An evaluation of the first phase of the

Irish Cervical Screening Programme

from the woman's perspective

The **Women's** Health Council
Comhairle Shláinte na mBan

An evaluation of the First Phase of the Irish Cervical Screening Programme (ICSP) from the woman's perspective

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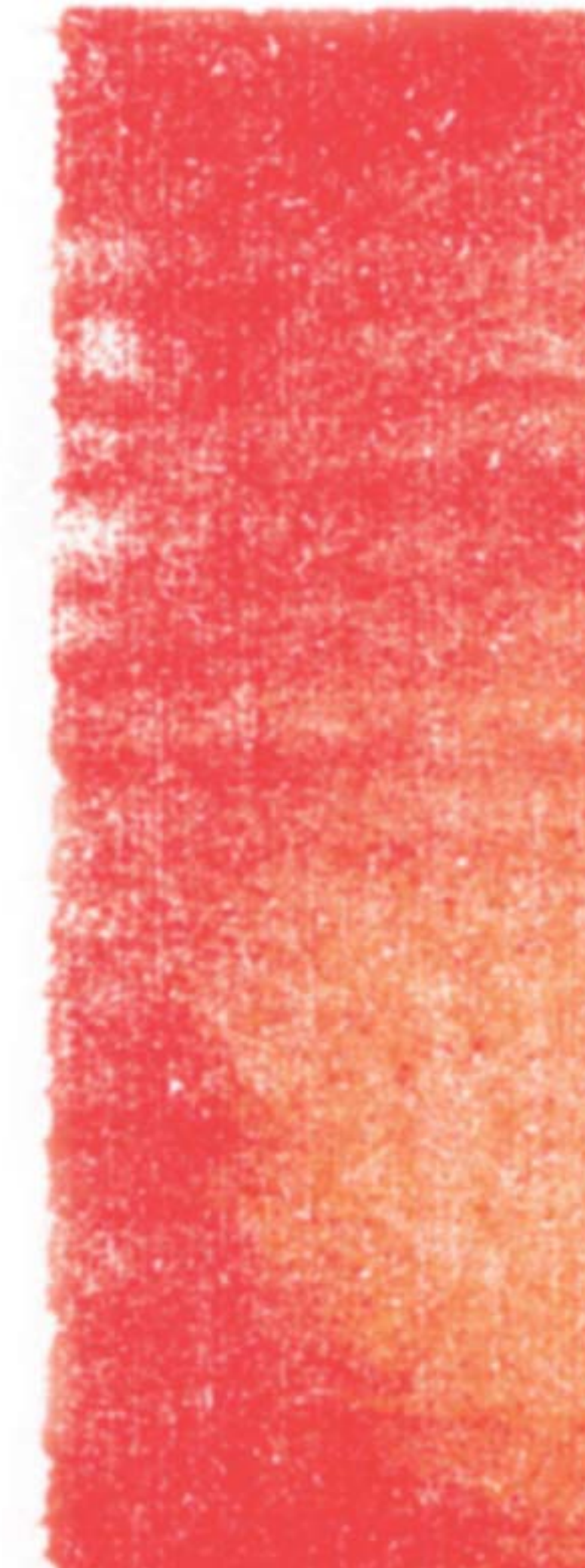

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Special thanks to Ms. Albha Bowe who conducted research for the evaluation and prepared this report on behalf of the Women's Health Council, and to Ms. Audrey Mc Mahon who assisted with the research.

Executive Summary

Women who participated in the evaluation were generally very positive about the Irish Cervical Screening Programme. They expressed their appreciation that the screening programme was available to them, that the programme contacted them with an invitation to attend for screening and that the service was offered free of charge. In the course of interviews women spoke positively about their contact with the programme and in particular the letters sent from the ICSP office and their experience of attendance for smear tests. The vast majority of women who attended for screening said that they would attend for another smear test when next contacted by the programme. Aspects of the programme with which women were dissatisfied included the length of time taken to return test results, delays relating to colpsocopy and the five year screening interval. Issues were also raised relating to informed consent, referral for further tests and rural access to smeartakers. The key issues identified during the review and corresponding recommendations are outlined below.

Waiting Time for Smear Test Results

Women expressed dissatisfaction with the six-week target time for returning smear test results and suggested that this be reduced. In this context most women suggested that smear test results be returned within two to three weeks. Women who had repeat smear tests experienced higher levels of anxiety while waiting for those results and suggested that results of repeat smear tests are returned particularly promptly.

- Review six-week target time for smear test results.
- If six-week target time is maintained, ensure that the target is met as often as possible.
- Establish a target time for repeat smear tests that is shorter than that for first smears.
- Senior Management to consider the effect that expansion of the programme might have on time taken to obtain results. Identify actions that could be undertaken to avoid further delays in this context.

Informed Consent

Interviews with women who attended for screening and preliminary interviews with smeartakers registered with the programme highlighted a number of issues relating to consent. These include the need for greater uniformity in the information provided to women prior to obtaining their consent and in the way in which consent is obtained.

- Senior Management at ICSP to review what consenting to participate in the ICSP actually means and to specify the components of consent – what it covers and what it does not. Ensure that any documentation or literature produced by the programme and referring to consent is consistent with that understanding. Ensuring clarity with regard to consent would be particularly significant prior to undertaking an expansion of the programme nationally.
- The information to be provided to women regarding medical aspects of screening prior to giving consent should be clarified. This information should include the nature of the test, possible results, false positives and false negatives. Ensure that smeartakers are aware of all the medical issues to be addressed with regard to consent and that there is uniformity in the information relayed to women in this context.

- The information to be provided to women regarding administrative aspects of the screening programme should be clarified. This information should include use of and access to information held on the register pertaining to clients. Identify best possible means of informing women of these issues. One possibility might be to provide women with an information sheet that outlines these issues in a short, concise manner. This information sheet could be provided to women while waiting at smeartakers' surgeries for their appointment.
- Edit the consent form in line with the recommendations above. Ensure that women are given a written record of what they have consented to. For example, women could be given one part of the consent form to keep or a duplicate of the form.

Colposcopy

Women were generally positive about their experiences at the colposcopy clinic and particularly with regard to their dealings with clinic staff. However, a number of women experienced and were critical of delays relating to colposcopy. Interviews with women who attended for colposcopy also highlighted a number of issues relating to consent.

- Assess the possibility of increasing the number of colposcopy clinics held in order to firstly reduce the length of time taken to secure an appointment and secondly reduce the length of time women wait to be seen at the clinic. Two options that could be considered in this context are the recruitment of an additional Consultant Obstetrician & Gynaecologist and/or the adoption of protected time for the clinic.

- Review the length of time taken for test results to be returned from the colposcopy clinic. Establish if there are means of reducing time taken to return results.
- Senior Management at ICSP to consider the introduction of written consent for colposcopy and any treatment or biopsy undertaken at the colposcopy clinic. In this context the drafting of good practice guidelines for obtaining consent may be useful.

Five-Year Recall

The vast majority of women who attended for screening stated that they would attend for a smear test when next contacted by the programme. However, in interviews and focus group discussions women expressed the view that the ICSP's five-year interval for screening was too long and suggested that this be reduced.

- Review the possibility of introducing a three-year rather than a five-year recall. This includes identifying operational issues to be addressed and additional costs that would be incurred. The practice of recalling women for a smear test one year after their first 'programme' smear may not be considered necessary in this context.
- If a three-year interval is not introduced, senior management should identify ways of reassuring women about the five-year interval. This might include incorporating reasons for a five-year screening interval in the information literature and on the website. The programme may also wish to consider further communication and discussion about the issue with its registered smeartakers in formal training or through the programme newsletter. An interactive website discussion could also be considered in this context.

Referrals for further tests

Women who attended for repeat smear tests and women who attended for colposcopy raised issues relating to referrals. Women who attended for repeat smear tests were dissatisfied with the letter sent by the ICSP, advising that they make an appointment for a repeat smear, and suggested a number of changes to it. Interviews with women who were referred for colposcopy highlighted issues relating to the information provided by smeartakers at the time of referral.

- Amend the results letters advising women to have a repeat smear in three months or six months. Include more detail on the result of the first test, specifically what was found and why women are being advised to have the test repeated. Specify that women may contact their smeartaker if they require further information or have any questions relating to their individual result.
- Ensure that smeartakers are aware of the information to relay to women when they are referred for colposcopy. This should include the possibility that a biopsy or treatment will be conducted during their first visit to the clinic.

The Register

Currently the ICSP uses the database at the Department of Social and Family Affairs as the data source for its population register. Use of only one data source for the register may mean that some women in the target population are being omitted.

- Reassess the use of one data source for the programme register to ensure that some women in the target population are not excluded. In this context, access to databases at VHI, BUPA and the General Medical Services Payments Board may be particularly useful.

Social Inclusion

There is recognition internationally that women's participation in cervical screening programmes is influenced by socio-economic factors such as economic circumstances, age and ethnic background. It is important, therefore, that the ICSP consider the relationship between socio-economic factors and attendance for screening. This would be particularly significant in the context of expansion of the programme to national level.

- Senior management to identify socio-economic information of most relevance to the programme. Issues relating to the collection of socio-economic information would also have to be clarified such as identifying ways of facilitating women to volunteer this information and ensuring women understand why such information is being sought and how it will be used.
- Record socio-economic data for individual women on the programme database. This information should be collated and used for on-going monitoring and analysis of the programme and in particular of the relationship between attendance/non-attendance for screening and socio-economic factors.
- On the basis of findings from on-going monitoring identify groups that are under-represented in the programme. Undertake promotional and other activities targeted at those groups to facilitate their attendance for screening.

Contact Details for Registered smeartakers

Women identified as an issue lack of information about registered smeartakers in the invitation letter. This had contributed to a delay in making an appointment for a smear test for some women. In other cases it had contributed to women not attending for screening at all.

- Specify in the main text of the invitation letter that women may contact the information line for details of smeartakers registered with the programme

and/or

- Attach a list of registered smeartakers to the invitation letter. Given that there are over three hundred registered smeartakers in the Mid-Western Health Board region it may be preferable to divide the list into three parts, one part for each county - and to attach a list for the county in which the woman is living. A similar practice could be applied if the programme is expanded to national level.

Rural Access to Smeartakers

Many women expressed a preference for smear tests to be taken by female smeartakers rather than male smeartakers. A number of women also expressed a preference for smear tests to be taken by someone who was unknown to them or who did not live in their local community. Given these preferences some women in rural areas described difficulties in accessing smeartakers registered with the programme and located in an area convenient to them. This appeared to be an issue in particular for women living in East Clare.

- ICSP to investigate if access to registered smeartakers in all rural areas within the Mid-Western Health Board region is adequate taking into account many women's preference for a female smeartaker and/or a smeartaker other than their local GP. Accessibility of registered smeartakers to women in all rural areas would be a significant issue to consider prior to expansion of the programme.

Information Leaflet 'About Your Smear Test'

From interviews it was apparent that while women appreciate information about screening being made available to them by the programme, most do not read the information leaflet 'About Your Smear Test' which is enclosed with the invitation letter. In focus group discussions women described the leaflet as too long and suggested that the amount of information contained in the leaflet be reduced.

- Edit the information leaflet 'About Your Smear Test'. Produce a shorter version of the leaflet that covers fewer issues and is more concise. Specify in the revised leaflet that women may access the website or contact the ICSP office if they have any questions or require further information.

- The current version of 'About Your Smear Test' could be sent to women who contact the ICSP office requesting additional information and/or women who do not have access to the internet. Alternatively an up-dated version of that leaflet could be produced, perhaps in booklet form, outlining additional relevant information such as frequently asked questions.

- Consider producing information leaflets that cater to women with low literacy levels and women who do not have English as a first language. This is particularly significant if the programme is expanded to national level.

Chapter 1: Background to the Review

1.1 Cervical Cancer in Ireland

Statistics produced by the National Cervical Registry indicate an average of 77 deaths per year from cervical cancer in Ireland from 1994 to 2002. During this period the average number of incident cases[1] of cervical cancer was 177 cases per year while in-situ cancers[2] averaged at 756 cases (The National Cancer Registry of Ireland, 2002). Cervical cancer is the third most common cancer affecting women in Ireland today. The Irish mortality rate for cervical cancer is significantly higher than the European average at 4.3 deaths per 100,000 in 1998 compared with an EU average of 2.7 deaths per 100,000 (Eurostat, 2002).

Evidence from other countries indicates that mortality from cervical cancer can be reduced by screening (Department of Health, 1996). Cervical screening involves testing the cells in the neck of the womb (the cervix) for early changes which can be treated before they develop into cancer. It has been found that mortality from the disease has fallen in countries where effective national screening programmes have been introduced (Martyn, 2003).

A Working Party was appointed in 1992 by the then Minister for Health to review cervical screening in Ireland. This included reviewing the general efficacy and cost effectiveness of existing systems and considering what further cost effective improvements could be made.
The committee recommended the establishment of a national cervical screening programme based on an age sex register (Department of Health Cervical Screening Committee, 1996).
It recommended that women aged from 25 to 60 years be screened and that screening be carried out at a five yearly interval and within a primary care setting. The committee also suggested that an expert advisory committee be put in place to oversee the establishment, implementation and monitoring of the cervical screening programme.

1.2 Phase I of the Irish Cervical Screening Programme

In 1997 a ministerial decision was taken to establish a national cervical screening programme, the first phase of which was to operate in the Mid-Western Health Board region. The aim of the programme, which is part of the National Cancer Strategy 1996 (Deloitte Management Consultants, 2003), is to reduce the incidence of and death rate from cervical cancer. A National Expert Advisory Group began meeting in April 1997.

A Steering Group was established to oversee the implementation of Phase I of the programme and a programme office was established in Limerick. Phase I was officially launched in October 2000 covering the Mid-Western Health Board area and targeting approximately 67,000 women between the ages of 25 and 60 living in counties Limerick, Clare and north Tipperary. EU nationals with an address in the area, migrant workers and refugee and asylum-seeking women resident in the area are also eligible for the programme. The programme offers women screening free of charge at five yearly intervals. Smear tests are taken in a primary care setting by GPs and practice nurses.

1 The number of incident cases of cervical cancer is the number of newly diagnosed cases of cervical cancer within a particular time period.

2 In-situ cancer refers to early cancer that has not spread to neighbouring tissue. Some in-situ cases of cervical cancer become malignant but others do not (Personal Communication, National Cancer Registry).

3 Cytology Pattern P2.

The aims of the first phase of the programme are:

- to develop and implement a call/recall cervical screening programme in a defined area, and
- to test all of the operational issues relating to the implementation of a screening programme of this kind (Irish Cervical Screening Programme, 2001).

1.3 The Review

In 2003 the Women's Health Council was commissioned by a subgroup of the Health Board Executive to conduct an evaluation of the effectiveness of the first phase of the Irish Cervical Screening Programme 'from the woman's perspective'.

In this context, the Women's Health Council was asked to evaluate all service aspects of Phase I of the programme from a woman's perspective. This includes correspondence, information materials and administrative processes as well as tests and treatment. The purpose of the review is to investigate the programme's effectiveness and availability, accessibility and acceptability to the women it aims to target.

The ICSP's Charter for Women was to be used as a reference point for the review. The Charter for Women outlines women's rights within the programme such as the right to give informed consent, the right to confidentiality and the right to provide feedback. The Charter also outlines the responsibilities of various service providers attached to the programme such as smeartakers, laboratories and the programme office.

The aims of the review are:

- to identify gaps in the current programme as highlighted by its target group, and
- to outline improvements that could be made to address those gaps with a particular emphasis on issues of relevance to expansion of the programme to national level.

