SECTION 6

Women's participation in cervical screening

Women's participation in cervical screening

Aim of section
This section discusses the woman's participation in screening and the barriers women may experience in relation to attendance. It also discusses what information is beneficial to promote the participation of all eligible women in the Programme.

6.1 Women's participation in cervical screening

The success of any cervical screening programme is dependent on the participation of women. It is of prime importance to CervicalCheck that cervical cancer screening is effective in targeting at risk populations, and that once an abnormality has been identified, follow-up screening and treatment are provided with the minimum distress to women. The Programme aims to reduce the incidence and mortality from cervical cancer in women aged 25 to 60 years overall. The achievement of this target requires that 80per cent of the target population avail of screening. Women who have a positive experience when attending for a cervical smear will continue to participate in the Programme. Adverse comments about smear tests from other women may influence a woman's attendance for a smear test (Doyle, 2006).

Women who have had a good experience tell others.
Women who have had a bad experience also speak freely of it.

The woman's motivation to have a cervical smear is influenced by specific attitudes, beliefs and perceptions. These include:

- The influences of her family and friends
- Her understanding of the test and possible results
- The distress and the embarrassment of the smear test
- Her perceived susceptibility to cervical cancer
- Her understanding of the importance of the disease
- The social consequences of developing the disease
- The benefits of having a cervical smear

It is important to understand the various reasons given by women who decline the opportunity to have a cervical smear. A recent study (Walsh, 2006), based on a sample of over 1,000 women who were participants of the ICSP, highlighted specific barriers associated with poor attendance (Table 6.1).

Table 6.1 Per cent reporting specific barriers to attendance for cervical screening (N=1,114)

REPORTED BARRIERS	%
Male smeartaker	35%
Unsuitable appointment times	22%
Other commitments	19%
Lack of time	7%
Difficulty getting to surgery	5%

Source: European Journal of Contraception & Reproductive Health Care (2006)

CervicalCheck has identified that reasons for non-attendance can be divided between personal and practical reasons as follows:

NON-ATTENDANCE DUE TO PERSONAL REASONS	NON-ATTENDANCE DUE TO PRACTICAL REASONS
• Previous bad experience • Male smeartaker • Embarrassment • Fear of test • Fear of result • Not understanding test • Adverse comments about smear tests from other women or the media • Ethnic differences	• Not invited • Forgot appointment • Sick • Away • Opting out • Appointment time unsuitable • Fears about lack of confidentiality

Of those women who attend for smear tests, the factors that positively influence a woman's experience are outlined below.

POSITIVE INFLUENCES ON WOMEN'S EXPERIENCES
• Choice of smeartaker • Provision of information • Adequate time for test • Satisfactory physical environment • Explanation of how results are received • Advice on waiting times for results

6.2 Interventions to improve attendance

6.2.1 Women's views

CervicalCheck recognises the importance of the woman's view in relation to cervical screening. The following quotes are from women who completed client feedback forms following their smear testing with trainees enrolled in the ICSP Smeartaker Training Programme. The quotes are in response to questions as to what prompted them to attend for the smear test.

'Nurse enquired about last smear when I attended for bloods.'
'The practice posted me a letter to let me know my next test was due.'
'Doctor's advice.'
'Having attended a talk on Health Awareness for women by a GP in my local hall.'
'Nurse advised me when I was vaccinating my baby.'
'My mother died so I decided to have a full check up.'
'Advert.'
'Discussion with friends.'

6.2.2 Provision of information

Women need clear information on the indications, benefits, and procedures of cervical screening; such information is effective in increasing attendance for primary screening. Women's high levels of anxiety on the receipt of an abnormal smear result may originate in a lack of understanding of the meaning of cervical abnormalities. The provision of information in such cases may reduce anxiety. The following are quotes from women who were asked to give feedback on information received and their experience of the smear test.

'Full explanation put me at ease straight away.'

'Everything was explained before and during the procedure.'

'I felt free to ask any question even if I did think that they may sound silly.'

'Due to clear explanations I was less anxious about follow-up.'

