertains to both the language, pictures and symbols used and to the content. Again, being explicit rather than taking knowledge for granted was a theme running through all aspects of the provision of information, and has implications for the ways in which face-to-face as well as written information should be structured.

It was also clear, particularly from interviews with carers, that input from specialists in learning disability was under-used, and where it happened was particularly valued as a support to information-giving.

<u>Recommended guidance and action</u>

- The production of pictorial leaflet in a range of formats is required for women and carers which specifically describes eligibility for cervical screening, and risk factors for cervical cancer.
- This leaflet should be used in practices to support health professionals in their discussions with women about their eligibility for screening.
- The production of a pictorial leaflet in a range of formats is required for women and carers which describes the smear test from invitation onwards.
- When issuing supporting materials, practices should routinely use this leaflet for their learning disability patients.

7.5 Decision-making about screening

It is difficult to assess on the basis of these findings the overall extent to which uptake of screening was properly informed, nor the part that the information women were provided with about screening information played in their decisions to take up or decline offers of screening. This is a contentious area in relation to women in the general population, and has generally been under-researched. What is clear, however, is that at least in some cases women's consent to screening was not well-informed and they had a smear with little idea of the precise risks and benefits of screening. The decision to have a smear for some women was, furthermore, based on wider life experiences and views rather than an explicit weighing up of the risks and benefits of screening (such as previous encounters with illness amongst themselves and their friends), and in others screening had simply been incorporated into their routine. All these findings have parallels in the research literature on the factors shaping uptake of screening in the general population. (Regnauld, 2003)

Findings make very clear, however, great variance in the extent to which women were actually involved in the decision to have or decline a smear, and suggest that decisions are particularly likely to be taken on behalf of this group of women by health professionals as well as carers. This may be a more distinctive finding in relation to women with learning disabilities. In some cases, decisions about screening were made with no involvement from the women concerned at all. This may have been appropriate where the woman did not have the capacity to understand or engage in the process and where it would have caused great anxiety. In other cases, however, women clearly did have the capacity to engage in discussion (as evidenced by their ability to engage in being interviewed) but were screened – or not – against their expressed opinion in a process that can hardly be termed 'consent', in accordance with the views of the health professionals of what was in their best interests.

In some cases, women did not passively accept the course of action argued for them by health professionals, but tried to approach them "…from a different direction" as one woman put it, but there was also a sense amongst others that '..the doctor knows best', in ways with which they were neither willing nor able to argue. Whereas this has parallels in wider research findings on uptake of screening, provision of screening in this population should be particularly sensitive to the fact that people with learning disabilities may be more accepting of authority than the general population, or at least have fewer resources at their disposal to enable them to argue with authority or express disagreement with recommended courses of action. It is important that the concerns with issues of consent running through debates on cervical screening and learning disability should not become preoccupied with technical issues of eliciting consent (in terms of formulating protocols, for example) at the expense of tackling the more subtle issues of power in interactions between people with learning disabilities and health professionals. Findings suggest that sensitivity to these more embedded issues – which are not specifically highlighted in previous guidance – should inform support for decision-making about screening amongst women with learning disabilities.

Decisions which were effectively made for women by health professionals rested in a number of cases on assumptions about women's sexuality, which was problematised in ways partly echoed in the wider literature on cervical screening and learning disability. The emphasis of research literature and guidance has been to express caution about assumptions that women with learning disabilities are not sexually active and therefore not eligible for cervical screening. Some women interviewed were certainly assumed to be sexually inactive on the basis of their disabilities (both physical and learning disabilities) without being involved in a discussion about their sexual histories. However, findings here – echoing those elsewhere, and high-profile media cases – suggest that women with learning disabilities may also be assumed to be problematically sexually active or promiscuous, and that this can equally lead to inappropriate screening and some trauma. It is clearly imperative that health professionals sensitively talk and listen to the woman herself about her sex life, and decisions are not made based on assumptions about perceived behaviours. However, it is equally clear from the audit findings that staff do not necessarily feel equipped to do this, and that this is an area where they feel that they need guidance and support. Good practice rests on women having a space with health professionals where they can discuss their sex lives and sexuality free of constraint (which means being offered sessions independently of carers). It also rests on health professionals being able to draw on advice from or directly involving those who specialise in learning disability.

Carers in particular highlighted the importance of the involvement of practitioners with expertise in learning disabilities in supporting decision-making. This suggests a tension between carers' wishes and prevailing practice in Primary Care, where an endorsement of the importance of working with specialists in learning disability such as Community Learning Disability Nurses was infrequently acted upon in practice, and was not formalised. More generally, harnessing help from health professionals was easier if people felt understood and 'known', and that people did not feel stigmatised by their learning disability – that, as one woman said, people did not "think the worst of you." Finally, in the area of decision-making gender was crucial as it was in other areas, and a strong preference was expressed for a female professional with whom to discuss cervical screening and decision-making.