Chapter 2: The Programme To-date

2.1 The Register

One of the first tasks undertaken by the programme office was the establishment of a computerised population register for women between the ages of 25 and 60 in the Mid-Western Health Board region. Prior to April 2000 the ICSP used four different data sources for the register, which led to considerable duplication of records. To avoid further duplication on the register it was decided that only one data source be used. Since April 2000 data for the ICSP register is accessed from the Department of Social Community and Family Affairs. Use of the Department's database also gives the ICSP access to women's Personal Public Service (PPS) number. The register is updated on a monthly basis to ensure that 'new' women are added to it, such as women who have recently reached the age of 25 or women who have recently moved to the Mid-Western Health Board region. Any changes noted in the 'demographics' of women currently on the register, such as a change of address, are also made.

There are two other possible ways in which women may be added the register. Firstly the programme office may receive a notification of a smear test from a cytology laboratory for a woman who had not been included in the register. Secondly a woman who was not previously on the register may 'self register' by completing one of the registration forms available in various outlets such as GP surgeries and pharmacies.

The programme assigns a CSP (Cervical Screening Programme) reference number to each woman on the register. As noted above the ICSP also records women's Personal Public Service (PPS) number where available. This has been found to be particularly useful for tracking women within the programme and maintaining accurate records for each individual. Each woman's CSP number and PPS number is quoted in correspondence to her from the programme office.

2.2 Call & Recall

On a weekly basis the programme office identifies women on the population register with particular birthdays during the previous week. Women who turned 25, 30, 35, 40, 45, 50, 55, 56, 57, 58, 59 or 60 in the previous week are selected for invitation for screening. A standard letter is posted to selected women inviting them to make an appointment for a free smear test in 'the next 2 weeks'. Women are asked to make the appointment with 'a Smeartaker registered with the programme (i.e. Family Doctor or Practice Nurse)'. However details of registered smeartakers are not included with the letter. Women are advised to contact the programme's information line with queries as follows: 'If you have any queries please telephone the Programme's Information Line: Callsave 1800 256 600. This sentence appears at the bottom of the page and is not part of the main text of the letter (Refer to Appendix A). A leaflet entitled 'About Your Smear Test' is enclosed with the invitation letter (Refer to Appendix B).

If the programme does not receive notification that a woman has attended for a smear test a reminder letter is issued to her two months after the invitation letter. A second reminder letter is sent two months later if the programme still has not received notification that the woman has

attended for a smear test. Women who have not attended for a smear test two months after the second reminder are sent a letter informing them that they will be sent an invitation for a free smear test in another five years. Management at the ICSP has reviewed this process recently and will be reducing the number of reminder letters from three to two.

Women who attend for a smear test are recalled after one year if the programme has no record of previous tests they have had. This in fact applies to most women who participate in the programme. If that test is clear women are then put on routine recall, which means they will be invited to have a smear test every five years. In some cases, however, the programme has records of previous smear tests that women have had taken. In that case if a woman does not have a history of abnormal results and her first 'programme' smear is clear she is automatically placed on routine recall.

2.3 Results

The programme office is responsible for notifying women of the result of their smear test by letter and aims to do so within a six-week period. There are five possible outcomes for women who have attended for smear tests, as follows:

- They may receive a letter stating that the test was clear, specifically that there was 'no abnormality detected', and that they will be contacted by the programme for another routine smear in five years or in twelve months if it is their first smear test on record with the ICSP.
- They may receive a letter stating that the smear test was 'inadequate or unsatisfactory' and that the laboratory 'could not read the smear'. The letter advises that they contact their chosen doctor or nurse and have a repeat smear taken 'straight away'.
- They may receive a letter indicating that the smear 'has been reported as needing a repeat within 6 months'. They are advised to contact their 'chosen doctor or nurse to have the test' within the next six months.
- They may receive a letter stating that the smear 'has been reported as needing a repeat within 3 months'. The letter advises them to contact their 'chosen doctor or nurse to have the test' within the next three months.
- Finally, they may receive a letter stating that their smear test was 'reported as needing follow-up'. They are advised to contact their smeartaker for 'further information about their result'. This letter is sent to women who are to be referred for colposcopy by their smeartaker.

A leaflet entitled 'What Your Cervical Smear Test Results Mean' (refer to Appendix C) is enclosed with all results letters.

2.4 Information Materials & Promotion

As noted two leaflets that have been produced by the programme, 'About Your Smear Test' and 'What Your Cervical Smear Test Results Mean', are enclosed with invitation letters and results letters respectively. Other information leaflets produced by the programme are entitled: 'The Cervical Smear Test', 'Colposcopy' and 'Cervical Screening Following A Hysterectomy'. The programme also uses a leaflet produced by the Irish Cancer Society, entitled 'Cervical Cancer'. These leaflets are distributed to smeartakers registered with the programme for display in their surgeries. Leaflets are also displayed in the waiting room of the colposcopy clinic.

In 2003, the programme conducted two promotional campaigns, one in Ennis and one in Limerick. Advertisements were placed on local radio and promotional activities were undertaken such as having display stands in shopping centres. Promotional materials, including an information leaflet, were produced specific to each campaign.

Notices promoting the programme are displayed on an on-going basis in public toilets in places like cafes and shopping centres throughout the mid-western region.

2.5 Smeartakers

There are currently 330 smeartakers registered with the programme, comprised of general practitioners and nurses in general practice and smeartakers attached to family planning clinics. Women have the option of attending their local/family GP for their free smear test if that GP is registered with the programme. Alternatively women may chose to attend any other of the smeartakers registered with the programme and operating in the Mid-Western Health Board area.

As noted above, the invitation letter suggests that women 'make an appointment with a Smeartaker registered with the Programme (i.e. Family Doctor or Practice Nurse)' and specifies the ICSP's information line as the number to contact with any queries. A list of registered smeartakers is not attached to the invitation letter, however, this list is available on the ICSP's website. The website allows women to select smeartakers on the basis of sex and/or geographical area. Currently there are 293 smeartakers listed on the website for Limerick, Clare and Tipperary collectively. An additional 37 smeartakers are listed for areas just outside the border of the Mid-Western Health Board, in counties Cork, Galway, Laois, Offaly and Kilkenny.

All smeartakers registered with the programme comply with a contract agreed by the Mid-Western Health Board and the Irish Medical Organisation. The contract outlines quality assurance targets for smeartakers as well as their responsibilities within the programme. All registered smeartakers have received training in smear taking from the programme. The programme maintains on-going contact and communication with smeartakers primarily through the activities of a full-time staff member at the ICSP office, the Smeartaker Co-ordinator. The programme has also produced a *Resource Manual for Smeartakers* (Ni Riain et al., 2003). The manual outlines key operational aspects of the programme, medical procedure for taking a smear and issues relating to communication with women about screening.

2.6 Colposcopy

Women referred for colposcopy within the ICSP attend a clinic at the Regional Maternity Hospital in Limerick. Three Consultant Obstetrician & Gynaecologists work in the clinic and other staff include a colposcopy nurse and a receptionist.

Women are referred for colposcopy in the following circumstances:

- Three consecutive inadequate smear tests
- Three smear tests with borderline nuclear abnormality
- Three abnormal and untreated smears in a ten year period
- Two consecutive reports of 'mild squamous Dyskaryosis'/CIN 1
- One smear test with Moderate (CIN 2) or Severe Squamous Dyskaryosis (CIN 3)
- When a smear test is negative but cervical cancer is suspected due to a clinically suspicious cervix.

Chapter 3: Methodology

3.1 Study Design

The study design for the review was drafted by the Research Sub-Committee of the Women's Health Council following consultation with the Director of the ICSP. This is a cross sectional study of samples of 25 to 60 year old women in the Mid-Western Health Board region. The samples are chosen according to the nature and extent of their contact with the programme as follows:

- *Non-Attendees Subgroup 1:* Women who were invited but never attended for screening.
- *Non-Attendees Subgroup 2:* Women who were invited, did not attend for screening within the appointed time-frame but attended after the appointed timeframe (after the call had been closed on the system which occurs six months after the invitation letter is issued).
- *Attendees Subgroup 3:* Women who attended for screening, received a 'no abnormalities detected' result[3] and were returned to routine call.
- *Attendees Subgroup 4:* Women who attended for screening, received an initial 'not normal' result,[4] had a repeat smear, received a 'no abnormalities detected' result and were returned to routine call.
- *Attendees Subgroup 5:* Women who attended for screening, received a 'not normal' result, had one or more repeat smears and attended for colposcopy.
- *Recently Contacted Women:* Women who received an invitation letter from the ICSP one week prior to being contacted for interview.
- *Non-Contacted Women:* Women who are in the target population but have not yet been contacted by the programme.

Telephone interviews and focus groups were identified as the most suitable approach for gathering qualitative information regarding women's views and experiences of the Irish Cervical Screening Programme. Telephone interviews were to be conducted with Subgroups 1 to 5 and Recently Contacted Women. In addition focus groups were to be conducted with Subgroups 3, 4, 5 and possibly Recently Contacted Women. Quota sampling methods were to be used to access Non-Contacted Women. In this context women were to be approached on the street and asked to participate in a short interview.

The total number of women identified in Subgroups 1 to 4 was as follows: 29 in Subgroup 1, 68 in Subgroup 2, 1,101 in Subgroup 3 and 35 in Subgroup 4. A figure was not available for the total number of women in Subgroup 5 as the ICSP office is in the process of updating its records for this subgroup. The programme issues up to 200 letters per week inviting women for free screening. 140 invitation letters were issued during the week selected for the review and this therefore comprises the total number of women in the Recently Contacted Women group. The total for the group Non-Contacted Women was identified as approximately 20,000 women.

4 Cytology Pattern P3, P4, P5, P6, P7, P8 or P9.

During the study design topic guides were drafted for each group and subgroup. Sample sizes were set at 20 women per group/subgroup. This number was estimated to be sufficient to hear a variety of women's experiences without excessive repetition. In the course of the research an additional sample of 40 women was obtained for Subgroup 3 as most women contacted by the programme fit within this subgroup and to ensure that any issues they might have would be identified.

3.2 Preliminary Research

Key staff from the ICSP office briefed the researcher on all aspects of the programme. Programme documents such as internal reports, external reviews, correspondence and information materials were examined.

Interviews with service providers

The colposcopy clinic in Limerick was visited and preliminary interviews were held with five smeartakers attached to the programme and based in the three counties. The interviews, which were semi-structured and face-to-face, were conducted in the smeartaker's surgeries. The purpose of the interviews was to identify questions and concerns raised by women in relation to smear taking and/or the screening programme in general. Issues raised in this context were incorporated into the topic guides drafted by the Research Sub-Committee.

3.3 Telephone Interviews

Subgroups 1-4

Criteria for the subgroups were clarified and the IT section of the ICSP office was asked to provide a randomly selected sample of 20 women for each subgroup from the programme database. The Random Number Generator from the Excel AnalysisPak was used to assign numbers to women in each subgroup. The first 20 numbers were then selected as the sample for that subgroup. A letter was sent from the Women's Health Council to all women in the selected samples outlining the purpose of the review and informing them that researchers would contact them for interview. Women who did not wish to participate were asked to contact a freephone number that was established for that purpose. Attempts were made to contact all women listed in the samples by telephone. The number of telephone interviews conducted for each subgroup was as follows: 14 for Subgroup 1, 12 for Subgroup 2, 17 for Subgroup 3 and 16 for Subgroup 4. As noted an additional sample of 40 women was selected for Subgroup 3. 34 telephone interviews were conducted from the additional sample bringing the total number of interviews for Subgroup 3 to 51.

Subgroup 5

The sample for Subgroup 5 was provided by staff at the colposcopy clinic as the ICSP office did not have up-to-date records on women discharged from colposcopy. Women identified in the sample were sent letters regarding the evaluation as in Subgroups 1 to 4 above.

Recently Contacted Women

Women in the Recently Contacted Group were to be interviewed within one week of receiving an invitation letter from the programme. The sample for this group was randomly selected from a list of women to whom invitation letters were sent during one week in late January. Again a letter was sent to women in the sample informing them that they would be contacted regarding the evaluation.

General Information

In total 160 women, from Subgroups 1 to 5 and Recently Contacted Women, were selected for telephone interviews. 117 women participated in telephone interviews representing a response rate of 73%. Of the remaining 43 women, 13 refused to participate. Thirty women were unavailable for interview, that is they could not be contacted or were contacted but unable to participate within the time-frame in which interviews were conducted.

Table 1: **Participation in Telephone Interviews**

Response	Number	Percentage
Participated	117	73%
Refused	13	8%
Unavailable for interview	30	19%
Total	**160**	**100%**

Demographic Details

Demographic details for women who participated in telephone interviews are outlined in Tables 2, 3 and 4.

Table 2: **Age Range of Participants**

Age Range	Number	Percentage
25-29	4	3%
30-39	37	32%
40-49	49	42%
50-60	27	23%
Total	**117**	**100%**

Table 3: **Geographical Location**

Geographical Location	Number	Percentage
Rural	66	56%
Urban	51	44%
Total	**117**	**100%**

Table 4: **Medical Card Details**

Medical Card Details	Number	Percentage
Has a Medical Card	20	17%
Does not have a Medical Card	90	77%
Information not available	7	6%
Total	**117**	**100%**

3.4 Focus Groups

When telephone interviews were completed focus groups were conducted for Subgroups 3, 4 and 5. Five focus groups were conducted as follows: two for Subgroup 3, two for Subgroup 4 and one for Subgroup 5. Attendance at the focus groups was low in general and particularly low for Subgroup 4. The number of women who attended each focus group was as follows: Subgroup 3 Focus Group 1 (5), Subgroup 3 Focus Group 2 (4), Subgroup 4 Focus Group 1 (2), Subgroup 4 Focus Group 2 (2), and Subgroup 5 (4).

Issues and themes that had been identified in the original topic guides and discussed during telephone interviews were further explored in focus groups. In addition 'new' issues that had emerged during telephone interviews were discussed.

3.5 Quota Sampling

Quota sampling was conducted in Limerick, Clare and north Tipperary to identify and access Non-Contacted Women. 536 women were approached on the street and agreed to participate in a short interview. 468 women, who were within the ICSP's target age group but had not previously been contacted by the ICSP, were found to fit the criteria for Non-Contacted Women. Interviews from the remaining 68 women were excluded from the analysis as those women had received an invitation letter from the programme.

Chapter 4:
Interviews with Service Providers

4.1 Purpose of Interviews with Service Providers

Prior to interviewing women with regard to their experiences and views of the Irish Cervical Screening Programme, interviews were conducted with six service providers registered with the programme. The interviews were one-to-one, semi-structured and conducted in the service providers' practices and clinics. Five of the service providers were smeartakers, of whom four were General Practitioners and one was a Practice Nurse. The sixth service provider was a staff member at the colposcopy clinic. The primary purpose of the interviews was to establish questions and concerns commonly raised by women with regard to screening. Issues raised in this context were incorporated into topic guides for interviews and focus groups with women. However, the interviews were also useful for highlighting service providers' views of the programme including their perceptions of aspects of the programme that had worked well and those that could be improved. In general service providers were very positive about the programme and considered it to be working well.

4.2 Aspects of the ICSP that have worked well as identified by Service Providers:

Administrative Processes

Smeartakers regarded the programme as very effective in terms of its administrative systems and described it as very efficient and well run. One smeartaker expressed the view that the programme had not worked well administratively for the first one or two years, particularly with regard to sending out results, but added that the programme seemed to be working well now in that regard. There was recognition that the main emphasis of the programme in its early stages was on administrative processes and an understanding that this was necessary to ensure the programme operated effectively in the long term.