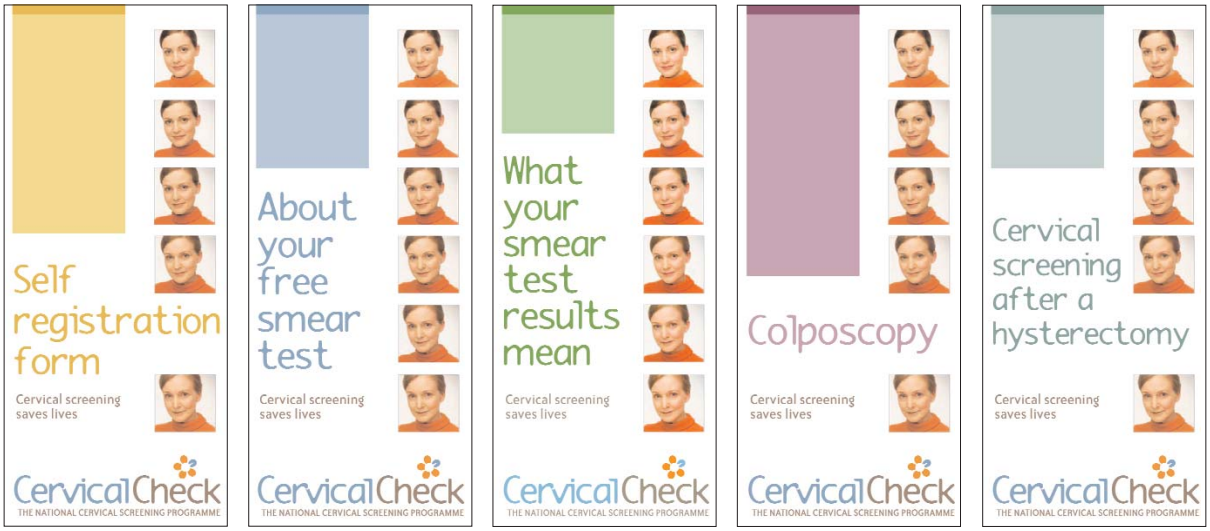
'The nurse was very gentle and put me at ease and explained everything before starting, this helped in keeping me calm during procedure.'

'My last experience was awful. It had been extremely painful and distressing. I was in dread of attending. Nurse took lots of time and did not rush when I found it sore, just gave me minutes to adjust.'

'The practice nurse was very gentle and she said she would stop if I needed her to.'

6.2.3 Health promotion

> Health promotion is the process of enabling people to increase control over, and to improve their health.
>
> Ottawa Charter for Health Promotion, WHO Geneva 1986.



Health promotion strategies can develop and change lifestyles, and have an impact on the social, economic and environmental conditions that determine health. Health promotion is a practical approach to achieving greater equity in health. The five strategies set out in the Ottawa Charter for Health Promotion are essential for success.

- Building healthy public policy
- Creating supportive environments
- Re-orienting the health services
- Strengthening community action
- Developing personal skills

The overall aim of the CervicalCheck screening promotion programme is to provide a strategic method for promoting both the services of CervicalCheck and the importance of regular cervical screening for eligible women.

Cervical cancer rates for women living in the most deprived areas are 2.6 times higher than women living in least deprived areas (Women's Health Council, 2006). This suggests that an important task for CervicalCheck is to increase the uptake of screening among socially disadvantaged women who are known to be at the highest risk of cervical cancer. Traditional approaches of encouraging marginalised women to attend for screening tend to be less effective in disadvantaged communities. Thus, alternative options to increasing awareness and attendance for screening have been explored. CervicalCheck will determine its capacity to identify an area of very low uptake and consider the screening needs of women and develop appropriate strategies to support the increased participation of women as demonstrated by ICSP in the Southill Campaign Evaluation Report 2006.