Recommended guidance and action

- A guide for health practitioners is required that gives advice on good practice in consent to cervical screening including checking understanding of cervical screening; how to establish eligibility for screening; consequences of screening and free choice; and within this include tips to assisting communication.
- The provision of training to health practitioners is required to raise the topic of power issues between practitioner and patient.

- The local community learning disability teams have developed a tool on assessing the sexual health needs of people with learning disabilities. Practitioners should consider drawing on their advice, or directly involving them, if further input on sexual health is required.

7.6 Preparation for a smear

Making sure that a woman is fully prepared for her smear is flagged as key in much literature and in guidance (Broughton and Thomson, 2000; NHSCSP Good Practice Guides, 2000, 2006). It should be part of an iterative process, providing a further opportunity to check that a woman understands the purpose of a smear and what it involves, and cannot be discretely separated from the provision of information and decision-making. It also provides an opportunity to discuss with the woman the specifics of what a smear will involve – for example, the details of the positions that they may be in whilst the smear is taken. Findings from both arms of the research endorse the need for women to be well-prepared for smears. Carers' responses suggested that this is again best done by harnessing those experienced in working with women with learning difficulties and sensitive to their needs. Responses from women interviewed suggest that experiences of having a smear were more comfortable if women had been well-prepared and knew exactly what to expect, and women described some examples of extremely good practice in this area.

While good preparation for having a smear is endorsed by research findings, and is a woman's right, however, findings in relation to how women want to be prepared for having a smear were far more equivocal. Women's individual preferences came out very strongly in this area, and there is also some evidence of tension between views expressed generally by women on the one hand and by carers on the other. Findings here also offer the opportunity to reflect on good-practice guidance in relation to offering pre-smear or specific preparation sessions. Findings from the audit and from both arms of this research suggest that although preparation sessions form an important part of the good practice guidance, it happens locally on an ad hoc rather than a routine basis, and only a small minority of women had been offered such specific sessions. Preparation tended to happen in a more opportunistic manner, including preparatory to the smear itself.[6] While several carers had had experience of the benefits of a pre-smear session for the women they cared for carried out (at least in one case) by a specialist in learning disability, and called for opportunities for such sessions, women interviewed were more ambivalent. This was primarily on the grounds that they wanted the smear 'over and done with': being offered a dedicated session and having to return for a smear would, in the experience of some women, heighten their anxiety, although several women noted that it may be fine for others, and should be offered.

This suggests that an important and difficult balance needs to be struck between ensuring adequate preparation (on which properly informed consent is built) and ensuring that women had time to absorb information on the one hand, and not heightening a woman's anxieties on the other. It further suggests caution in absorbing preparation sessions into routine good practice. While good practice should entail the routine **offer** of such sessions, this has to be in the context of discussing with a woman

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[6] In this connection it is worth noting findings from Rachael Wood's (2004) audit suggesting that longer smear sessions were not routinely offered to women with learning disabilities, presumably raising issues of time constraints which can be assumed to have reflected on the scope for thorough preparation.

her preferred ways and pace of being prepared for a smear. The same caution applies to the content of preparation however it takes place: whereas some women were keen to see the specula used in smear-taking, for example, others described how this would have enhanced their anxiety.

Timing again is critical as the findings suggest that some women with learning disabilities were less able to absorb information about the smear test during their actual appointment. Therefore, more time is needed to enable them to assimilate this to adequately prepare for the test.

Recommended guidance and action

- How to best to prepare a woman for cervical screening is highly individual: a guide for health practitioners is required to prompt the practitioner to consider a range of options to facilitate preparation.
- Primary care and community learning disability teams should work closely together to ensure adequate preparation. The community learning disability team can have an important role in preparing a woman in having a smear. Speech and Language Therapists have a specific role in supporting and facilitating communication.
- A range of resources are required for women, carers and health practitioners to facilitate preparation including a range of health information resources and relaxation training.

7.7 Experiences of the smear test

Experiences of having a smear varied between women, and also over the course of their lives in ways which again have strong parallels with findings from the research literature based on the general population (Regnauld, 2003). Where women and carers described positive experiences, this was always in the context of being known to the health professional, and where sensitivity and adaptation to their particular needs was demonstrated. It also related to the approach of the professional, and in particular to women not feeling stigmatised, or being made to feel stupid. Conversely, where smear-taking was not adapted to their needs – including their need for physical comfort which was particularly important where women had physical disabilities – women described traumatic or distressing encounters.