Information & Promotion

All service providers were positive about the information materials used by the programme. The leaflets were described as being 'excellent', 'very good' and 'pitched at a good level'. It was noted that information leaflets were displayed in each of the six waiting rooms visited. Some service providers described how they sometimes found it helpful to give women information leaflets during consultations. All service providers had observed an increase not only in women's awareness of the existence of the programme in recent years but also in their understanding of cervical cancer and aspects of screening. A Limerick-based smeartaker was very positive about a promotion campaign that had been conducted in the area in previous months. That smeartaker noted an increase in the number of women attending for smear tests during the campaign.

Training & Communication

Two smeartakers referred to the training provided on smear taking as a positive aspect of the programme. A third smeartaker described the way in which the ICSP communicates with GPs as very effective, particularly in terms of ensuring that GPs are aware of what is happening within the programme. Another identified the programme's newsletter as a 'good start' to ensuring on-going communication with smeartakers.

Relationship and Cooperation between Key Actors

Three service providers described how the programme had resulted in an improvement in the performance of some key actors and/or improved relationships between key actors involved in screening. In this context the staff member at the colposcopy clinic described how participation in the programme had directly contributed to the improvement of quality standards in the clinic. Further, the programme had indirectly contributed to an improvement in the relationship between GPs and clinic staff as GPs registered with the programme had acquired greater understanding of the work of the clinic and greater confidence in clinic staff. A GP gave the example of an improvement in the performance of the laboratory with which their practice deals and also referred to the more effective use of resources overall as a result of having an integrated programme in place. A second GP described the laboratory reports produced since the establishment of the programme as 'excellent'.

4.3 Administrative & Operational Areas for Improvement as identified by Service Providers

Delays for Colposcopy Appointments

Three smeartakers identified the period of time between being informed of the need to have a colposcopy and attending for colposcopy as a particularly anxious time for women. The smeartakers were positive about the work done at the clinic and particularly about clinic staff, whom they described as 'excellent', 'brilliant', 'lovely' and 'good at putting patients at ease'. Nonetheless they all had experience of women waiting several months, in some cases four or five months, before being seen for colposcopy.

The delay that some women experience in obtaining an appointment for colposcopy was acknowledged in the preliminary interview with the staff member from the colposcopy clinic. However, the staff member was particularly concerned with the amount of time women wait to be seen when they are at the clinic and in this context identified the inadequate number of clinics currently being run as an issue that needs to be addressed. Clinics were described as very busy with doctors sometimes being called away for deliveries, which results in longer waiting times for women attending the clinic on that day. Some women had made complaints about the amount of time they waited to be seen at the clinic. The staff member suggested that perhaps another colposcopist (Consultant Obstetrician & Gynaecologist) be assigned to the clinic to address this.

One smeartaker identified the length of time taken to get smear test results as an area needing improvement, stating that six weeks was too long a time for women to wait.

Supplies

Supplies were an issue for two smeartakers. An Ennis-based smeartaker was unhappy with a change in the practice from providing speculums at the local Health Board office to posting speculums from the ICSP office in Limerick. A Limerick-based smeartaker found it inconvenient that staff from their practice had to drive to the ICSP office for supplies particularly as on some occasions supplies were not available at all or not available in the quantities requested. The smeartaker added that GPs encountering similar problems sometimes contact their practice to get supplies.

Other Administrative Issues

One smeartaker suggested that women's PPS number be made available to GPs on-line rather than having to telephone the ICSP office to obtain it.

Another smeartaker suggested that the invitation letter be amended to advise women that smear tests be done in the middle of their menstrual cycle.

4.4 Other Issues identified by Service Providers for Consideration and/or Improvement

Non-Attendees

Three smeartakers expressed concern about a group of women that one smeartaker described as 'women in hiding' that is women who have never had a smear test and who refuse to attend for screening. Two smeartakers did not have specific suggestions or recommendations in relation to this but believed it was an issue that merited more consideration by the programme. The third smeartaker, a GP, suggested that the programme undertake more promotional work such as advertisements on the radio and talks with women's groups to encourage these women to attend. The GP expressed the view that facilitating women to visit a smeartaker solely to talk about the test and any concerns they may have relating to the test may be a way of encouraging these women to attend.

Follow-up

One smeartaker, a GP, was concerned about the amount of nursing time spent in their practice on follow-up that is where women have been advised to attend for a repeat smear test or follow-up treatment but have failed to respond. The GP stated that follow-up involved much more administrative work than was originally anticipated and expressed the view that the difficulty involved in getting some women to attend for repeat smears or follow-up treatment may be due in part to women having more confidence in smear tests than they merit. In this context the GP speculated that if the programme were to make women more aware of the limitations of the test, for example of the high incidence of false negatives, they may be more likely to attend for follow-up when advised. In this context it was suggested that the programme use less neutral wording about the limitations of the test and state more definitely the error rate for the test in information leaflets and the consent form.

Another smeartaker was particularly concerned about women who could not be located and informed of their need for follow-up tests or treatment. The smeartaker was not aware of what action the programme takes in relation to those cases and indicated that this information would be useful.

A third smeartaker emphasised the importance of 'what happens in primary care' for the success of the programme in the long-term. In this context, they argued that whether or not women return for follow-up tests, treatment or when recalled for a routine smear test largely depends on women's experience at the first smear test. The smeartaker expressed the view that there needs to be greater recognition of this within the programme office and suggested that the programme now focus less on administrative issues and more on primary care. The smeartaker also suggested that more effort be made to ensure that the programme office is accessible to smeartakers in general and identified the Smeartaker Co-ordinator as having a central role to play in this regard.

Five-Year Recall

Two smeartakers explained that some of their patients attend for smear tests on a more regular basis than the programme allows, such as every two or three years. They expressed the view that many of those women are unlikely to attend only once every five years and one questioned the impact that might have on the programme in the long term. A third smeartaker described the five year gap between smear tests as 'extremely generous' and expressed the view that because 'the programme is erring on the infrequent side' in terms of how often smear tests are taken it is all the more important that women do attend when recalled both for repeat and routine smear tests.

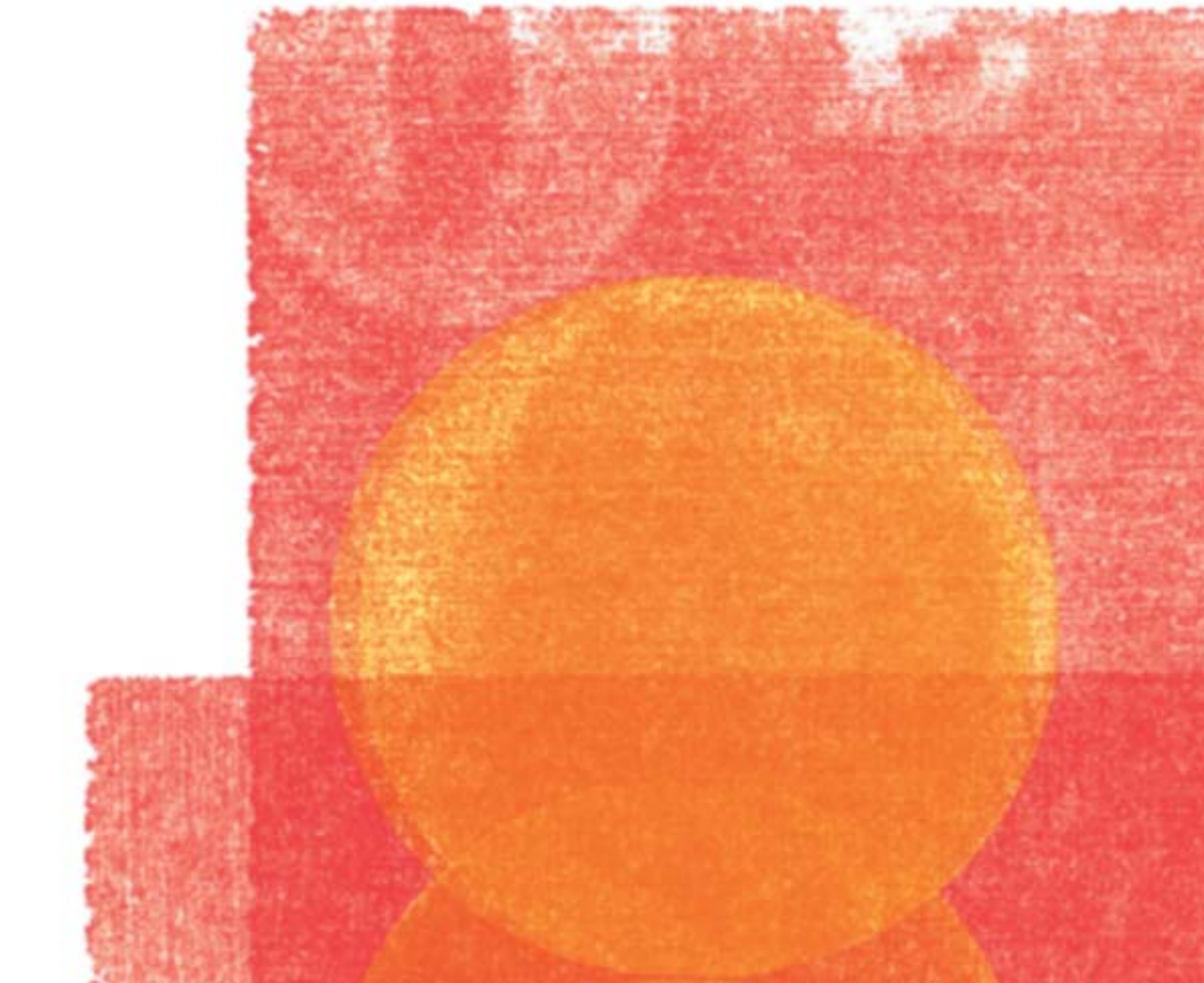
Sexual Activity

One smeartaker, a GP, described an inconsistency between the programme and 'medical position' with regard to screening and sexual activity. The GP accepted that the programme has made a

decision not to refer to sexual activity in its information literature but expressed the view that lack of acknowledgement of the relevance of sexual activity to screening had created some difficulties for GPs. In particular there is lack of recognition within the programme of the need for GPs to establish prior to performing a smear test and for the purposes of medical accuracy whether or not women have been sexually active. The smeartaker described hearing of cases where women who have never been sexually active have received an invitation letter from the ICSP and attended for screening.

Follow-up to Training

One smeartaker who had a very positive experience as a participant in ICSP training suggested that the programme organise a meeting some time after training has been completed at which smeartakers are given feedback about their performance.



Chapter 5: Interviews with Women

Telephone interviews were held with women from Subgroups 1 to 5 and Recently Contacted Women. In addition, focus groups were held with women in Subgroups 3, 4 and 5. One to one interviews were conducted with Non-Contacted Women, who were accessed using Quota Sampling methods. Key issues for all groups and subgroups are outlined below.

5.1 Non-Attendees (Subgroups 1 & 2)

Non-Attendees Subgroup 1 comprises women who were invited but did not attend for screening. Non-Attendees Subgroup 2 comprises women who were invited, did not attend for screening within the appointed time-frame but attended after the appointed time-frame (after the call had been closed on the system). A total of 26 women were interviewed from Subgroups 1 and 2, 14 from the former and 12 from the latter.

Reasons for late or non-attendance

During interviews women were asked their reasons for attending a smear test late or for not attending at all. Some women gave more than one reason for delays or non-attendance. Hence the total number of reasons given is greater than the total number of women interviewed.

Pregnancy

Five of the women interviewed were pregnant at the time they received the invitation letter and one woman had had a smear test as part of a post-pregnancy examination prior to receiving the invitation letter.

Demands on time

Six of the women interviewed indicated that the delay in making an appointment for a test or non-attendance for screening was due to demands on their time such as paid employment and childcare. Women with young children described finding it particularly difficult to make time to attend for a smear test.

> *'I have three small children and am just trying to get jobs done here in the house'.*

> *'You have to sit in my GP's office for about two hours usually before you get to see him... and with a one year old baby that's just not convenient.'*

Lack of information about smeartakers

For six of the women interviewed lack of information about smeartakers registered with the programme had contributed to either a delay in making an appointment or non-attendance. Four of these women stated they did not wish to attend their GP for the test because the GP was male and/or lived in their local area.

> *'I wouldn't do it with my local doctor... I don't want to do it locally'.*

> *'I don't want to do it at the doctor because he is a man doctor... and I know his wife would do it but I know them so well...I'd prefer a stranger than somebody I know.'*

> *'Maybe it's just that deep down I feel a bit uncomfortable about him doing it you know because I know him so well.'*

The women did not wish to contact their GP for details of alternative smeartakers and did not know whom else they could contact for this information.

The fifth woman described how lack of information about the venue for screening discouraged her from attending for a test.

> *'I don't think the venue was mentioned. I mean it might have been a mobile caravan for all I knew.'*

The sixth woman had understood from the letter that she would have to go to Limerick city to have the test, which is a considerable distance from where she lives.

A number of these women suggested that the programme enclose a list of registered smeartakers with the invitation letter.

Lack of access to smeartakers

As noted above four women indicated that lack of information about alternative smeartakers to their GPs had contributed to a delay or non-attendance for screening. It is interesting to note that 3 of those 4 women live in East Clare. This suggests that in some parts of the mid-western region women may have difficulty accessing smeartakers.

> *'My friend was going to try and make contact with somebody to see could we find a list of outside doctors maybe in the Shannon region'.*

> *'I am not aware if the health clinic in Shannon does it. It didn't state in the letter it does and I'm not aware that there is another nurse here in Shannon that actually does it as well'.*

A fourth woman, also from East Clare, stated quite clearly that the reason she had not yet availed of a free smear test was because of the lack of smeartakers in her area.

> *'In my area there is a clinic in Shannon which is my nearest town. If I could have my smear test there it would have been done months ago... (but) they don't take smear tests there... None of the options that are actually available are convenient to me.'*

Nature of the test

Four of the women interviewed described how they had delayed making an appointment or had not attended for screening by the time of interview because of the nature of the test. They had all attended for smear tests before and were aware of what the procedure involved. They described a smear test as something that they did not look forward to and tended to postpone for as long as possible.

> *'You know it's just making the concentrated effort to make the appointment and set a date and just go. I suppose it's the nature of the test that it's not the most you know... some people wouldn't be terribly comfortable with having it done.'*

> *'I kept putting it off, saying I must do that and I must do it. That was all really, making the effort to go.'*

Administrative Issues

Issues relating to administration at the ICSP office were of relevance to four of the women interviewed. Two women had not received one or more of the invitation/reminder letters from the programme, which had contributed to a delay in making an appointment for a test. The third had not received any invitation/reminder letters and therefore was unaware that she had been invited for a free smear test until contacted for interview. The fourth had attended for a smear test after receiving the invitation letter. However it appears the test had not been recorded on the database as the programme continued to send reminder letters to her.

GPs not part of programme

This issue was of relevance to 3 of the women interviewed. One woman stated that she had received a letter from the ICSP but had chosen not to have a free smear test. She explained that she attends her GP, who is not registered with the programme, for regular smear tests and wished to continue with that arrangement.

> *'To be honest I get it done at the doctor's and I'm quite comfortable getting it done there'.*

Another woman also opted to continue having private smear tests with her GP who is not

registered with the programme rather than attend an alternative smeartaker for a free test. A third woman delayed making an appointment for screening as her GP is not registered with the programme and her preference was to attend her GP. She eventually had the test at a family planning clinic but found the clinic 'impersonal'.

Anxiety about first test

Two of the women who had not responded to the ICSP's invitation for screening had in fact never attended for a smear test and described being very anxious about it. Their anxiety appeared to centre on fears about what the test might involve.

'I'd be curious like but at the same time I suppose I'd be sort of afraid... I don't know maybe it's just the thoughts of the actual test itself.'

'I haven't the courage to go and get it done.'