STRATEGIES TO INCREASE PARTICIPATION

- Health and screening promotion strategy
- Dedicated awareness campaigns
- Peer education
- Direct contact with local community networks
- Workplace sessions
- Information sessions

6.2.4 Sources of information for women

Providing information on cervical screening by all categories of health care providers, particularly those in primary care settings, is essential for raising awareness and reducing illness and deaths. Women can source information in a number of ways such as through the CervicalCheck screening promotion initiatives including the CervicalCheck information leaflets, website and freephone information Line. However, the primary source of information for most women is their doctor.

70 per cent of women get their cervical screening information from their doctor.

Sources of information on cervical screening – summary

Role of smeartaker in encouraging women to have smear test

- The doctor was the primary source (Walsh, 2003)
- The practice nurse and the ICSP were the second choice (Walsh, 2003)
- The doctor and practice nurse play major role in encouraging women to have smear (Doyle, 2006)
- Seow et al. (1995) also found that the doctor or nurse were the primary source of information on the smear test

Primary care: The doctor and practice nurse are often the first line of contact in the primary care setting. Research suggests that one of the most effective ways of encouraging women to have a smear test is for a doctor to advise them to have one. This is particularly effective in women over 40 years of age (Cockburn et al. 1990; Brent 1992). Walsh (2006) found that the majority of women (70 per cent) get their cervical screening information from their doctor. Therefore, it is vital that smeartakers use this opportunity to provide women with appropriate information about cervical screening.

The smeartaker may use the *'Information sheet for women'* and other information leaflets containing cervical screening.

CervicalCheck literature: A suite of information leaflets has been developed by CervicalCheck to provide women with information about the Programme with specific information on cervical screening including an explanation of the various possible results of a cervical smear test. The leaflets have been reviewed and updated based on the outcome of focus testing. The current information leaflets include:

- About your free smear
- What your smear test results mean
- Colposcopy
- Cervical screening after a hysterectomy

CervicalCheck information line: 1800 454555 The freephone information line service has been developed to support users' needs and provides information on the Programme, CervicalCheck registered smeartakers, and offers a facility for women to register. It is a freephone service and is advertised on all CervicalCheck literature. The information line deals with approximately 700 calls per month increasing at times of media coverage or a particular promotion. Advice is of an administrative nature only and women seeking clinical information are advised to talk to their smeartaker or family doctor.

CervicalCheck website: This is an excellent resource which provides up to date information on cervical screening. The website www.cervicalcheck.ie provides a facility for on-line registration and feedback to the Programme.

Information provided to women by CervicalCheck

About CervicalCheck	CervicalCheck offers free cervical screening to women aged 25 to 60 years. Women aged 25 to 44 years will be screened every three years and women aged 45 to 60 years will be screened every five years. Women who are registered with the Programme will be sent a letter advising when to make an appointment for a free smear test with a CervicalCheck registered smeartaker of their choice. Cervical screening is a worthwhile preventative health measure. Smear tests can detect early changes in the neck of the womb; the earlier a change is found the easier it is to treat.
About the CervicalCheck register	The CervicalCheck register is a secure electronic database, which contains a woman's name, address, date of birth, Personal Public Service Number (PPS No.) and unique identification number for the Programme, known as the Cervical Screening Programme ID (CSP ID). The register also records women's screening history and results of cervical smear tests, any colposcopy procedures and any biopsies taken in a colposcopy clinic.
How a woman can register	A woman can self-register, which means she can contact CervicalCheck to give her details. She can self-register in one of three ways: 1. Ring the Freephone information line 2. Register online at the website 3. Email details directly to the CervicalCheck office If the woman's details are not already on the register, CervicalCheck will send her a letter acknowledging her self-registration.
How to defer	If a woman gets an invitation offering her a smear test that does not suit (due to having a recent smear test, going on holidays, pregnancy etc), she can arrange another date to have the smear test. The woman must contact CervicalCheck to defer having her smear test.
Opting out of the Programme	If a woman does not wish to receive the free services of the Programme, she may choose to permanently opt-out, by writing to CervicalCheck. This means that she will not be entitled to the benefits of being registered and she will receive no further communication from the Programme. However her details will remain on the register.