Support in its widest sense was clearly important, although for a majority of women interviewed this did not necessarily translate into taking a carer or supporter with them when they were having the smear. Most had gone on their own through preference. This could be interpreted as an expression of healthy autonomy, and a desire for privacy in what is an intimate procedure. Support could however be provided within the surgery itself, and findings suggest that women could benefit from being offered support from one person to do the hand-holding and reassurance whilst the other takes the smear – a procedure which is routinely offered to (and widely appreciated by) women attending for colposcopy, for example. The option for women to bring along a carer or supporter should always be offered, however, and in this connection, women being cared for by paid support should always have the option of female carers.

Relaxation, again in its widest sense, emerged as an important issue in both arms of the research in ways which may have more general resonance in the provision of screening.

Generally, support was not widely offered in helping women to relax, or talking through with them ahead of time what may help them to relax. Women were rather simply told to relax, and in many cases found this difficult. They were, conversely, full of ideas for what would help them, individually, to relax. Preparation, in whatever form it takes, could usefully include discussion of this, and smear-takers could usefully be flexible about welcoming, for example, preferred music to be brought along to the smear-taking session. This would entail a longer than average appointment, which is anyway suggested as routine good practice for women with learning disabilities, and which these findings would endorse.

Women and carers again both stressed that they wanted to be reassured that smears could be carried out by female health professionals, endorsing findings from research carried out amongst both women with learning disabilities and women in the general population. In Lothian there are currently few if any sites where smears are taken which do not have female smear-taker (Milne et al, 2004). The availability of female smear-takers, and women's right to request them, should be emphasised in all forms of information about screening, in the context of the fact that women with learning disabilities may be less aware of their rights in this area than others, as has been pointed out elsewhere (Broughton and Thomson, 2000)

The theme of physical disability and specific barriers of access were raised during the research. Previous research has identified health professional's perceptions of technical difficulties in performing the smear test due to the woman's disability. Findings from the current research suggest that these barriers are not insurmountable: a flexible, considered approach from the health professional to the positioning of a physically disabled woman does facilitate access and remove barriers to cervical screening. Home visits were effectively used to facilitate access to screening. These were suggested by carers not only for women who had physical disabilities, but also for women who may find the procedure distressing and where being in their familiar home environment could put them at their ease. Where these had taken place, they were much appreciated by both women and carers.

<u>Recommended guidance and action</u>

- How to best to carry out the smear test is highly individual: a guide for health practitioners is required to highlight the ways in which screening can be sensitively provided to meet the needs of women with learning disabilities. This can include consideration of:
    1. Offering the woman the choice of whether she wants another practitioner with her for support during the procedure, or her carer, if she has one.
    2. Where possible, ensuring that the smear taker is female and familiar to the woman.
    3. Providing opportunities to allow sufficient time to explain to the woman how the sample is taken before taking the smear.
    4. Any physical limitations with regards to the practice environment for women with a physical disability and where required, offer a viable alternative.
    5. If the woman is physically disabled, practitioners should offer the woman a choice of position and in particular, lying on her side.

6. If the woman is resistant or uncooperative, offer her another appointment and consider including relaxation training before proceeding with the smear taking.

7.8 After the test: results, abnormalities and treatment

It is striking that the existing body of research literature and guidance focuses almost exclusively on uptake of cervical screening, invitations, knowledge and experiences of the smear-taking process, whilst having little to say on how women with learning disabilities receive the results of screening, or how they experience news of cervical abnormalities and treatment. The NHSCSP Good Practice Guide (2000), for example, details the technical consequences of receiving an abnormal result but remains silent on how this information and process can be adapted for women with learning disabilities. This relative lack of emphasis on the consequences of screening has parallels in research, guidance and provision for other minority groups. Little of the literature on screening for minority ethnic women, for example, discusses the potential consequences of screening, and focuses rather on ways of enhancing uptake.

Interestingly, the issue of receiving results did not emerge as a particularly problematic area in interviews with women, in contrast to perceived problems with receiving invitations to screening. It is also worth noting that the audit found that about half of practices surveyed attempted to communicate results in an accessible way. There was apprehension amongst women about the consequences of screening, however, and suggestions that these should be clearly addressed in a reassuring way with initial information accompanying invitations to screening.

Those women who had had abnormal results wanted something to explain what these might mean. In particular, some women wanted information on what abnormal and unsatisfactory results were, what treatment is offered and the efficacy of the treatment. This points to the importance of making good the paucity of adapted resources in this area.