Irregular menstrual cycle

This was an issue for one of the women interviewed. Because her menstrual cycle was irregular she had been unable to identify times at which she should attend for a smear test.

Subgroup 1 and likelihood of attendance

Most of the women in Subgroup 1, that is women who were invited but did not attend for screening, indicated that they planned to attend for a smear test in the future. Of the total of 14 women interviewed 10 said that they would attend for a smear test in the future. Three women said they were unsure if they would attend. One woman who was identified by the programme as not having responded to their letters had in fact attended for a free smear test.

In this context, a number of women spoke positively about the correspondence from the programme and described the letters as something that would encourage them to attend.

'Every time I got them I said that's right, I have to do this... so I mean it was good to send the letters I do think.'

Subgroup 2 and attendance

Women in Subgroup 2, that is women who attended for screening outside of the appointed time frame, were asked for reasons why they eventually attended for a smear test. Again women sometimes gave more than one reason hence the total number of reasons is greater than the total number of women.

Programme Letters

Eight of the 12 women interviewed described the letters they received as encouraging them to attend for a smear test. Although women in this subgroup did not act on the invitation letter immediately but rather made an appointment after several reminder letters had been sent they were positive about the invitation letter.

'I was surprised because I hadn't heard that it was on offer like... I was delighted to receive the letter and probably wouldn't have gone for another test if I didn't get the letter you know.'

'I was delighted to get it really to be honest with you.'

In some cases the letters collectively encouraged women to attend for screening. In others women were prompted to make an appointment after receiving a particular letter such as the first reminder letter.

'I had thought about it and I was going to do it and then it didn't work out and when I got the next letter then I said here I'd better do it like you know.'

The final reminder which states that the programme will contact women again in five years seems to be particularly significant in this context.

'It was my last chance of getting it done and then I wouldn't get a reminder for a couple of years again... and I suppose it kind of dawned on me.'

Felt it was time to have a test
Six women said that they eventually attended for a smear test because they believed it was time for them to go. In this context women referred to factors such as their age, the length of time since their last smear test and having had an abnormal smear test in the past.

> *'I kind of knew my five years was up and... that I should have it done.'*

> *'If I was younger I'd probably would have said I'll do it again you know but I think it was my age... and plus there was a big gap since my last (smear test).'*

Attending a medical professional for other reasons
Three women described how they had smear tests as a result of being examined or treated for other medical reasons. One woman was attending her GP's surgery and decided to make an appointment for a free smear test while there. Another woman had a smear test while attending a family planning clinic for other reasons. The third had her smear test as part of a routine post-pregnancy gynaecological examination.

No longer pregnant
One woman said that she would have made an appointment for a free smear test when she received the invitation letter if she had not been pregnant at the time. She made the appointment for a test with the programme after her baby was born.

Information Leaflets
As noted women in Subgroups 1 and 2 were generally positive about the letters they received from the programme. However they had difficulty answering questions about and in some cases even recalling the information leaflet 'About Your Smear Test' which is enclosed with the invitation

letter. Thirteen of the 26 women interviewed could not recall receiving the leaflet. Of those some were certain that they had not received the leaflet while others thought it possible that they had received the leaflet it but could not recall it.

Of the 13 women who could recall receiving the leaflet, 5 said that they did not read it at all. This means that of the total of 26 women, 18 did not read the information leaflet. The remaining eight women described reading the leaflet in varying degrees of detail from 'glancing at it' to reading through each section.

Women who had read the leaflet in detail were positive about the information it presented.

> *'There was loads of information on it... they answered the questions... all the stuff that you would be asking yourself like.'*

> *'The colour and layout was eye-catching that's why I picked it up and it was quite informative.'*

However it is worth noting in this context that less than one third of the women in Subgroups 1 and 2 read the information leaflet in detail.

A number of women who did not read the leaflet at all or did not read it in detail referred to the fact that they had had smear tests before and knew what to expect.

> *'Well to be honest, I know what it's about... because I get them done on a regular basis when they're due... I would probably have just glanced at it and then put it in the rubbish.'*

> *'I skimmed through I'd say and bin... I felt I suppose that I'm getting it done... and sure what do I need this for now to be honest.'*

5.2 Attendees (Subgroups 3 & 4)

Attendees Subgroup 3 is comprised of women who attended for screening received a 'no abnormalities detected' result and were returned to routine call. Attendees Subgroup 4 is comprised of women who attended for screening received an initial 'not normal' result, had a repeat smear, received a 'no abnormalities detected' result and were then returned to routine recall.

Overall Experience of Smear Tests & the Programme

In general women in Subgroups 3 and 4 were very positive about their smear tests and contact with the programme. A number of women expressed their appreciation that the screening programme was available to them.

> *'I thought it was excellent... that they did send out this to all women in the Mid-West. I thought it was very good.'*

> *'It's a good programme... and fair dues to the people that do it because you know it's good for people to do those things.'*

> *'It thought it was great to have it done. I really did you know.'*

Having a choice of smeartakers and in particular the option of attending a female smeartaker was identified by many women as a positive aspect of the programme.

> *'I wanted a woman to do the test... It's great that this programme allows you to go to someone else if you wish as I would probably not have the test if it was left to my own doctor.'*

> *'I prefer female. I wouldn't feel all that comfortable with a male...I think it's very encouraging as many women are not comfortable with a male doctor.'*

Some women identified not having to pay for the test as an incentive to attend for screening.

> *'I hadn't gone for a test in over 20 years and I probably wouldn't have gone only for the fact that it's free.'*

A minority of women raised issues relating to their particular experience such as waiting a long time in the waiting room on the day of the appointment, the smeartaker being too business-like or not talking enough. However, the majority

of women were satisfied with the smear test they had with the programme and described it as a positive experience. Only one woman reported having a particularly negative experience at her smear test. In her case the brush being used by a nurse to take the smear became stuck in the woman's cervix. The woman was sent home in this condition as there was not a doctor present to remove the brush. She informed the programme of the incident after some time and was satisfied with the way in which programme staff dealt with the issue.

Consent

Women in Subgroups 3 and 4 were asked a number of questions relating to consent. These were the questions that women in the two subgroups had greatest difficulty answering during interviews. To begin with women were asked if they could recall signing a consent form (Appendix D) prior to their smear test. Of the total of 67 women in the two subgroups 22 women could not recall signing the form. There was considerable variation across the remaining 45 women with regard to this. Some women could vaguely recall signing a form, or as a few put it they could remember signing 'something', while other women were quite clear that they had signed a form for consent.

Many women had difficulty recalling what happened before they signed the form, specifically if they read the form or if it was explained to them. Significantly more women recalled having the form explained to them by their smeartaker than recalled reading it themselves (25 compared with 7). A few women stated that the form was neither explained to them nor given to them to read.

'She gave me something and I just signed it.'

'The nurse came in with the form. She said sign here and I did. I had no idea what I was signing.'

Where women were given explanations by their smeartakers prior to signing the form there appeared to be some variation in the issues covered. Further it appeared that certain aspects of the programme such as the existence of a register and the processing of results were often explained. Other aspects of the programme however such as the use of information for monitoring, and in particular for research and teaching, were less commonly explained. In fact many of the women interviewed were not aware that information about them could be used by the programme and a few women suggested that this be explained better when consent is being obtained.

'Maybe it should be explained a bit better if information could be used about you.'

'Maybe it should be explained better if they're using your info. but I mean if it's private and it's used to improve things then that's fine.''

One woman who first became aware of this during her interview was particularly concerned.

'That is personal you know. If somebody is using something belonging to me without my consent I wouldn't actually like that. I'd be concerned.'

None of the women interviewed described having the limitations of screening and in particular the possibility of false negative results explained to them prior to signing the form[5].

Signing the ICSP's consent form is to acknowledge 'having been informed about the ICSP' and to agree 'to participate in all aspects of the ICSP'. During interviews women were asked what in their understanding they were consenting to when signing the form. Most women had difficulty answering this question and required some time to do so. Some women were unable to answer the question at all. Of the 30 women who gave an answer 14 said that they were consenting to having the test done, seven said that they were consenting to having the test done and being part of the programme, four said they were consenting to being part of the programme, three said that they were consenting to the test and to getting results, two said they were consenting to getting test results.

A number of women made the point that they may

5 A false negative result is one in which abnormal cells in the cervix are not identified during a smear test. This means that a woman is informed that her smear test is clear or that no abnormalities have been found when in fact abnormal cells do exist.

have had difficulty recalling the information they were given prior to their smear test because they were nervous at the time. For example a couple of women stated that the way in which the programme uses information for monitoring, research, etc. may have been explained to them but they were unable to remember. In this context some women speculated that as women in general want to have smear tests done as quickly as possible once they attend for screening it may be difficult for them to absorb information given just before a test.

'I'd be thinking of having the smear you know and think well it has to be done anyway and just sign it rather than reading all this load of stuff.'

'You know when you're given a form in the doctors you just sign it and may not take in the information they tell you.'

'Some women may forget at that time if they are nervous.'

Smear Test Results

Undoubtedly the aspect of the programme about which women in Subgroups 3 and 4 had greatest issue was the length of time required to return smear test results. Of the total of 67 women in both subgroups, 36 women reported receiving their results within the target time of six weeks, 24 reported receiving their results after the target time of six weeks and for the remaining seven women this information was not available. (Note for women in Subgroup 4 this information relates to their first smear test with the programme).

Of the 24 women who waited more than six weeks, 11 waited for between seven and twelve weeks, four were unsure of when exactly they had received their results but knew it was sometime after six weeks and nine waited for more than twelve weeks. Of the women who waited more than twelve weeks, two women had not received their results at the time of interview, four women had received their results between three and four months after the test while the remaining three had waited five to six months for results.

'I had to wait but it was too long and I wouldn't like to have to wait that long again.' (Woman who waited for three months).

'I wasn't happy that I had to wait four months to get my results back... I thought it was a long time to have to wait.'

'The only thing I will say is that it took an awful long time for them to come back with results... it took six months with the result and I thought that was very bad.'

A few women made the point that the programme should ensure that all women get their results within six weeks if that is the time women are told within which to expect results.

'If they say six weeks then it should be and not any longer.'

'If it's recommended that the results will take six weeks well then it should be back by then.'

However, many women in the two subgroups expressed reservations about a waiting time of six weeks for smear test results and this was regardless of the length of time that they had waited for results individually. In other words even women who received their results within a six-week period expressed reservations about the screening programme having a target time of six weeks for returning smear test results. Of the total of 67 women in both subgroups, 24 women were satisfied with results being returned within six weeks while 33 women expressed the view that smear test results should be returned in less than six weeks. The remaining 10 women did not express a preference. The proportion of women who were dissatisfied with the target time of six weeks was higher in subgroup 4 (10 women in a total of 16) than it was in subgroup 3 (23 women in a total of 51).

Some of the women who were not satisfied with the six-week target time expressed the view that all smear tests should be returned within a shorter time frame. Others suggested that the programme apply the six-week target time for some smear tests and a shorter target time for others. Examples given of where the shorter time might apply were: where women have symptoms or a history of symptoms, where abnormalities are found and where women are particularly anxious about the outcome of the test. Suggestions for a shorter target time for returning smear test results ranged from one day to one month. The most common suggested time was between two and three weeks.

'It's an anxious time, thinking there could be a problem so I think it should be shortened to three weeks. Maybe that's not realistic but that's how I feel about it.' (Woman who got results within six weeks).

'Well I think the time frame seems long particularly for someone who may worry about having something... somebody who maybe had a scare or some anxieties.' (Woman who got results within six weeks).

'If there was something wrong and you found out after six weeks I think I'd be mad that I didn't find out sooner.' (Woman who got results in five weeks).

It is worth noting that seven of the 25 women who were satisfied with a six week target time also presumed that the programme would contact them sooner if there were problems with their results such as abnormalities found. In fact all results letters are processed by the programme office in the same way regardless of the nature of the results. When the programme office is notified of a result by a laboratory a results letter is produced and sent to the woman in question. This means that women are not notified more quickly of their result if an abnormality is detected than if their smear is clear.

'I thought it was fine but I presume if there was something wrong they would contact you earlier... nobody wants to be hanging around if there is a problem.'

'I presumed that... if there was anything amiss that I would be notified very quickly so it didn't bother me.'

'I'm sure if there was a problem they would let you know sooner.'

Generally women in Subgroup 4 described experiencing higher levels of anxiety while waiting for the results of their repeat smear than for their first smear test. In this context women emphasised the importance of the results of repeat smear tests being returned within a few weeks.

'The amount of time I had to wait for the results of the second smear test was way too long. I didn't worry too much about the results of the first test but when you have to go for a second it's worrying and having to wait makes it worse.'

'For my repeat smear test I got the results back within three to four weeks so I was very happy with that.'

Most women in this subgroup reported receiving the results of their repeat smear more quickly than the results of their first smear test or at least within the six week period. This is in line with the policy of laboratories to fast-track smear tests for women where irregularities or abnormalities were found in a previous test. However, there were a few exceptions where women waited longer for the results of their repeat smear test.

A few women in Subgroup 4 expressed dissatisfaction with the length of time they waited for the results of their first test then to be informed that the test would have to be repeated. This was particularly true of women who had waited several months for their results

'I wasn't happy that I had to wait four months to get my results back the first time I had the test.'

Referral for Repeat Smear Test

Women in Subgroup 4 were asked to describe what it was like for them to be informed that they required a repeat smear test. Most women described feeling anxious at that time with some women describing themselves as panicking at that information.

'I got a bit of a fright because there was an irregularity found... I got a bit upset.'

'I panicked... thinking that there was something seriously wrong.'

'My heart just stopped.'

A couple of women who described themselves as not being anxious explained that this was because they had had repeat smears in the past.

'I knew I would have been called back anyway you see from previous experience.'

'I did get a call back... another time... so I wasn't really that bothered.'

The most common response from women when informed they were to attend for a repeat test was to seek further information usually from their GP. In some cases women sought that information immediately while in others women waited until attending their GP for the test. Essentially, however, women emphasised two things in this context: the importance of getting more information about their individual result (as opposed to generic information about different types of results) and the importance of being assured by their smeartaker of the likelihood of a normal result for the repeat test[6].

'If there was something seriously wrong you would have to personally speak to the GP or somebody... because each individual would be different from the point of view of their results like.'

'When I went back in the doctor was very helpful and the nurse. They explained... that my test was just slightly off.'

A few women could recall reading the information leaflet attached to the letter ('What Your Results Mean') and finding that helpful. Women's responses to questions about the leaflet, however, again highlighted their preference to speak to a medical professional about their result rather than read about it.

'I wouldn't have looked to the leaflet for help... I would go to my doctor.'

'I think I would have been very nervous if I hadn't spoken to the GP about it.'

More than half of the women interviewed (9 of the 16) had issues with the way in which they were informed that they required a repeat smear test. As most women were informed of this by letter, the issues they raised in this context related mainly to the letter sent. The main criticism of the letter was that it did not provide enough information about the test result. Women described being unclear as to what exactly had been found in their first test and why they were being advised to have the test repeated. A couple of women suggested that the letter state more clearly whom they could talk to about their individual result. For example, one woman called the ICSP's information line, which is listed at the bottom of the letter, and was advised to contact her smeartaker. She found this unhelpful:

'I didn't get anywhere with the phone call I made back to the actual number that was on the letter... I didn't get any satisfaction there really or kind of relief.'

One woman expressed the view that women who are being called for a repeat smear test should not be informed of their results by letter at all. She suggested rather that they be advised in a letter to contact their smeartaker for results.