6.3 Psychological effects of cervical screening on women

> When a woman has an abnormal smear, she faces issues around her sexuality, her fertility and her mortality.
>
> Dr. Patrick Walker

Many women do not attend for smears or return for treatment because the emotional impact is too daunting. The anxieties and distress experienced by women receiving an abnormal smear result and attending for colposcopy are well documented (Gath et al. 1995; Fylan, 1998; Idestrom et al. 2003). Even where a screening programme is offered with follow-up diagnosis and treatment, it is often difficult to ensure that the patients are emotionally supported as well as medically treated. Emotional support can reduce distress and the number of psychological side effects on women. While it is beneficial to try to reduce any factors relating to fear, it is not appropriate to give blanket reassurances.

The role of the smeartaker can be significant in ensuring a positive experience in terms of the psychological impact of the smear test. The following are key areas that the smeartaker should consider in this regard.

- Provide appropriate, accurate information and explain how a smear is carried out
- Obtain informed consent from the woman
- Support informed consent and choice of smeartaker
- Be mindful that this is an intimate examination
- Be careful not to transmit a value judgement or attitude in the choice of words, tone of voice or demeanour
- Reassure the woman that the procedure can be stopped at any time
- Stress the importance of regular smears as a preventative measure

6.4 Specific groups

6.4.1 Women under 25 years

Sexually active women under 25 are quite likely to have cellular changes that are transient. There is no benefit from having transient changes detected or treated. Cancer of the cervix is very rare under the age of 25 (Sasieni, 2003). When screening starts at the age of 25, lesions that are destined to progress are screen-detectable. Those that would regress will no longer be a source of anxiety. Younger women will not have to undergo unnecessary investigations and treatments.

Prevalence of HPV is highest in women under 25 years of age. However, the vast majority of women clear the virus from their systems and such transient changes reported on their smears at this time do not require treatment. Ablative treatments at colposcopy may have an effect on the subsequent competence of the cervix. Women under 25 who had an abnormal result prior to the commencement of CervicalCheck (1st sept 2008) that indicated a repeat smear test are eligible (the smeartaker is requested to attach a copy of the abnormal result & management recommendation to the referral form).

6.4.2 Women over 60 years

As CIN 3 rarely develops de novo after 45 years of age, it is considered that screening can be safely discontinued for women aged 60 who have been regularly screened and who have had normal smears. However, women over 60 should be encouraged to have a smear if they have not done so previously. CervicalCheck will continue to call participating women who are over 60 years until a normal smear result is reported. CervicalCheck will pay for and follow-up on initial smears and on second smears after three years, assuming the first one is an adequate smear with a normal result.

6.4.3 Post-menopausal women

Post-menopausal women with atrophic cervices can be identified both from their personal details and also from the condition of the vagina and cervix. There are two main problems in taking smears from these women. The cervical cell yield from the smear test can be scanty. An atrophic smear is a smear with too few cells to allow a cytologist to report on it. Liquid-based cytology helps overcome this problem as all the cells retrieved are collected in the spinning process. The squamo-columnar junction is high up within the cervical canal. If this is apparent, local oestrogen can be used. This allows the squamo-columnar junction to evert and so avoid an atrophic result.

6.4.4 Pregnancy

It may be psychologically inappropriate or unwelcome by the women to have a smear during or shortly after pregnancy. If the woman's previous smears are normal, a smear should be deferred. A deferral form should be completed by the smeartaker and sent to CervicalCheck. A woman does not require a screening smear postnatally unless she is due to have a smear within her call/recall recommendations.

See Section **Section 1** on Deferrals

6.4.5 Hysterectomised women

Women who have had hysterectomy with CIN present are potentially at risk of developing Vaginal Intraepithelial Neoplasia (VaIN) and invasive vaginal disease (NHSCSP, 2004). Women who have undergone total hysterectomy because of invasive carcinoma of the cervix should continue to have screening via vault smears, according to specialist instruction. Follow-up after a hysterectomy for CIN should include three smears at six monthly intervals before discharge from the cervical screening programme.

Women who have had total hysterectomies for benign reasons and who have no history of abnormal or cancerous cell growth may be excluded from screening. However, women who have had a sub-total hysterectomy should continue to have screening.