Recommended guidance and action

- There is a 7 day gap between SCCRS informing practices of results and issuing letter to the woman. When an alert comes to practices about an abnormality, practices should cross check with the QOF Learning Disability Register to identify a woman with a known learning disability and she should be proactively invited for a consultation to discuss the results and possible interventions.
- Accessible leaflets on (1) abnormal cervical smear results and (2) colposcopy and cervical screening treatment respectively are required to be developed.

7.9 Strengths and limitations to the study

Central to the research project was that it should, as far as possible, take into account women's expressed needs based on their existing and past experiences of cervical screening and primary care services. This was instead of relying on health or other professionals to act as proxies for their needs. Through the use of interviews with women with learning disabilities, this provided a detailed and rarely seen insight into the views and experiences of women with learning disabilities regarding the cervical screening process.

The interview schedule design was rooted in the findings from previous research and developed from the emerging good practice in researching the experiences of those with learning disabilities. To support and augment communication, language was kept as straightforward as possible and integrated appropriate stimuli including pictures, symbols and photographs. The sample of women with learning disabilities was selected from a wide range of service providers in the project area and in Lothian. Furthermore, given that participants were sampled through a range of services should in theory represent a wider set of experiences of women with learning disabilities.

The sample group of women with learning disability, which included women with mild to moderate learning disabilities, was carefully considered as women had to consent to participation. The use of qualitative research methods and in particular, semi-structured interviews can be justified as appropriate, as findings have emerged through in-depth discussion and the probing of themes and issues. However, these findings are not intended to be generalised.

Although the researchers understood the ethical need to assure participant protection, the research has limitations by the fact it excluded the views and experiences of women with more severe or profound learning disability (NHS Health Scotland, 2004). This cohort of people may have valuable insights or experiences that could have informed the research findings and ultimately, cervical screening service development.

Carers views were sought because their views, as those whose role is to support women who are invited for cervical screening is valuable. The results of the questionnaire add to and build on those of the interviews and provide detailed information on carer's views and experiences of supporting a woman with a learning disability through the cervical screening process.