6 Studies in other countries have also found that many women experience considerable distress in learning of abnormal Pap smear results and that women often look to their GP's to provide them with more detailed information or explanations of their results. Refer to Karasz, A., McKee, D. and Roybal, K. (2003). 'Women's Experiences of Abnormal Cervical Cytology: Illness Representations, Care Processes, and Outcomes'. *Annals of Family Medicine, 1 (4), pp. 196 - 202. November/December 2003 .*

One woman was informed of her results by a phone call from her smeartaker (a letter from the programme arrived a few days later). She was not satisfied with this as she was at work at the time and unable to talk freely. Another woman called to the clinic where she had her test to get her results. She was asked for her details and informed of her results in a reception area where other women were waiting which she felt was insensitive and '*indiscreet*'.

Recall

Women in Subgroups 3 and 4 were asked if they would attend for smear tests in the future when contacted by the programme. The vast majority of women, 59 of a total of 67, said that they would attend. This information was not available for seven of the women interviewed and one woman said she did not know if she would attend in the future as her previous smear tests had been clear. None of the women interviewed said that they would not attend for another smear test with the programme.

Eleven women questioned the programme's policy of a five-year interval for smear tests. These women expressed the view that five years was too long and stated that their preference would be for a shorter interval. Suggestions ranged from six months to three years with the majority of women suggesting two to three years. In some cases women's concern about a five-year interval appeared to stem from misinformation about cervical cancer. For example, a belief that cervical cancer advanced at a rapid rate or that older women should be screened more often as they are more at risk.

> *'Well I mean I'm getting older now. I think when you're older you would probably prefer to be called back after two years... It could be very advanced in five years, you could be dead in five years you know.'*

In other cases, however, women who were quite well informed about the disease expressed the view that the test ought to be carried out more often than every five years. Further, in a couple of cases it appeared women were being encouraged by their GPs to attend more regularly.

> *'The nurse explained that cervical cancer takes a long time to develop and that after five years it would still be in its early stages. But I think five years is a bit much.'*

'I would prefer to go sooner than that because when I went to the GP that time she said that I will be called in five years but to come myself in say two and a half years.'

It is important to note in this context that only some women in these subgroups (23 of the total of 67) were asked for their views on the five-year interval. This issue had not been included initially in the topic guide for interviews but rather was incorporated when raised by a number of women. However, most women who expressed a preference for a shorter interval did so in response to a question as opposed to raising the issue independently. This suggests that if all women in the two subgroups had been asked about the five-year interval the number of women expressing a preference for a shorter interval might have been significantly larger.

Some of the women asked did express satisfaction with being called every five years.

'I would definitely go back in five years yeah. I had one last... just nearly five and a half years ago so the time was just about right anyway.'

'I would be happy that I wouldn't be bothered for five years again.'

Information Leaflets

Women in Subgroup 3 were asked if they could recall receiving the information leaflet 'About Your Smear Test' and their impressions of that leaflet. Of the total of 51 women in that subgroup, 17 women stated that they did not receive or could not recall receiving the information leaflet, 32 women could recall receiving the leaflet and there were two women for whom this information was not available. It is interesting to note that the proportion of women who could recall receiving the leaflet was significantly higher for Subgroup 3 than for Subgroups 1 and 2.

Of the 31 women who could recall receiving the information leaflet, three women stated that they did not read the leaflet at all. There appeared to be considerable variation, however, across the remaining 28 with regard to the degree of detail in which they read the leaflet. Some women stated that they read the leaflet in detail when they received it and found it helpful at that time.

'It was good actually. It was very helpful I thought.'

'I found it very detailed... it was easy to understand. I was happy with it.'

Other women however, while stating that they had read the leaflet, were unable to recall the contents when asked to give their impressions of it, which suggests that they didn't read it in great detail. A few women stated quite clearly that they had read the leaflet very quickly and/or had read only certain parts of it.

Charter for Women

The terms of reference for the review specified that the evaluation be conducted with reference to the ICSP's Charter for Women. Women in Subgroups 3 and 4 were asked if they had seen the Charter. One woman in Subgroup 3 had seen the Charter (in a pharmacy) but had not read it and one woman in Subgroup 4 had heard of the Charter but had not seen it. The remaining 65 women had not seen the Charter nor heard of it prior to the interview. None of the 67 women in Subgroups 3 and 4 had read the Charter for Women.

Focus Groups

In addition to telephone interviews focus groups were held for women in Subgroups 3 and 4 (two focus groups per subgroup). Similar concerns were raised during focus groups discussions as had been raised in telephone interviews. Specifically most participants were dissatisfied with the length of time they waited to receive smear test results and/or the six-week target time. Most participants also favoured an interval for screening that was shorter than five years.

Women in the two subgroups were asked to read and comment on the information leaflet 'About Your Smear Test'. The main issues raised in relation to the leaflet were as follows:

- In several focus groups women expressed the view that the leaflet did not give a strong enough message about the importance of attending for screening. In this context some women described the leaflet as being 'too neutral' in terms of the language used and the way in which information is presented. Comments included: *'They should be a little bit more urgent'. 'They don't really say this is vital, you should do this, it's very important.'*

- Some women expressed the view that the leaflet cover should be changed to make it more encouraging to women to read and again to make it *'more urgent'*. One suggestion was to move the phrase 'Now it's time to look after yourself... ' from the inside of the leaflet to the cover *('you need something like that on the outside')*. Another was to remove the photographs *('I don't know what relevance these four women have to the subject')*.

- Several women identified the information about the risk of cervical cancer as very important. It was suggested that the relevant sentences *('Cancer of the cervix is the third most common female cancer. There is a lifetime risk that about 1 in 100 Irish women will develop cancer of the cervix.')* be moved from the bottom of the page to another part of the leaflet where they would be more easily noticed.

- A number of women commented on the length of the leaflet. They expressed the view that the leaflet was too long and had too much information in it. It was described as *'very long', 'very bulky', 'cumbersome'*. A couple of women suggested that there is too much information about the programme in the leaflet and that a lot of that information is unnecessary.

- Some women identified items of information in the leaflet that they believed should be emphasised more. These included: the best time to have the test being two weeks after a period *('that I wouldn't have known and I think it is important information')* and where to go to have a smear test *('if they had where you can go for it... the places where you can have it done')*.

5.3 Attendees (Subgroup 5/Colposcopy)

General Feedback

Subgroup 5 is comprised of women who attended for screening, received a 'not normal' result, had one or more repeat smears and attended for colposcopy. The women interviewed in Subgroup 5 were generally very positive about their experience of colposcopy. Eleven of the 12 women interviewed were satisfied with their dealings with clinic staff and in particular with the way in which staff communicated with them during clinic visits. Specifically, they felt staff explained procedures clearly, answered any questions that they had and were reassuring and helpful.

> *'She explained all that to me. She told me exactly what was going to happen and why.'*

> *'They were very pleasant and co-operative and easy to talk to while I was there.'*

> *'I thought he was particularly nice, the particular doctor I met the first day... and the nurse was particularly nice as well.'*

A number of women made positive comments about the way in which the clinic is decorated and equipped.

> *'Even though the hospital itself looks crap this part was sort of modernised.'*

> *'It's a beautiful place, lovely waiting room, everything was nice.'*

> *'They* (the chairs in the examination rooms) *were much more comfortable and you felt more in control.'*

Waiting Times

Women in Subgroup 5 had a number of issues with waiting times relating to colposcopy as

follows: the length of time they waited to get an appointment for colposcopy, the length of time they waited to be seen on the day of their appointment and the length of time they waited for the results of tests carried out at the colposcopy clinic. Eight of the 12 women interviewed experienced delays in one or more of these areas. The remaining three women did not experience delays.

Six of the women interviewed obtained their appointments for colposcopy within six weeks while the other six were waiting for more than three months. Some of the women who waited several months described being very anxious during that time.

'I had to wait three months anyway and I was nearly gone around the bend and back again... if there was something there... that seems like an awful long time to leave it.'

'If they could speed it up a bit. It's very nerve-wracking waiting you know.'

From interviews it appears that there is considerable variation in the amount of time women wait to be seen at the clinic on the day of their appointment. A couple of women described being seen very quickly.

'I was in and out in no time.'

'You weren't left waiting.'

Four women, however, were dissatisfied with the length of time they had to wait on the day of their appointment. Two women waited for forty-five minutes, one for over two hours and another for four hours.

'The only thing was waiting in the waiting room... I think it had been forty-five minutes... you know fifteen minutes seemed like an hour anyway at that stage.'

'The waiting was dreadful... well more than that you have children at home as well and they're left with people and you've said you have an appointment and you'll be back out.'
(Woman who waited for over two hours).

Women who waited for a long time on the day of their appointment also found the clinic very busy and that appeared to add to the anxiety they experienced.

'They were running behind and there was a lot of people waiting... They could have been bit more efficient with the waiting around. You... just want to have your appointment and leave.'

'The receptionist was taking in people that seemed to come in after me. I didn't know what the set-up was and eventually I just went and stood in the corridor until I was taken... They need to change the system... not to give everybody the same appointment or not to give somebody an appointment five minutes later than myself...'

Four women were critical of the length of time they waited to get results of tests carried out at the colposcopy clinic. One of these women waited 'a good few weeks' for her results while the other three waited between three and four months).

'No matter what anybody tells you when you think you've got cancer nothing is going to ease your mind you know until you get the results back.'
(Woman who waited three months for results.)

'I was told I would have the results within about six weeks which I thought was long anyway... it was (specifies a date four months later) *before I got the results which I thought was very long.'*

Referral

Two of the women interviewed were not satisfied with the information they got from their GPs about colposcopy at the time of referral.

> *'I thought my GP would have had a talk to me or something about it.'*

> *'My doctor explained that I had to go in and you know it would be like a more severe* (smear) *test... it might hurt more but that's all she said.'*

Other women, however, were positive about the explanation given to them of colposcopy by their GP, or in a couple of cases another medical professional, at the time of referral.

Nonetheless it is interesting to note that most of the women interviewed were unaware when they attended the colposcopy clinic that treatment or a biopsy may be undertaken during their first visit. Rather they had understood that they were attending the clinic for examination only.

> *'Well actually what my own doctor had said to me was that they probably wouldn't do anything on the first day, that if I had to have something done I would probably have to come back so I wasn't really prepared for anything.'*

Biopsies & Treatment

Nine of the 12 women interviewed appeared to have had treatments or biopsies done during their visits to the colposcopy clinic and in many cases during their first visit. A number of women described being quite shocked when informed during examination at the clinic that a biopsy or treatment would be undertaken immediately.

> *'They did a biopsy and that was very sore because I didn't expect it. They just said that they would do a biopsy while I was there and like that in your senses it's quite sore.''*

> *'He said I might just try to take it out now... I didn't feel a thing but I got a fright.'*

Some women stated that although initially shocked they were glad that they had not been aware prior to their visit what procedures would be performed as this would have caused them greater anxiety.

> *'You're better off being talked through it because you're half way there anyway.'*

Other women, however, expressed dissatisfaction with the way in which this was handled. One woman who had had a biopsy on her first visit, for which she had not been prepared, refused to allow anything other than an examination on her second visit.

> *'When I went back... I did say to them I wasn't giving my permission for a biopsy... it was just looking and checking and that was it.'*

Two women stated that if they had known prior to their visit that treatment or a biopsy would be performed they would have arranged for another person to drive them home.

> *'I went by myself and I had to drive home afterwards... I could have arranged it differently.'*

A couple of women interviewed from the subgroup were aware that a procedure had been carried out during visits to the clinic but did not know what exactly that procedure was.

> *'I think he did a biopsy. I'm not certain.'*

One Negative Experience

As noted in general women in Subgroup 5 were positive about their experience of colposcopy. There was one woman interviewed, however, who found attendance for colposcopy to be a negative experience. The woman in question did not understand what procedure was being performed during her visit and this caused her anxiety. She felt that staff did not explain clearly what they were doing and that they were not attentive to her. In addition she experienced irritation for a few days after her visit that she had not expected and which caused her concern.

'There was two (clinic staff) *there now talking to one another, not talking to me kind of you know. I kind of felt you were an object and they were experimenting on you.'*

It is worth noting that this woman is 60 years of age and was in fact the only woman interviewed in Subgroup 5 over 50. It is possible that she may have been less comfortable asking questions or seeking clarification at the clinic than many younger women. For example, in the course of interviews a number of women from this subgroup described how they asked questions at various points during their visits to the clinic or explained how they would not have had difficulty asking questions if they had had any.

'From the minute I went in I asked questions about everything like you know.'

'I think with all hospitals unless you ask the question it's not going to be explained.'

Focus Group

In addition to telephone interviews a focus group was held for women in Subgroup 5. Again the issues raised by women during the focus group discussion were very similar to the issues identified during telephone interviews. A number of participants described the clinic as very busy during their visits and suggested that something be done to address this. The need for appointments to be made more promptly and for test results to be returned more quickly were also identified as issues. A number of participants emphasised the importance of providing a detailed explanation of what colposcopy is at the time of referral. In this context, it was suggested that an explanation of colopscopy is particularly important at the time of referral given that many women have never heard of colposcopy prior to that. In addition, all the participants agreed that they would prefer to have smear tests from now on every year or couple of years rather than being returned to a routine call every five years. In this context, one woman described her attitude to smear tests since her colposcopy as: *'bring them on like!'*

5.4 Recently Contacted Women

This group is comprised of women who had been sent a letter by the programme inviting them to have a free smear test in the week prior to being interviewed. The information leaflet 'About Your Smear Test' was attached to the letter. During interviews women were asked for their impressions of the letter and leaflet.

Invitation Letter

Generally women were very positive about the letter from the programme and described it as encouraging them to go for a smear test.

'Receiving the letter makes you think and gives you an incentive and reminder to go and get it done.'

'It's about eight years since I've had one so this will push me to go and have one done.'

In fact 8 of the 12 women in this group had already made an appointment for a smear test by the time they were contacted for interview. The remaining 4 women stated that they would be making an appointment for a smear test in the near future. Two of those women were unable to attend for a test within the specified two-week period and had understood that they would not be eligible for a free test after that time. When informed that they would still be eligible they indicated that they would make an appointment for a test.

Three women described being unclear when they received the letter as to where they could go to have the test. In this context two women suggested that a list of smeartakers be included with the letter. The third suggested that it be made clearer that female smeartakers are available to perform the test.

'I had to read it a couple of times to find out where I should go for the test. That was maybe a little unclear.'

'Maybe a list of doctors one could go to in each area.'

'It didn't give a list of names but I just went to my own GP... I think having a female smeartaker is extremely important... it may be useful if the letter could say that the practice nurse could perform it... '

The fact that the test was free was identified by a number of women as an incentive to attend for screening.

'I definitely think that it's brilliant. Any regular offers of a free check-up is brilliant incentive for me.'

'The early diagnosis thing is important and certainly the fact that it's free was a big incentive into making people go do it.'

Information Leaflet

One woman couldn't remember receiving the information leaflet, one received it but didn't read it and a third said that she gave it only a *'quick browse'* because she found it too long. The remaining nine women said that they read the leaflet but when asked for their impressions had difficulty speaking about it in anything but general terms such as *'fine'*, *'good'*, *'very good'*. This suggests that they may not have read it in great detail.

During their interviews three women spoke about the importance of not being overloaded with information in leaflets in general.

'I'm just speaking from general experience... people just read the first paragraph or two and then they just skim through the rest of it.'

'I think too much information is off-putting in a leaflet.'

'Most people don't want a big background history. They're just happy to know that the organisation is run well and that it provides a good service.'

5.5 Non-Contacted Women

Quota sampling methods were used to access Non-Contacted Women that is women who were within the ICSP's target age group but who had not previously been contacted by the programme. Women were approached on the street and asked a number of questions relating to their awareness of the programme and their willingness to attend for screening.

536 interviews were conducted in total in Limerick, Clare and North Tipperary. 68 interviews were excluded from the analysis when it was established that those women had in fact received an invitation letter from the ICSP. Analysis was conducted on interviews with the remaining 468 women who were found to fit the criteria for the Non-Contacted group.