If the normality of the cervix before hysterectomy cannot be verified, CervicalCheck recommends that two vault smear tests should be taken one year apart and if both are normal, screening can stop.

6.4.6 Women who are immuno-compromised

Women who present for screening may have difficulties with their immune system. This may be due to HIV, TB or immuno-suppressant medication used in the management of arthritis, SLE / lupus, asthma, post-transplantion, etc.

Women who are infected with HIV are at a greater risk for developing dysplasia. The risk appears to increase as the number of CD4 cells (cells that play a critical role in immune responses) decreases. HIV-positive women also have a higher rate of persistent HPV infections and may be infected with the strains that are associated with severe dysplasia and cervical cancer (Cubie et al. 2000).

Women whose immune systems are suppressed for other reasons, such as by drugs that prevent rejection of organ transplants, are also at greater risk (Alloub et al. 1989). This suggests that women with weakened immunity are more likely to be infected with HPV and to have a persistent infection that does not resolve. The optimum screening interval and management for this group of women has yet to be determined but may be more frequent than three or five-yearly as per the CervicalCheck guidelines.

6.4.7 Women with disabilities

Women with disabilities who have ever been sexually active have similar or greater risks for cervical cancer as their peers. However, population research across various diagnostic groups has demonstrated that women with disabilities do not receive the same level of preventative health care as the general female population.

Women with physical disabilities: Women with physical disabilities are frequently seen by those around them as 'asexual' (Scuillion, 1999). Consequently they may not be told about cervical screening or advised on how to have it. Women with major lower extremity difficulties have much lower odds of receiving a smear test (Lezzoni et al. 2001).

Women with physical disabilities may find it difficult to maintain the required position for obtaining a cervical screening sample. The smeartaker needs to be aware of the potential difficulties such women may face, and ensure that suitable locations and equipment for screening are available to enable women to have the best opportunity to be screened.

The woman with a physical disability is probably the best expert on her own disability needs and this will contribute greatly to building a smooth and positive interaction. It will also reinforce the woman's sense of control and participation in her health care (Peters, 1982). Use of questions such as, 'what would make this easier for you?', 'what is the best way to transfer you to the examination table?' will make the examination easier for both the woman and the smeartaker (Becker et al. 1997; Welner et al. 1999).

For women with contractures, spasticity or skeletal deformities, the traditional lithotomy position for a smear test may not be possible for them to assume. The lateral recumbent and knee-chest examination positions may be suitable alternatives. In the lateral recumbent position the woman lies on her side with the superior leg bought forward over the lower leg. In the knee-chest position, the client lies face down on the examination table with her knees bent forward under her chest. In both these alternative positions the speculum is inserted posteriorly (Peters, 1982).

Women with intellectual disabilities: A study conducted on women with learning disabilities (n 398), aged 20-64 years, living in one English health district found that only 13 per cent had a recorded smear test in the previous five years, which is markedly lower than the cervical screening rate for the general female population (Stein & Allen, 1999).

Women with intellectual disabilities (ID) are generally considered to be low risk for cervical cancer. However sexually active women with ID are high risk as they are less likely to have been screened. There may be no acknowledgment within families or the organisation that they have been sexually active. Good practice guidelines in cervical screening for women with ID is discussed in more detail in Appendix 6A.

6.4.8 Women from ethnic and minority groups

Assessment of the special needs of subsets within the target population, such as ethnic or immigrant minorities with diverse cultural and religious backgrounds, warrants particular attention. Previous studies have attributed low uptake of cervical screening amongst minority women to their lack of basic information, and to their cultural beliefs and attitudes (McAvoy, 1988; Doyle, 1991; Naish et al. 1994). Non-English speaking women are enthusiastic about cervical screening when the nature of the test is explained to them in their own language (Naish et al. 1994). The Health Education Authority's report on the health and lifestyles survey of black and white minority ethnic groups in England (Rudat, 1994) has also identified a lack of information as the major reason for low uptake of cervical screening amongst minority groups. In a study conducted in New Zealand, language was consistently identified as the main barrier to screening (Lovell et al. 2007).