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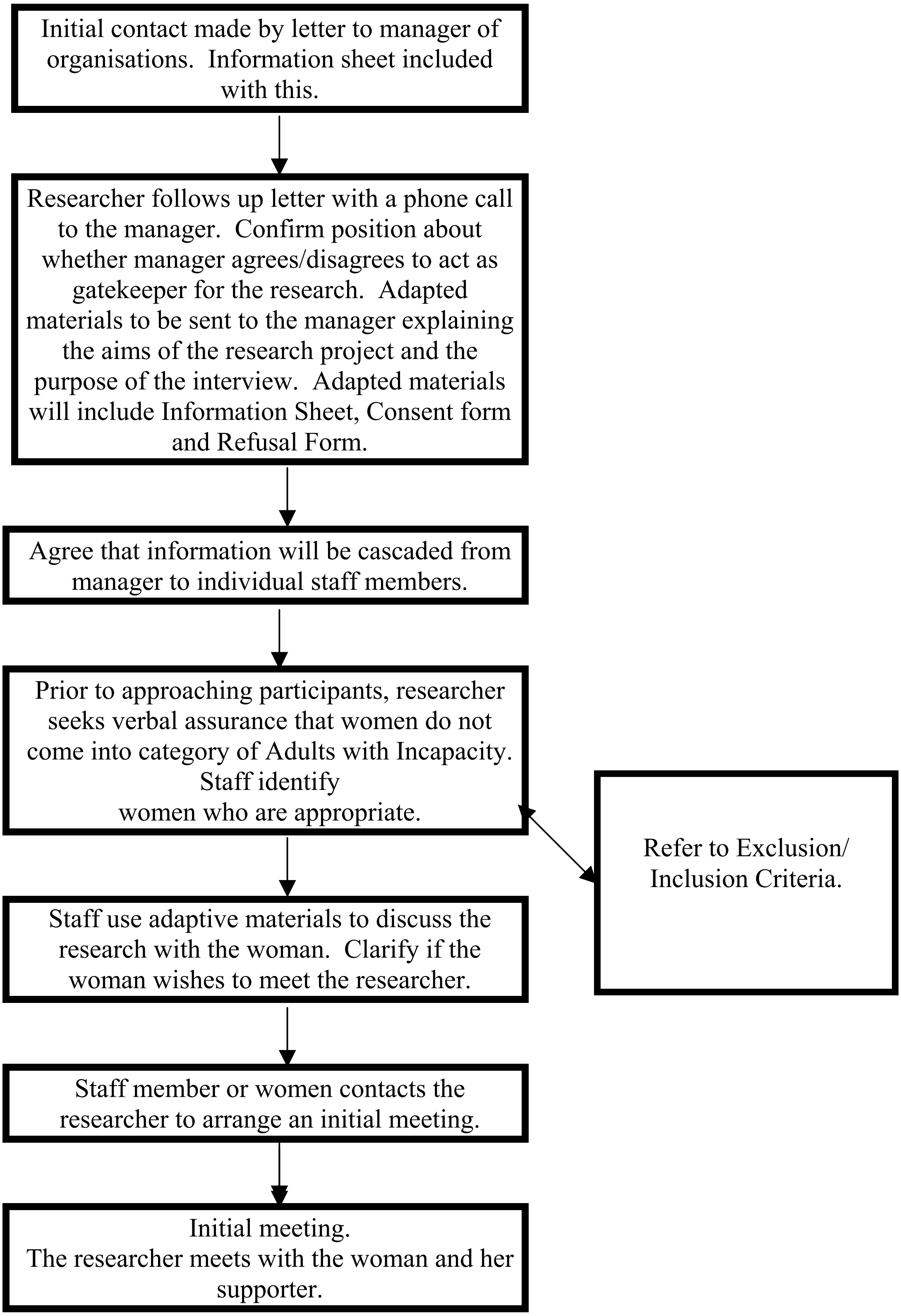
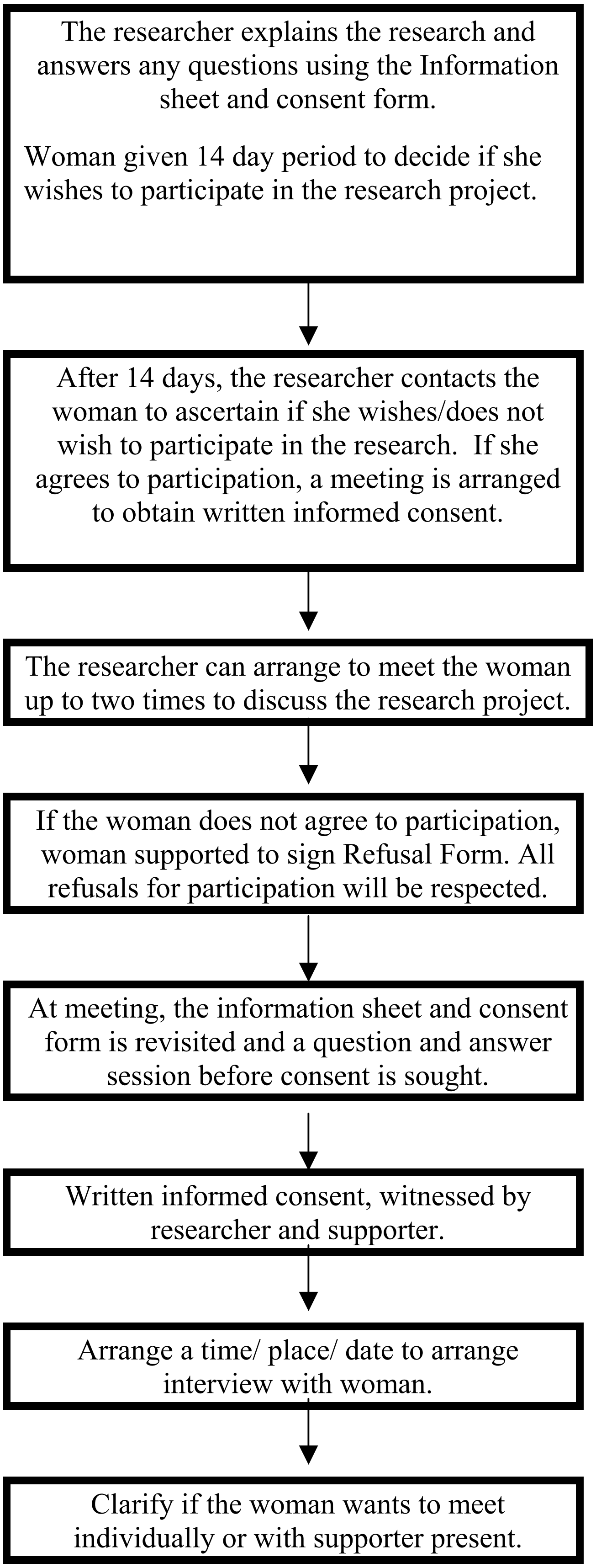
Appendix 1: Flowchart of the methodological approaches used in the research

Interviews with a woman with a learning disability





The researcher explains the research and answers any questions using the Information sheet and consent form.

Woman given 14 day period to decide if she wishes to participate in the research project.

After 14 days, the researcher contacts the woman to ascertain if she wishes/does not wish to participate in the research. If she agrees to participation, a meeting is arranged to obtain written informed consent.