The profile of Non-Contacted Women in terms of age group, marital status, number of children, education and ownership of a medical card, is outlined in the tables below. (Note data was missing for one woman in Tables 7 and 8 and two women in Table 9 hence totals are less than 468).

Table 5: **Age Group**

Age Group	Number	Percentage
25-29	127	27%
30-39	116	25%
40-49	142	30%
50-60	83	18%
Total	**468**	**100%**

As Table 5 illustrates the largest proportion of women interviewed was the 40-49 age group, followed by the 25-29 age group. All age groups, however, were well represented in interviews.

Table 6: **Marital Status**

Marital Status	Number	Percentage
Single	138	29%
Married	279	60%
Separated	14	3%
Divorced	3	1%
Widowed	34	7%
Total	**468**	**100%**

As illustrated the largest proportion of Non-Contacted Women, 60%, were married.

Table 7: **Number of children**

Number of children	Number (of women)	Percentage
None	131	28%
1	36	8%
2	71	15%
3	102	22%
4	74	16%
5 or more	53	11%
Total	**467**	**100%**

28% of women in the Non-Contacted group did not have children. The remaining 72% had one or more children.

Table 8: **Education Level**

Level of Education	Number	Percentage
Primary	16	3%
Secondary	187	40%
Some third level	77	17%
Third level	187	40%
Total	**467**	**100%**

3% of women interviewed were educated to primary level only. 40% were educated to secondary level and 57% had completed third level or had some third level education.

Table 9: **Medical Card**

Medical Card	Number	Percentage
Yes	148	32%
No	318	68%
Total	**466**	**100%**

A minority of women in the Non-Contacted group, 32%, had medical cards. This compares with 17% of women from subgroups that participated in telephone interviews (refer Table 4, Chapter 3).

375 women, representing 80% of the Non-Contacted group, were aware that there is a cervical screening programme operating in the Mid-Western Health Board region. This suggests a high level of awareness of the ICSP in the target population. GPs and nurses in general practice were the most common source of information about the programme and were identified by 19% of women. Family members and friends were the next most common source of information about the programme and were identified by 18% of women. Other sources of information about the programme identified by women were: nurses in health centres (11%), posters in public toilets (9%), leaflets from information stands and pharmacies (6%) and newspaper advertisements (4%).

Level of awareness of the ICSP was found to vary with age. The highest level of awareness was in the 30-39 and 40-49 age groups at 90% and 89% respectively. The lowest level of awareness, at 50%, was in the 25-29 age group. 86% of women in the 50-60 age group were aware of the programme. No significant relationship was found between levels of awareness of the programme and ownership of a medical card. However, marital status and number of children were found to be significant. Women who were married at the time of interview or had been married at some point were two times more likely to be aware of the programme than single women. While the percentage of women who were aware of the ICSP was 92% among women with children compared with 41% among women who did not have children.

When asked if they would make an appointment for a smear test if invited for free screening 417 women, representing 89% of the Non-Contacted group, said that they would. The remaining 38 women who stated that they would not gave reasons as follows: anxiety about the test, regarding the test as unnecessary and being too busy with work and/or family commitments.

Non-Contacted Women were also asked if they had seen the ICSP's self-registration form in doctor's surgeries or health clinics. 411 women (88%) reported that they had never seen the self-registration form.

Chapter 6: Key Issues

In Chapter 5 women's views of the Irish Cervical Screening Programme were outlined. As noted, women were in general positive about the programme. Key issues identified from interviews and focus group discussions are outlined below along with corresponding recommendations.

6.1 Waiting Time for Results

As outlined in the last chapter, one aspect of the programme with which women who attended for screening (Subgroups 3 and 4) had considerable issue was the length of time taken for smear test results to be returned. Just over one third of the women interviewed waited for more than six weeks for their results and 11 of those women waited for more than three months. Most women who attended for a repeat smear waited less time for the results of the repeat than for results of their first smear but there were exceptions to this. Generally women reported higher levels of anxiety when waiting for the results of repeat smear tests. In this context a number of women emphasised the importance of repeat smear results being returned as quickly as possible.

It is worth noting that while the ICSP has set six weeks as the target time within which it aims to inform women of their results half of the women interviewed in Subgroups 3 and 4 were not satisfied with a six-week target time. Suggestions for a shorter target time ranged from one day to one month. In this context most women suggested that results be returned within two to three weeks.

Recommendations:
Review the six-week target time for smear test results.

If the six-week target time is maintained, ensure that the target is met as often as possible.

Establish a target time for repeat smear tests that is shorter than that for first smears.

Senior Management to consider the effect that expansion of the programme might have on time taken to obtain results. Identify actions that could be undertaken to avoid further delays in this context.

6.2 Informed Consent

There has been considerable debate internationally about informed consent in the context of screening programmes among health professionals and organisations working in women's health (Austoker, 1999, Coney, 2000, General Medical Council, 1998, Raffle, 2001). This discussion has focused primarily on the type of information that should be provided to women to ensure that their consent to screening is informed consent (Jorgensen and Gotzsche, 2004, Nottingham, 1999). Preliminary interviews with smeartakers registered with the ICSP indicated that they differ in terms of their understanding and hence presentation to women of information that is of relevance to consent. Some smeartakers described how they explain to women they are consenting to having information about them stored on a register/computer and refer to practices relating to results and recall in this context. Other smeartakers described how they use the consent form primarily to explain the medical procedure involved.

Interviews with women who attended for screening (Subgroups 3 and 4) indicated that

many were unaware that the programme could use information about them for monitoring, research and teaching. While some women had the possibility of false positives explained by their smeartaker none appear to have had the possibility of false negatives mentioned to them. These issues are outlined in the consent form and information leaflet, 'About Your Smear Test'. However, interviews with women indicated that they are more likely to have had parts of the consent form explained to them by their smeartaker than they are to have read the form. Further, it was apparent from interviews that many women are unlikely to read the information leaflet in detail.

Almost half of the women interviewed had no recollection of signing a form or were unsure if they had signed one. Where women could recall signing the consent form many were unsure what it was that they had consented to and some stated that they did not know what they had consented to. The most common understanding was that consent had been to have the test. In fact signing the consent form is taken to mean the following 'Having been informed about the ICSP, I agree to participate in all aspects of the ICSP'. The phrase 'having been informed about the ICSP' is ambiguous. It is also problematic given the variation in information provided to women about the ICSP prior to signing the consent form and further given that certain aspects of the screening programme of relevance to women are not always explained to them. Further, it could be questioned how appropriate it is at that point to ask women to consent to participate in all aspects of the ICSP, such as for example colposcopy or treatment at a colposcopy clinic. This is dealt with in greater detail in section 6.3 below.

Finally, some of the information on the consent form clearly relates to medical aspects of screening such as the smear test, limitations of the test and possible test results. It is appropriate that smeartakers explain these aspects of screening to women when they attend for screening. Other issues included in the form, however, deal with administrative aspects of the programme such as the register and access to and use of client information. How appropriate or practical it is for smeartakers to explain these aspects of the programme could be questioned, particularly given the constraints on smeartakers' time.

Recommendations

Senior Management at ICSP to review what consenting to participate in the ICSP actually means and to specify the components of consent – what it covers and what it does not. Ensure that any documentation or literature produced by the programme and referring to consent is consistent with that understanding. Ensuring clarity with regard to consent would be particularly significant prior to undertaking an expansion of the programme nationally.

The information to be provided to women regarding medical aspects of screening prior to giving consent should be clarified. This information should include the nature of the test, possible results, false positives and false negatives. Ensure that smeartakers are aware of all the medical issues to be addressed with regard to consent and that there is uniformity in the information relayed to women in this context.

The information to be provided to women regarding administrative aspects of the screening programme should be clarified. These include the use of and access to information held on the ICSP register pertaining to clients. Identify best possible means of informing women of these issues. One possibility might be to provide women with an information sheet that outlines these issues in a short, concise manner. This information sheet could be provided to women while waiting at smeartakers' surgeries for their appointment.

Edit the consent form in line with the recommendations above. Ensure that women are given a written record of what they have consented to. For example women could be given one part of the form to keep or a duplicate of the form.

6.3 Colposcopy

Women who attended for colposcopy (Subgroup 5) had concerns in relation to three main issues. Firstly, interviews with women highlighted considerable variation in the amount of time taken to get an appointment at the colposcopy clinic. While some women obtained an appointment within a couple of weeks, half of the women interviewed waited for more than three months. A number of women expressed their dissatisfaction with having to wait for such a long time. A number of smeartakers also raised this as an issue in preliminary interviews.

Secondly, interviews highlighted considerable variation in the length of time women spend waiting to be seen on the day of their appointment. While some women reported being seen very quickly, others reported waiting for more than 45 minutes including two women who waited for more than two hours. Women who were in the waiting room for long periods also described the clinic as very busy and this appears to have added to the anxiety they experienced while waiting. This is consistent with information provided during a preliminary interview by a staff member from the colposcopy clinic who acknowledged that the number of clinics currently run is inadequate to meet demand.

Thirdly, some women were dissatisfied with the length of time taken for results to be returned for tests performed at the colposcopy clinic. Waiting times varied from two weeks to four months. In this context women described waiting for results from colposcopy as a particularly anxious time and suggested that results be returned more quickly.

A fourth issue, relating to informed consent, became apparent from the descriptions women gave of their visits to the clinic. A number of women described how surprised they were to be told that a treatment or biopsy would be carried out during their first visit to the clinic, as they had assumed that they would only be examined on that day. Further, although women generally felt that they were well informed by clinic staff of procedures that were being carried out, it was apparent that some women had not fully understood the explanations given to them. For example, some were unsure if they had had biopsies.

During a preliminary interview a staff member at the colposcopy clinic explained that women give verbal consent but not written consent to procedures undertaken there. It could be questioned, however, if verbal consent is obtained given that some women are unclear as to what procedures have been undertaken. Further, it appears from interviews with women that they are in effect informed that a procedure is about to be performed rather than asked to give their consent to performance of that procedure.

Recommendations

Assess the possibility of increasing the number of colposcopy clinics held in order to firstly reduce the length of time taken to secure an appointment and secondly reduce the length of time women wait to be examined at individual clinics. Two options that could be considered in this context are the recruitment of an additional Consultant Obstetrician & Gynaecologist and/or the adoption of protected time for the clinic.

Review the length of time taken for test results to be returned from the colposcopy clinic. Establish if there are means of reducing time taken to return results.

Senior Management at ICSP to consider the introduction of written consent for colposcopy and any treatment or biopsy undertaken at the colposcopy clinic. In this context the drafting of good practice guidelines for obtaining consent may be useful.

6.4 Five-Year Recall

About one sixth of the women who attended for screening (Subgroups 3 and 4) were dissatisfied with a 5-year interval for screening stating that they believed it was too long. Suggestions for a shorter interval ranged from six months to three years with most women suggesting two to three years. It is important to note in this context that only 23 of the 67 women interviewed in Subgroups 3 and 4 were asked for their views on the 5-year interval as this had not been identified as an issue when interview guides were drafted. Given that 11 of the 23 women asked disagreed with the 5-year interval it is likely that about half of the total number of women interviewed in Subgroups 3 and 4 would have disagreed with it had the question been included in all interviews. Women who attended for colpsocpy (Subgroup 5) also expressed a preference for a shorter screening interval during a focus group discussion.

Some of the smeartakers interviewed expressed the opinion that many women who had been attending for smear tests more regularly would continue to do so. If some women continue to attend for private smears as they have done in the past as well as programme smears at five yearly intervals this will have consequences for the ICSP. Specifically it will make it more difficult for the programme to control the volume of smears taken and sent to laboratories. It may also create difficulties with regard to the maintenance of records, as the ICSP office may not be notified of results of some private smears and hence there may be omissions in the programme database. Studies in other countries have found that where women regard regular smear tests as an important way of protecting their health they may not be open to the idea of reducing the frequency of testing (Smith et al., 2003).

Medical opinion has differed on this issue with some medical professionals supporting a 5-year interval (Raffle, 2004) and others advocating for a 3-year interval (IARC Working Group on Cervical Cancer, 1986). More recently some medical professionals have suggested the application of a 3-year interval to women in certain age groups and a 5-year interval to women in others (Sasieni et al., 2003). Given the divergence of medical opinion on screening intervals it may be appropriate for the programme to now review its position on this issue.

Recommendations:
Review the possibility of introducing a three-year rather than a five-year recall. This includes identifying operational issues to be addressed and additional costs that would be incurred. The practice of recalling women for a smear test one year after their first 'programme' smear may not be considered necessary in this context.

If a three-year interval is not introduced, senior management should identify ways of reassuring women about the five-year interval. This might include incorporating reasons for a five-year screening interval in the information literature. The programme may also wish to consider further communication and discussion about the issue with its registered smeartakers in formal training or through the programme newsletter. An interactive website discussion could also be considered in this context.

6.5 Referral for further tests

Women who attended for repeat smears (Subgroup 4) and colposcopy (Subgroup 5) raised a number of issues relating to referral for further tests. More than half of the women interviewed in Subgroup 4 were dissatisfied with the letter they received advising them to attend for a repeat smear test. They expressed the view that the letter did not contain enough information about what had been found in their first smear test and why they were being advised to have the test repeated. A couple of women also suggested that the letter specify whom they may contact for more information about their individual result.

Women who attended for colposcopy did not have issues with the letter they received (which advised that they contact their smeartaker for information about their result). However, a few women were dissatisfied with the information about colposcopy provided by their smeartaker stating that it was not detailed enough. Most women were satisfied with the information they received from their smeartaker at the time of referral and identified this as an important factor in their overall experience of colposcopy. From interviews it was apparent that most women who had biopsies or treatment on their first visit to the clinic had not been prepared for anything other than an examination. This suggests that some smeartakers are either unaware of the practice at the colposcopy clinic to perform procedures during a first visit or unaware of the need to relay this information to women when they are referred for colposcopy.

Recommendations:
Amend the results letters advising women to have a repeat smear test in three months or six months. Include more detail on the result of the first test, specifically what was found and why women are being advised to have the test repeated. Specify that women may contact their smeartaker if they require further information or have any questions relating to their individual result.

Ensure that smeartakers are aware of the information to relay to women when they are referred for colposcopy. This should include the possibility that a biopsy or treatment will be conducted during their first visit to the clinic.

6.6 The Register

As noted in Chapter 2, a decision was made in the ICSP office in April 2000 to reduce the number of data sources for the population register from four to one in order to reduce the incidence of duplication of records. Since then the database at the Department of Social and Family Affairs has been the only data source for the programme. While use of one data source for the register may be more efficient administratively it is possible that it may result in some women from the target population being omitted. For example, some women who are neither in paid employment nor claiming unemployment benefits may not be on the Department's database and hence may be excluded from the ICSP register. Further, given that the ICSP has since developed a mechanism within its computer system to merge any duplicate records that appear on the population register the programme may now be in a better

position to use more than one data source.

BreastCheck by contrast has used a number of different data sources for its population register since its establishment. These include primarily VHI, BUPA, General Medical Services Payments Board and the Department of Social and Family Affairs. At BreastCheck it has been found that the use of a number of different data sources has resulted in the inclusion of a significant number of women in the register who otherwise may have been omitted. Further, information from databases at VHI, BUPA and the General Medical Services Payments Boards has been found to be particularly accurate as clients renew on a yearly basis (Personal Communication, BreastCheck).

Recommendation:
Reassess the use of one data source for the programme register to ensure that some women in the target population are not excluded. In this context, access to databases at VHI, BUPA and the General Medical Services Payments Board may be particularly useful.