Advice for smeartakers

There is a responsibility upon the smeartaker to ensure that non-English speakers have quality information that would allow them to be informed of the purpose and the procedure of a cervical smear. Children should not be used as interpreters. Appointments for the smear test should be made in advance to support the woman; a link worker or an official interpreter should be allowed to attend. In order to ensure cultural sensitivity, a female smeartaker should be available as appropriate. It is also important that smeartakers are mindful that some women living in Ireland have undergone Female Genital Cutting.

6.4.9 Women with literacy difficulties

The last national literacy study conducted in Ireland found that a quarter of the Irish population is in a position where they struggle with basic literacy tasks. One in four Irish adults between the ages of 16 and 66 years have very poor literacy skills and cannot satisfactorily read the instructions on medication (Department of Education, IALS, 1997). Although the CervicalCheck materials have been written in liaision with NALA (The National Adult Literacy Association) because of literacy difficulties, many women may struggle to read and understand the information in the CervicalCheck invitation letters, CervicalCheck leaflets and the CervicalCheck consent form.

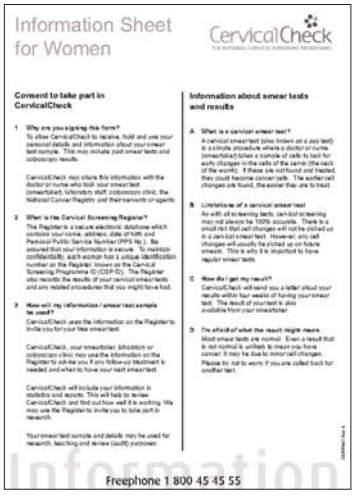
Where the smeartaker is interacting with a woman with low literacy skills, he/she will need to take greater care to ensure the woman fully understands the cervical smear. The smeartaker should not assume the woman is able to read the information provided or to complete necessary forms. Excuses like forgetting glasses, bad eyesight, bringing someone else along can be signs of literacy problems. A smeartaker can help by:

- Explaining everything in plain language throughout the information leaflet
- Using simple diagrams or images if possible
- Ensuring the woman understands everything that she needs to
- Explaining the CervicalCheck consent form in simple language before asking the woman to sign it

Summary of key information smeartakers should provide to all women

- What the test is for and what the test involves
- Signing consent means that she agrees to be part of CervicalCheck
- CervicalCheck call and recall system
- Age and interval of smear tests
- When and how results are made available
- The limitations of smear tests
- The meaning and likelihood of a normal smear result (approx. 92 per cent)
- The meaning and likelihood of an inadequate smear result (approx. 2 per cent)
- The meaning and likelihood of an abnormal smear result (approx. 6 per cent)
- The importance of reporting abnormal bleeding or discharge even after a negative smear result
- The value of regular screening

Sample of CervicalCheck useful information for women


Information Sheet for Women

CervicalCheck

Consent to take part in CervicalCheck

Information about smear tests and results

Freephone 1 800 45 45 55

APPENDIX 6

Appendix 6 A

6.5 Guidelines for good practice In taking smears in women with intellectual disability (ID)

6.5.1 Aim of guideline & context

The aim of this guideline is to help smeartakers in their practice to provide a quality service to women with an intellectual disability (ID) by outlining and addressing the particular considerations and difficulties when screening women for cervical cancer who have an ID.

Doctors have identified that they lack the necessary skills, knowledge and resources to offer health promotion and screening to women with disabilities (Kerr et al.1996). Women with ID vary widely in their degree of intellectual disability and in their ability to understand, reason and communicate. Many women with ID will be capable of making decisions and giving informed consent and in this context, it is important that each woman should be assessed with regard to her ability of making an informed choice.

Women with ID are generally considered to have a low risk of cervical cancer. However, sexually active women with ID are considered to have a high risk of cervical cancer as they are often overlooked for screening. The exclusion from screening may in part be due to the refusal by families or organisations to acknowledge that women with ID are or have been sexually active. To assume that a woman has never been sexually active on the basis of her disability ignores the fact that women with disabilities are more likely to have experienced sexual abuse than the general female population (Muccigrosso, 1991).