The researcher can arrange to meet the woman up to two times to discuss the research project.

If the woman does not agree to participation, woman supported to sign Refusal Form. All refusals for participation will be respected.

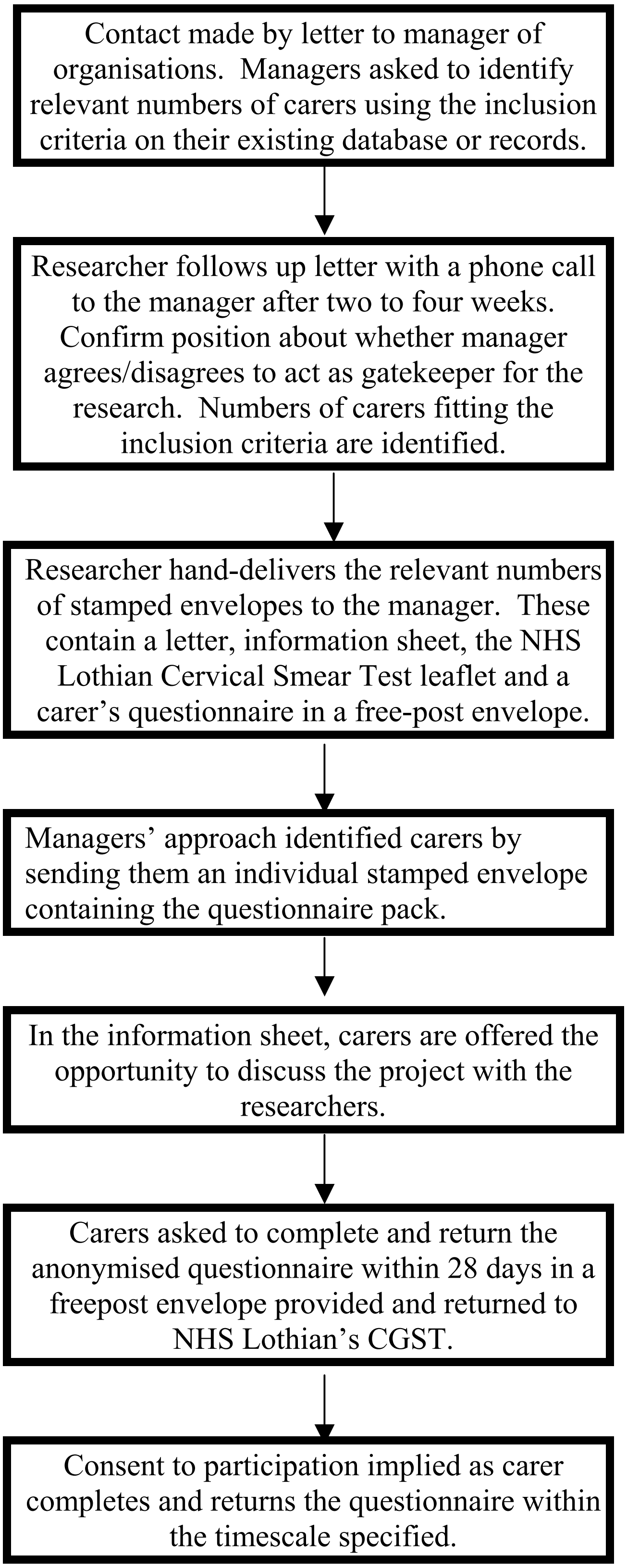
At meeting, the information sheet and consent form is revisited and a question and answer session before consent is sought.

Written informed consent, witnessed by researcher and supporter.

Arrange a time/ place/ date to arrange interview with woman.

Clarify if the woman wants to meet individually or with supporter present.

Carers' questionnaire.



Contact made by letter to manager of organisations. Managers asked to identify relevant numbers of carers using the inclusion criteria on their existing database or records.

Researcher follows up letter with a phone call to the manager after two to four weeks. Confirm position about whether manager agrees/disagrees to act as gatekeeper for the research. Numbers of carers fitting the inclusion criteria are identified.

Researcher hand-delivers the relevant numbers of stamped envelopes to the manager. These contain a letter, information sheet, the NHS Lothian Cervical Smear Test leaflet and a carer’s questionnaire in a free-post envelope.

Managers’ approach identified carers by sending them an individual stamped envelope containing the questionnaire pack.

In the information sheet, carers are offered the opportunity to discuss the project with the researchers.

Carers asked to complete and return the anonymised questionnaire within 28 days in a freepost envelope provided and returned to NHS Lothian’s CGST.

Consent to participation implied as carer completes and returns the questionnaire within the timescale specified.