6.7 Social Inclusion

It is recognised internationally that women's participation in screening is influenced by socio-economic circumstances. For example, women from low-income groups have been identified as being less likely to participate in cervical screening programmes than women from higher income groups (Adams et al., 2003). Women from ethnic minorities have been identified as having lower rates of participation in screening programmes relative to ethnic majorities (International Society of Nurses in Cancer Care, 2001). There is also general acknowledgement that women over 50 years of age are less likely to attend for cervical screening than women under 50 (Van Til et al., 2003, Miedema and Tatemichi, 2003). Therefore it is important for the ICSP to consider the issue of social inclusion and particularly in relation to any future expansion of the programme. This essentially means ensuring that screening is as accessible as possible to women regardless of factors such as age, economic position, ethnic background and marital status.

Currently the ICSP records women's age on the programme database but does not seek or record other socio-economic data such as, marital status, ethnic affiliation, whether or not women have a medical card. This means that the ICSP does not have a general profile of who is participating in the programme and who is not, hence, the programme is not currently in a position to monitor levels of participation along socio-economic lines. Specific groups of women who are under-represented in terms of attendance for screening may remain unidentified.

Further, facilitating equal access to screening for all women may require that the programme undertake promotional and other activities targeted at specific groups of women. Such activities may be necessary to facilitate greater awareness and understanding of the programme among particular groups. Targeted activities may also be used to identify and address the particular barriers to screening faced by specific groups of women.

Recommendations:
Senior Management to identify socio-economic information of most relevance to the programme. Issues relating to the collection of socio-economic information would also have to be clarified such as identifying ways of facilitating women to volunteer this information and ensuring women understand why such information is being sought and how it will be used.

Record socio-economic data for individual women on the programme database. This information should be collated and used for on-going monitoring and analysis of the programme and in particular of the relationship between attendance/non-attendance for screening and socio-economic factors.

On the basis of findings from on-going monitoring identify groups that are under-represented in the

programme. Undertake promotional and other activities targeted at those groups to facilitate their attendance for screening.

6.8 Contact Details for Registered Smeartakers

The omission of contact details for registered smeartakers was an issue for women in three of the subgroups interviewed. Most of the women interviewed in the Recently Contacted Group had made an appointment for a test by the time they were contacted for interview. Nonetheless, a number of women in the group indicated that they were unsure when they received the invitation letter where to go for the smear test. In this context women suggested that more information be provided about registered smeartakers to avoid confusion around this.

Lack of information and unwillingness to use their own GP were highlighted as factors contributing to a delay in making an appointment or in non-attendance for screening for women in Subgroups 1 and 2. Some women who did not wish to attend their GP for a smear test were also reluctant to contact their GP for information about other smeartakers. Other women simply did not understand where information about smeartakers could be obtained.

Recommendations:
Specify in the main text of the invitation letter that women may contact the information line for details of smeartakers registered with the programme,

and/or

Attach a list of registered smeartakers to the invitation letter. Given that there are over three hundred registered smeartakers in the Mid-Western Health Board region it may be preferable to divide the list into three parts - one part for each county – and to attach a list for the county in which the woman is living. A similar practice could be applied if the programme is expanded to national level.

6.9 Rural Access to Smeartakers

Many women and from all subgroups expressed a preference to have smear tests taken by female smeartakers rather than male smeartakers. It was not surprising therefore that when invited for a free smear test with the ICSP many women had sought a female smeartaker. A number of women also spoke of their preference to have their smear test done by a person who was unknown to them and/or who did not live in their local community. This preference was most commonly expressed by women living in rural areas.

A few women in rural areas spoke of the difficulty they had in accessing a smeartaker in an area convenient to them. It is not surprising that women's preference to have a female smeartaker and/or a smeartaker who is not from their local community may be more easily met in urban areas. It did appear, however, that difficulty in accessing a smeartaker was not uniform for women in all rural areas in the Mid-Western Health Board region. For example, it appeared from interviews that this is more problematic for women in rural parts of Clare, and in particular east Clare, than it is for women in rural parts of Limerick. This requires further investigation.

Recommendation:
ICSP to investigate if access to registered smeartakers in all rural areas within the Mid-Western Health Board region is adequate taking into account many women's preference for a female smeartaker and/or a smeartaker other than their local GP. Accessibility of registered smeartakers to women in all rural areas would be a significant issue to consider prior to expansion of the programme.

6.10 Information Leaflet 'About Your Smear Test'

Women who attended for free screening in a timely fashion (Subgroup 3) were more likely to recall receiving an information leaflet than those who attended late (Subgroup 2) or did not attend at all (Subgroup 1). Nonetheless, very few women overall had read the leaflet in detail or could recall its contents. This may be due in part to the length of time that had passed between receiving the leaflet and being interviewed. It is interesting to note, however, that the majority of women in the Recently Contacted group, who had received the information leaflet one week prior to their interview, also had difficulty recalling the contents.

Recommendations:
Edit the information leaflet 'About Your Smear Test'. Produce a shorter version of the leaflet that covers fewer issues and is more concise. Specify in the revised leaflet that women may access the website or contact the ICSP office if they have any questions or require further information.

The current version of 'About Your Smear Test' could be sent to women who request additional information and/or do not have access to the internet. Alternatively an up-dated version of that leaflet could be produced, perhaps in booklet form, outlining additional relevant information such as frequently asked questions.

Consider producing information leaflets that cater to women with low literacy levels and women who do not have English as a first language. This is particularly significant if the programme is expanded to national level.

Conclusion

Women who participated in the evaluation were generally very positive about the Irish Cervical Screening Programme. They expressed their appreciation that the screening programme was available to them, that the programme contacted them with an invitation to attend for screening and that the service was offered free of charge. In the course of interviews women spoke positively about their contact with the programme and in particular the letters sent from the ICSP office and their experience of attendance for smear tests.

During interviews and focus groups women described the anxiety that attendance for screening can cause. In this context they emphasised the importance of minimizing delays in the screening process particularly with regard to returning results for smear tests, repeat smears and tests performed at the colposcopy clinic. Some women were critical of the length of time taken to obtain appointments for colposcopy and of the length of time they were kept waiting at the clinic on the day of their appointment.

Access to registered smeartakers was an issue for some women in rural areas. The review identified shortcomings in current practice relating to consent. The review also identified the limitations of use of only one data source for the programme's population register. The benefits of use of socio-economic data to monitor attendance for screening in the target population were highlighted.

The vast majority of women who attended for screening said that they would attend for another smear test when next contacted by programme. However, many women expressed a preference to be screened more frequently than every five years and suggested that the ICSP reduce its screening interval. While clearly identifying aspects of the programme where improvements could be made, women who participated in the review were generally very positive in their attitude to the programme overall.

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Appendix A

Date: [system_date]

[fullname]
[address1]
[address2]
[address3]
[address4]
[address5]

CSP ID: [csp_id]
PPS No : [PPSN]

Dear Ms. [Surname],

You are invited to make an appointment for a **free smear test** within the next **2 weeks**. This free service is offered to all women aged between 25 and 60 years, in the Mid-Western Health Board, every 5 years.

Regular cervical smear tests are important as they can easily find early changes in the cervical cells at the neck of the womb. The earlier a change is found the easier it is to treat successfully.

To have this free test please make an appointment with a Smeartaker registered with the Programme (i.e. Family Doctor or Practice Nurse). It is important that you take this letter with you when going for your smear.

You should get the result from your Smeartaker. If you need more information or further care you should return to this Smeartaker.

Please read the enclosed leaflet and take advantage of this opportunity to take care of your health.

Yours sincerely,

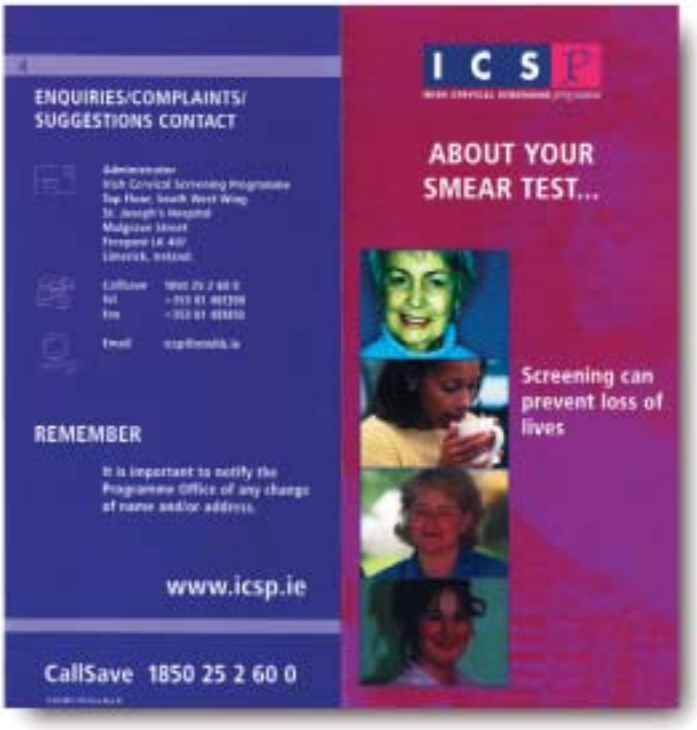
[name]
[title]
If you have any queries please telephone the Programme's Information Line: CallSave / 850 252 669
[tel]

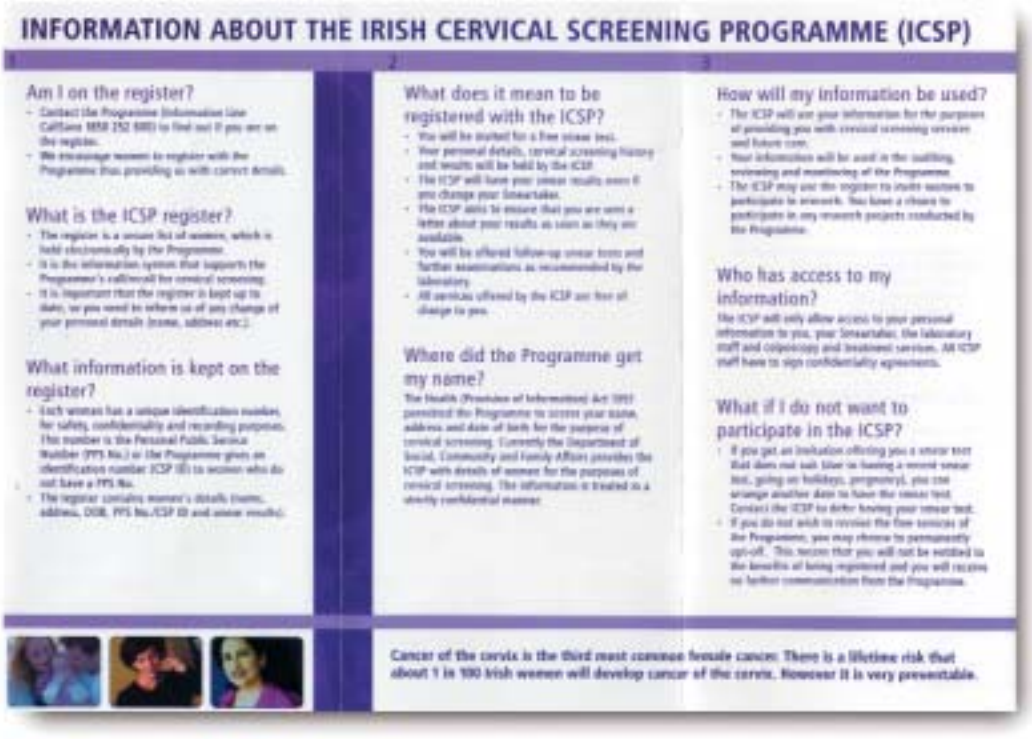
Appendix B


How do I get my result?
I'm afraid of what the result might mean...
How can I reduce my risk of getting cervical cancer?
Screening can prevent loss of lives
ICSP
About the Irish Cervical Screening Programme (ICSP)...
Screening can prevent loss of lives
CallSave 1850 25 2 60 0

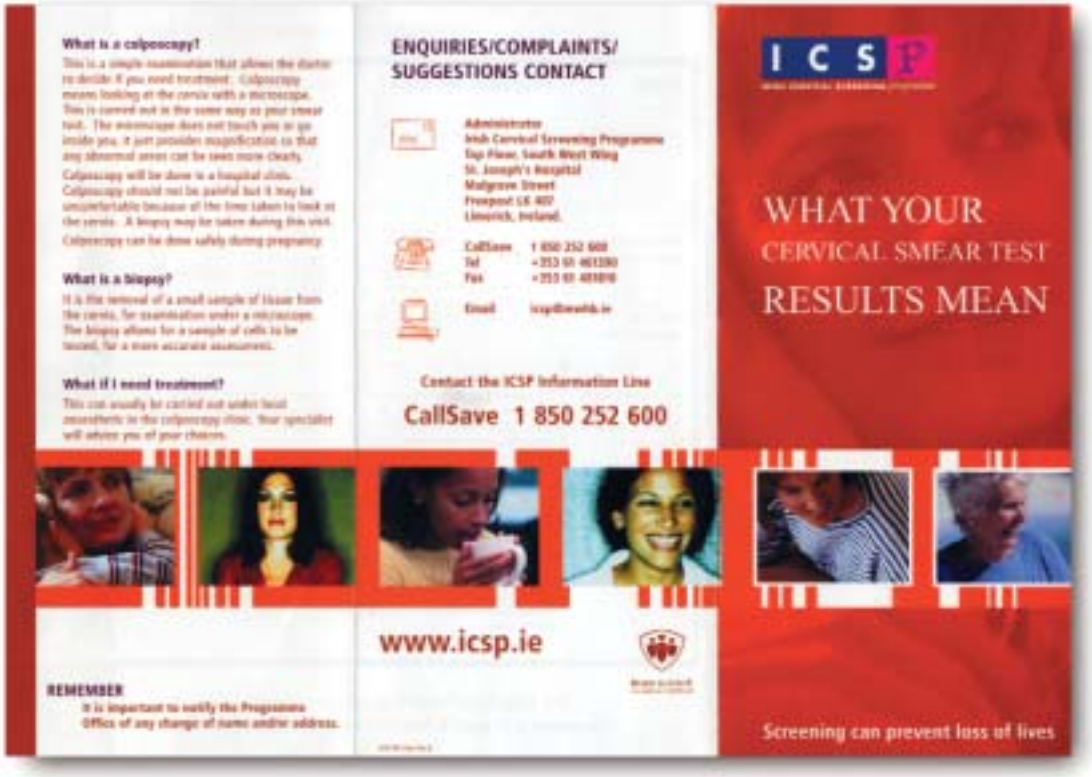

NOW ITS TIME TO LOOK AFTER YOURSELF...
What is a cervical smear test?
Who should have a cervical smear test?
How is a cervical smear test done?
When is the best time to have your cervical smear test?
What if I've had a hysterectomy?
Where can I have a cervical smear test?
How often will I be offered the test?
The majority of smear tests are normal. Even a result that is not normal is unlikely to mean you have cancer. It may be an infection or minor cell changes.