Inadequate knowledge amongst general practitioners concerning disability issues coupled with attitudinal barriers, provides one explanation for the low preventative screening rates of women with disabilities (Band, 1998; Lezzoni et al, 2001; Meehan et al, 1995; Singh 1997; Welner et al, 1999; Wilson & Haire, 1990).

6.5.2 Clinical challenges for smeartakers

The following are some of the challenges smeartakers may face when taking smears from women with ID:

- The woman may not understand the invitation to attend for a smear
- Extra time is required for the test
- Expertise is required
- There may be difficulties in obtaining a history
- There may be ethical issues in relation to informed consent
- The woman may have additional disabilities

6.5.3 Practical advice on how best to support quality smeartaking in women with ID

Rapport/ communication	• Be aware that while the woman may have difficulty speaking, she may understand what you say and you should involve her in the conversation • Take time to get to know how the woman communicates • Be aware that communication may take more time than usual, expect a response and wait 10 seconds • Supplement communication with signs, gestures and facial expressions to add meaning • Use open-ended questions where possible - some women with developmental disabilities may inappropriately say 'yes' to closed ended questions • Repetition is useful to reinforce the message
Ahead of the test	• Understand the issues relating to consent • Use one-to-one sessions with a person whom the woman knows and trusts • Use appropriate materials (picture leaflets, picture books) • Provide reassurance • Arrange a preliminary visit to the surgery at a quiet time to allow the woman to become familiar with the surroundings and to meet the smeartaker • Help the women to decide whether or not it is necessary to go for cervical screening
Making the appointment	• Book an appointment at a time when the surgery is not busy • Be mindful that the woman may also have a physical disability and that it is important to determine any special requirements prior to the appointment • If possible, provide space for those women who find it difficult to comply with the social expectations of a waiting room • Check that the supporter who will accompany the woman understands the screening process • Discuss issues of consent with the supporter • Show the speculum and brush to the woman and allow her to handle them
Preparing the woman for the smear test	• Make sure the room is comfortable and private • Ask the woman if she wants a supporter with her during the test • Allow sufficient time to explain to the woman how the smear is taken using the picture book • Use appropriate language for the individual woman • Respect the woman's privacy and dignity at all times • Be prepared for the possibility that the woman may become distressed • Be particularly patient and gentle

Preparing the woman for the smear test cont.	• If at any time the woman is resistant or uncooperative, stop and only proceed with her cooperation • Be prepared to make another appointment to take the smear if the woman needs more reassurance • Ensure that refusal at any stage before or during screening is seen positively as the woman's choice to refuse the test on this occasion • Reflect on the outcome and whether the preparation affected the outcome
After the smear test	• Ensure that the woman receives and understands her results • Follow up as appropriate with additional support if referral to colposcopy is necessary • Most colposcopy clinics have a colposcopy nurse who is experienced in explaining the process and providing support to women on an individual basis

Good practice summary - quality smeartaking in women with ID

In addition to best practice principles for smeartaking in the general population, the smeartaker should consider the following good practice is adhered to with women with ID:

- Use appropriate information materials
- Answer questions honestly to avoid the unexpected
- Two or three visits may be required before the test
- Allow sufficient time to explain the process to the woman
- Be prepared for the possibility of distress
- If at any time the woman is resistant or uncooperative, stop and only proceed with her cooperation
- Ensure that her refusal at any stage, before or during screening, is seen positively as it is the woman's choice to refuse the test on this occasion
- Try to book an appointment at a time when the surgery or clinic is not busy
- Show the screening instruments to the woman (if applicable)

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Websites

The following websites may be useful to provide multicultural information on cervical screening.

www.icgp.ie/index.cfm/loc/6-5-3.htm
www.nuigalwa.ie/dgp
www.mhcs.health.nsw.gov.au/
www.health.qld.gov.au/multicultural/policies/policies_plans.asp
www.mhcs.health.nsw.gov.au/mhcs/topics/Cancer.html

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