Appendix 2: Interview questions for Women with Learning Disabilities

1. Introduction.

1) What is your name?

2) What is your date of birth?
That makes you ________ years old.

3) Who do you live with?

(i) With your husband/partner/boyfriend (ii) With your parents, or other family members

(iii) By yourself (iv) In a home with others

(v) Other (Please specify)

4) Can you think of something that you are good at, or enjoy doing?
(Prompt: we are all good at something. Can you tell me something you are good at, or enjoy doing?)

5) Can you think of something that you might need help or support with?

6) Who helps you with this?

7) What do you do during the day? Go to:

(i) Work (ii) College (iii) Educational Activity

(iv) Day Centre (v) Other (Please specify)

8) Do you know the name of your GP?
(Prompt: The person you visit when you are unwell/have a tummy-bug is called a GP. You might call them your doctor)

9) Where do you visit your GP?

2. Cervical Smears and Smear History

Thank-you for agreeing to talk to me about smear tests.

10) Can you tell me why women have a smear test?

(Discussion of a smear test – adapt individual pictures from FAIR leaflet – p.4)

11) Have you been for a smear test? Can you remember when this was?
(Prompt: this year, last year, two years ago, three years ago, longer)

12) Was this the first time you had a smear test?

We'll start by talking about the last time you were invited to have a smear test.

3. Information

13) How were you asked to go for a smear test?

Prompts (could be more than one):

Through receiving a letter *(stress this as a prompt) and reading it yourself?*
What did it say in the letter? Did it say why you need a smear test and what happens?

Through your parents, partner, supporter or carer helping you to read the letter *or reading it for you?*
Through someone at the Health Centre or Family Planning clinic inviting you?
Perhaps when you went to the Health Centre about something else?
Through your community learning disability nurse inviting you?

14) Were you given any information about having a smear test to keep, or look over and read later?

Prompts (could be more than one):
Did you get a leaflet? Could you read it? Was it difficult to read? Did it have pictures?

15) Were you helped to go through the information? Who helped you?

Your parents?
Your husband?
Your supporter/carer?
A nurse or doctor at the health centre?
A nurse or doctor at the family planning clinic?
A community learning disability nurse?
Your friends or people you work with?
Or was it someone else? If so, who?

16) Did you understand it?

17) Would anything have made it easier to understand?

18) Would anything have been useful?
(Show "Prompt box" that will include practical examples for the woman to consider. This will include a range of leaflets, using difficult and easy words, pictures of equipment, visit to the health centre/picture of a treatment room, DOH's adapted invitation letter, more time, more discussion?)

4. Explanations and decision-making

19) Has anyone spoken to you about why you need a smear test? Who was this?

20) What were you told?

21) Before you had a smear test, did your nurse or GP ask you:

(i) If you have ever had sex?
(Prompt: What does sex mean to you? Use different phrases for sex)
(ii) If you smoke?

22) Did the information help you decide whether or not to go for a smear?

Prompts: Did you have any worries that you wanted to talk about?
Did you have any questions that you wanted to talk about?
Did the information you were given help to answer these?

23) Why did you think it was a good idea to go for a smear test?

24) Why did you not go for a smear test? What made you decide not to go?

25) Did someone help you think about it?

26) Who helped you?

27) How did this make you feel?

5. Going for a Smear

28) Where did you go for your smear?

Prompts:
Was it your usual doctors?
Was it your usual Family Planning Clinic?

29) Did you go by yourself or with someone else?
(Prompt: who did you go with? Did you find this helpful?)

30) Did you already know the nurse or GP?
(Prompt: did it help that you knew them? Would it have been helpful if you had known them?)

31) **Before** you had your smear, did the nurse or GP talk to you about what they were going to do?

32) What were they telling you?

33) Was it clear to you what was going to happen?

34) Were you able to ask them any questions? What questions did you ask?

35) Did you want to ask them questions but didn't feel you could? Why was this?

36) When you were **actually** having your smear test, did someone stay with you?

37) Was this helpful? Why?

38) When you were **actually** having your smear, did the nurse or GP tell you what they were doing?

39) What were they telling you?

40) Was it clear to you what was actually happening?

41) How did you feel when you were **actually** having your smear test?

(Prompt: some women have felt … appropriate symbols to include Nervous, Pain, Shy, OK, Embarrassed)

42) Can you think of anything to make it better*? (prompt box + prompts: relaxation techniques)*

43) **After** the smear test, what happened next? What were you told?

44) Were you told that you get results after having your smear test?

5. After the smear

45) How did you get the results of your smear test?
(Prompts: In a letter? Over the phone? Face to face with your GP or nurse? By someone telling you about your results?)

46) When were you told your results?
(Prompt: use calendar to show 1 month)

47) Who told you your results?

48) What was your result? What did it mean?
(Prompt: What does a negative/positive result mean?)

49) Would anything have made it easier to understand?
(Show "Prompt box" to include pictures, drawings, simple words, DOH's adapted results letter, more time, more discussion?)

6. Follow-up

50) When you got the results of your smear, were you asked to go back?

51) Why did you have to go back?

52) What happened?

53) Please tell me about it.

54) Was it clear to you (why you had to go back?)

55) How did you feel when you were asked to go back?
(Prompt: some women have felt … appropriate symbols to include Nervous, Pain, Shy, OK, Embarrassed)

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56) Is there anything you would like to ask me?

57) Is there anything about the smear test you would like to know?

Thank you for taking the time to answer these questions.

Remember:-
Explain that information will be transcribed and can be sent to the participant to check, before it goes forward to next stage – any additional comments, thoughts that emerge after and which they want to be included in analysis can be marked on script.

NHS
Lothian

Appendix 3: Carers' Postal Questionnaire

Carers Questionnaire: "Supporting a woman with a learning disability about cervical screening".

Please answer the following questions which refer to the woman with a learning disability whom you care for or support.

Introduction

1. In what capacity are you a carer/supporter?

☐ Parent ☐ Friend ☐ Partner ☐ Paid worker ☐ Other

____

2. Do you support the woman you care for to attend her GP?

☐ Yes ☐ No *(please go to Question 4)*

3. How do you support her to attend her GP? *(please tick all that apply)*

☐ By arranging her appointments

☐ By accompanying her to see her GP

☐ By supporting her in communicating issues/problems

☐ By communicating issues/problems on her behalf

☐ Other

____

Cervical Smears and Smear History

4. Has the woman you care for/support <u>ever had</u> a smear test?

☐ Yes ☐ No ☐ Don't know

5. Has the woman you care for/support <u>ever been invited</u> for a smear test?

☐ Yes ☐ No ☐ Don't know
(If no, please go to final question)

6. How was she invited for a smear test?

☐ Written letter

☐ Directly by the GP

☐ Directly by the nurse

☐ Directly by a member of the Community Learning Disability Team

☐ Other (please specify)

____

7. Was she given any information about having a smear test? (please tick all that apply)

☐ Written information ☐ Verbal information ☐ Adapted leaflet ☐ Video/CD-Rom

☐ None ☐ Don't know ☐ Other (please specify)____________

8. Did you support her to understand the information about having a smear test?

☐ Yes ☐ No

Explanation and Decision Making

9. Did the information help her decide whether or not to have a smear test?

☐ Yes ☐ No ☐ Don't know

10. Who was involved in making the decision about whether to have a smear test?

☐ The woman ☐ Yourself ☐ GP ☐ Nurse

☐ Others (please specify)

____

11. If she didn't have a smear test, please can you tell me why not?

☐ GP advised against ☐ Nurse advised against ☐ You advised against

☐ Woman decided against ☐ Other

____

Going for a smear

12. Where did the woman you care for/support have her smear test?

☐ GP's surgery ☐ Family Planning Clinic ☐ Hospital

☐ Don't know ☐ Other (please specify)

____

13. Did you go with her? ☐ Yes ☐ No ☐ Someone else

14. Who carried out the smear test?

☐ Doctor ☐ Nurse ☐ Don't know

15. Were you happy with the support she was given, in terms of?

Information given ☐ Yes ☐ No
☐ Don't know

Attitude and approach of staff involved ☐ Yes ☐ No
☐ Don't know

Discussion of procedure ☐ Yes ☐ No
☐ Don't know

Clear communication ☐ Yes ☐ No
☐ Don't know

Opportunity to see equipment and treatment room ☐ Yes ☐ No
☐ Don't know

Time allowed for test ☐ Yes ☐ No
☐ Don't know

Relaxation techniques ☐ Yes ☐ No
☐ Don't know

Please comment:____
____
____
____

After the Smear

16. How did the woman get her smear results?

☐ By letter ☐ By phone ☐ Directly from the GP ☐ Directly from the Nurse ☐ Don't know ☐ Other (please specify)

____

17. Did anyone help her to understand her smear results? ☐ Yes ☐ No If yes, who?

☐ Yourself ☐ GP ☐ Nurse ☐ Community Learning Disability Nurse

☐ Other (please specify)

____

18. Can you suggest anything that would make the cervical screening process easier for women with learning disabilities and their carers or supporters?

____

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____

____

Thank you for taking the time to answer this questionnaire – now please return it in the envelope provided (no stamp required)