Appendix B *Continued*

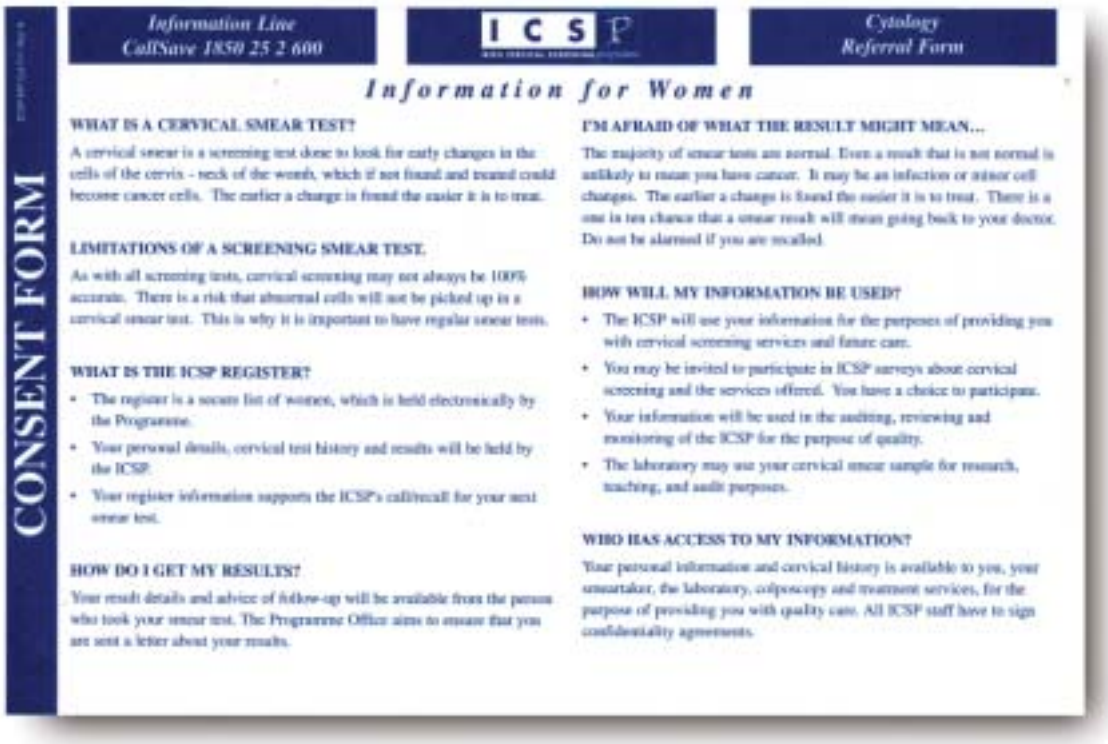




Appendix C


What is a colposcopy?
What is a biopsy?
What if I need treatment?
ENQUIRIES/COMPLAINTS/
SUGGESTIONS CONTACT
Contact the ICSP Information Line
CallSave 1 850 252 600
www.icsp.ie
REMEMBER
ICSP
WHAT YOUR
CERVICAL SMEAR TEST
RESULTS MEAN
Screening can prevent loss of lives
What your results mean
Not normal results
When should I have my next smear?
The best time to have your smear test is
screening can prevent loss of lives
Result
What does this mean?
What should I do?
The majority of smear results are normal.
The earlier a change is found the easier it is to treat.

Appendix D



CONSENT FORM

Information Line
CallSave 1850 25 2 600

ICSP

Cytology
Referral Form

Information for Women

WHAT IS A CERVICAL SMEAR TEST?

A cervical smear is a screening test done to look for early changes in the cells of the cervix - neck of the womb, which if not found and treated could become cancer cells. The earlier a change is found the easier it is to treat.

LIMITATIONS OF A SCREENING SMEAR TEST.

As with all screening tests, cervical screening may not always be 100% accurate. There is a risk that abnormal cells will not be picked up in a cervical smear test. This is why it is important to have regular smear tests.

WHAT IS THE ICSP REGISTER?

- The register is a secure list of women, which is held electronically by the Programme.
- Your personal details, cervical test history and results will be held by the ICSP.
- Your register information supports the ICSP's call/recall for your next smear test.

HOW DO I GET MY RESULTS?

Your result details and advice of follow-up will be available from the person who took your smear test. The Programme Office aims to ensure that you are sent a letter about your results.

I'M AFRAID OF WHAT THE RESULT MIGHT MEAN...

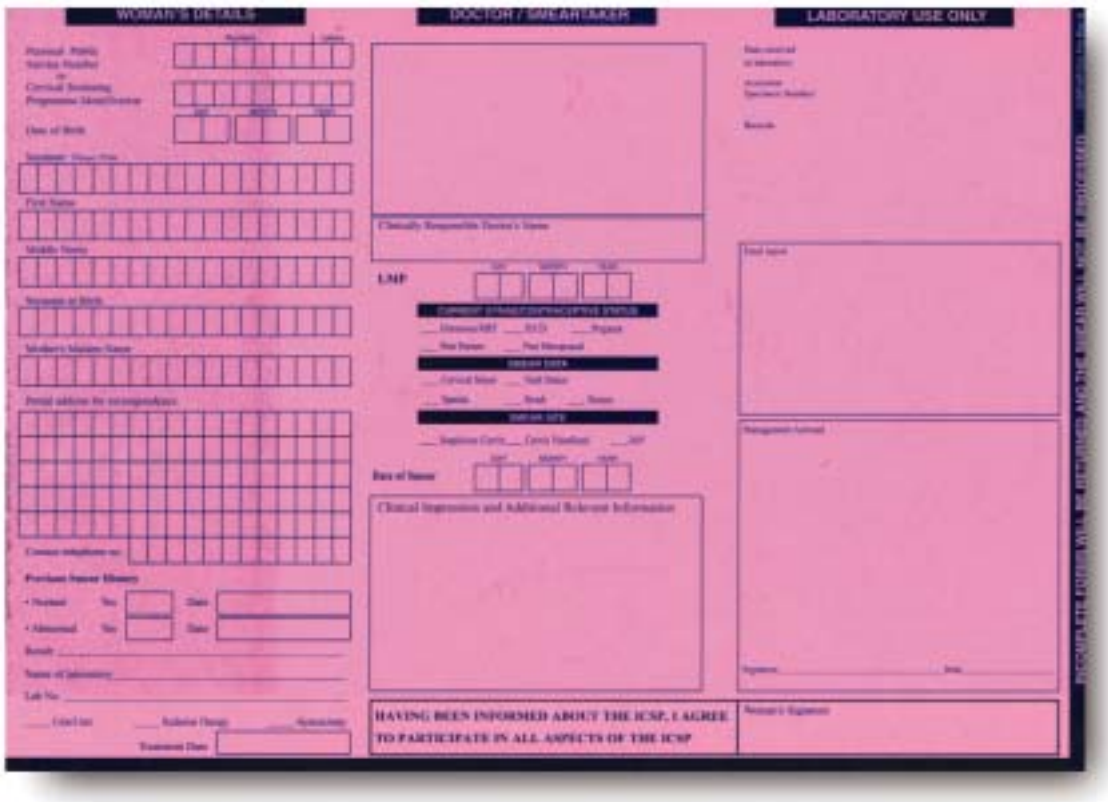
The majority of smear tests are normal. Even a result that is not normal is unlikely to mean you have cancer. It may be an infection or minor cell changes. The earlier a change is found the easier it is to treat. There is a one in ten chance that a smear result will mean going back to your doctor. Do not be alarmed if you are recalled.

HOW WILL MY INFORMATION BE USED?

- The ICSP will use your information for the purposes of providing you with cervical screening services and future care.
- You may be invited to participate in ICSP surveys about cervical screening and the services offered. You have a choice to participate.
- Your information will be used in the auditing, reviewing and monitoring of the ICSP for the purpose of quality.
- The laboratory may use your cervical smear sample for research, teaching, and audit purposes.

WHO HAS ACCESS TO MY INFORMATION?

Your personal information and cervical history is available to you, your smeartaker, the laboratory, colposcopy and treatment services, for the purpose of providing you with quality care. All ICSP staff have to sign confidentiality agreements.



WOMAN'S DETAILS

DOCTOR / SMEARTAKER

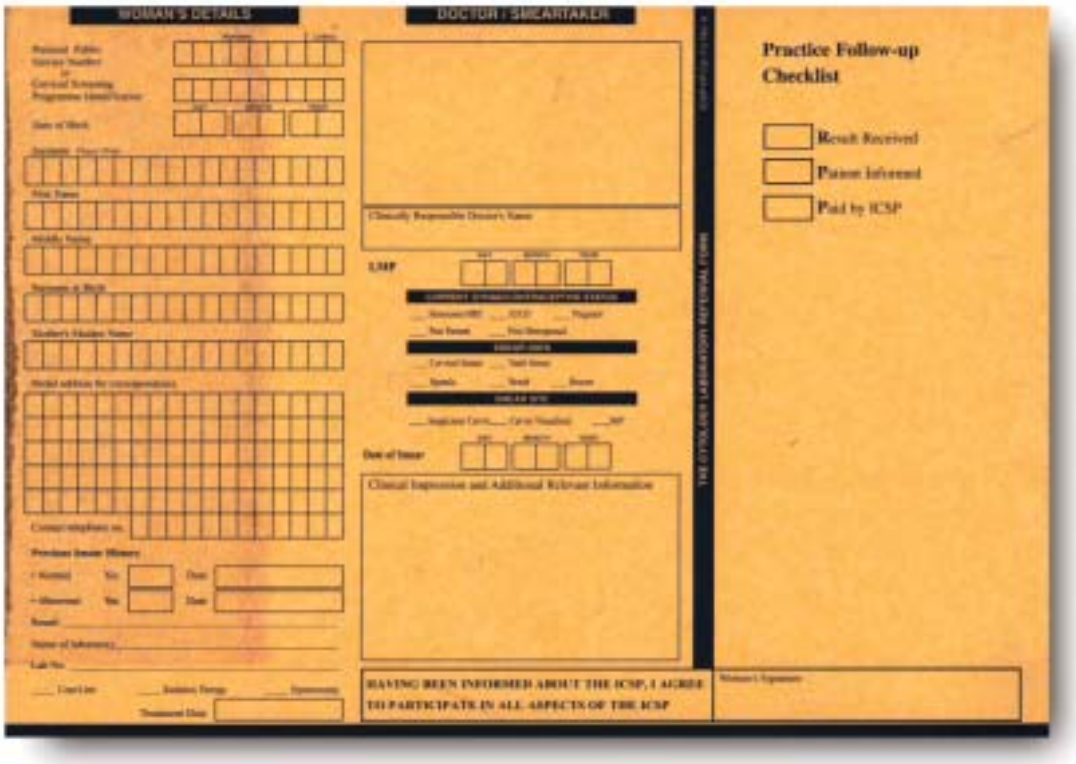
LABORATORY USE ONLY

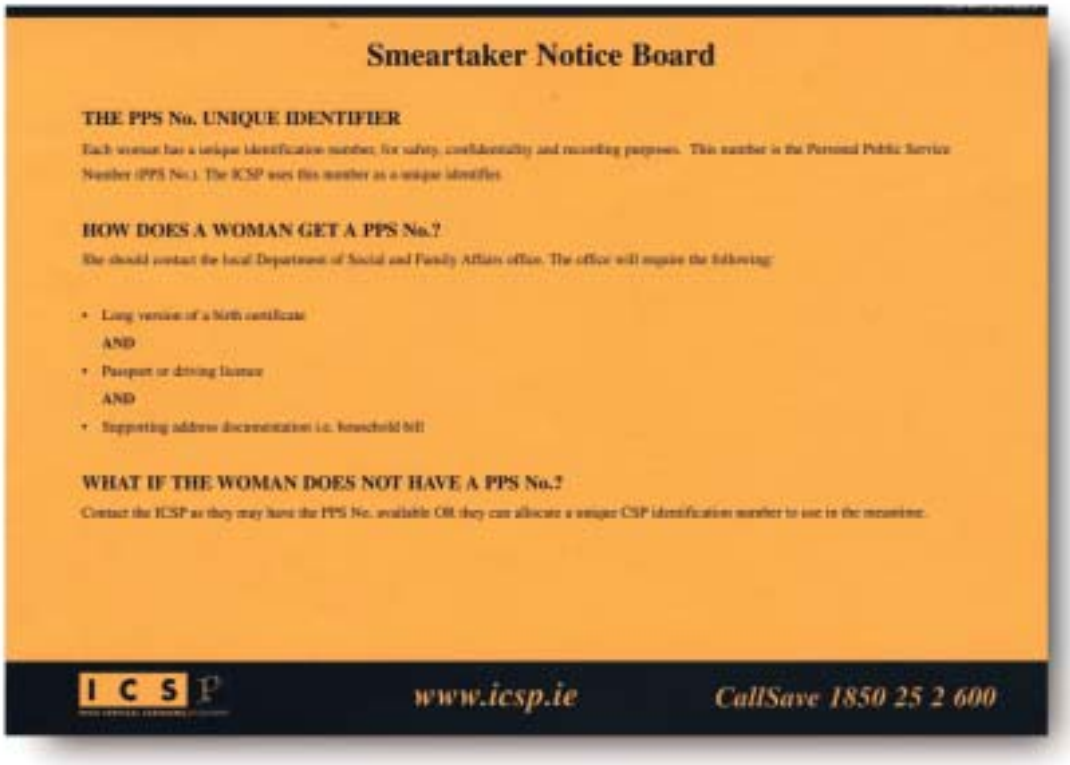
LMP

Clinical Impression and Additional Relevant Information

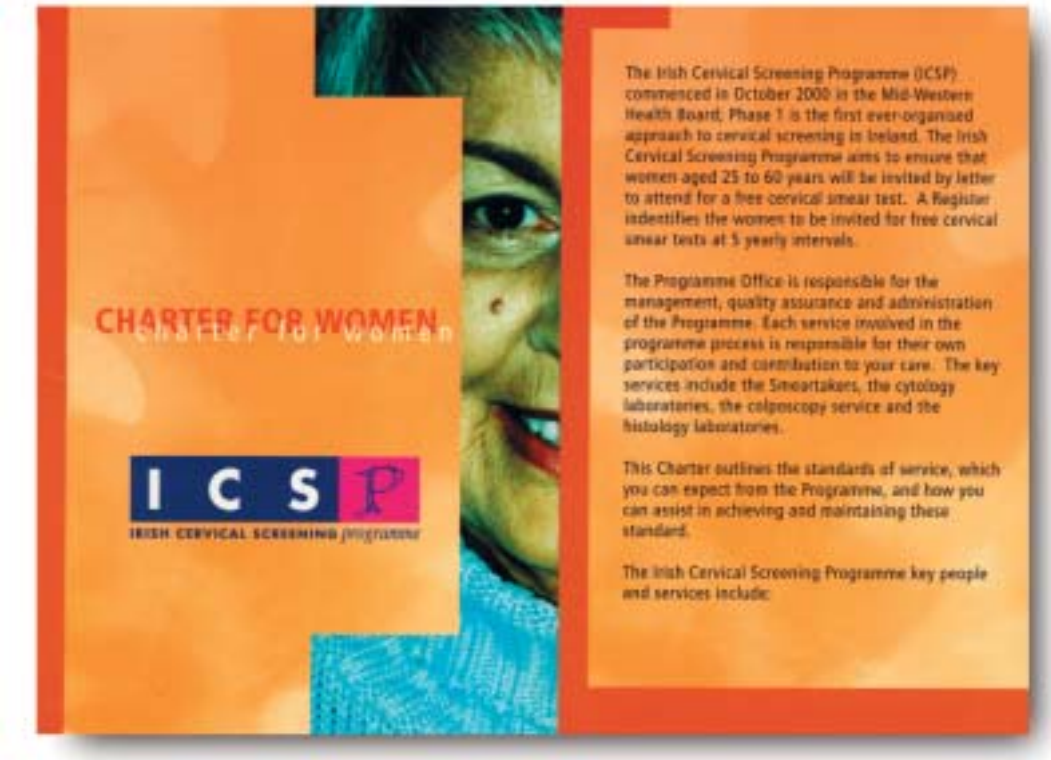
HAVING BEEN INFORMED ABOUT THE ICSP, I AGREE TO PARTICIPATE IN ALL ASPECTS OF THE ICSP

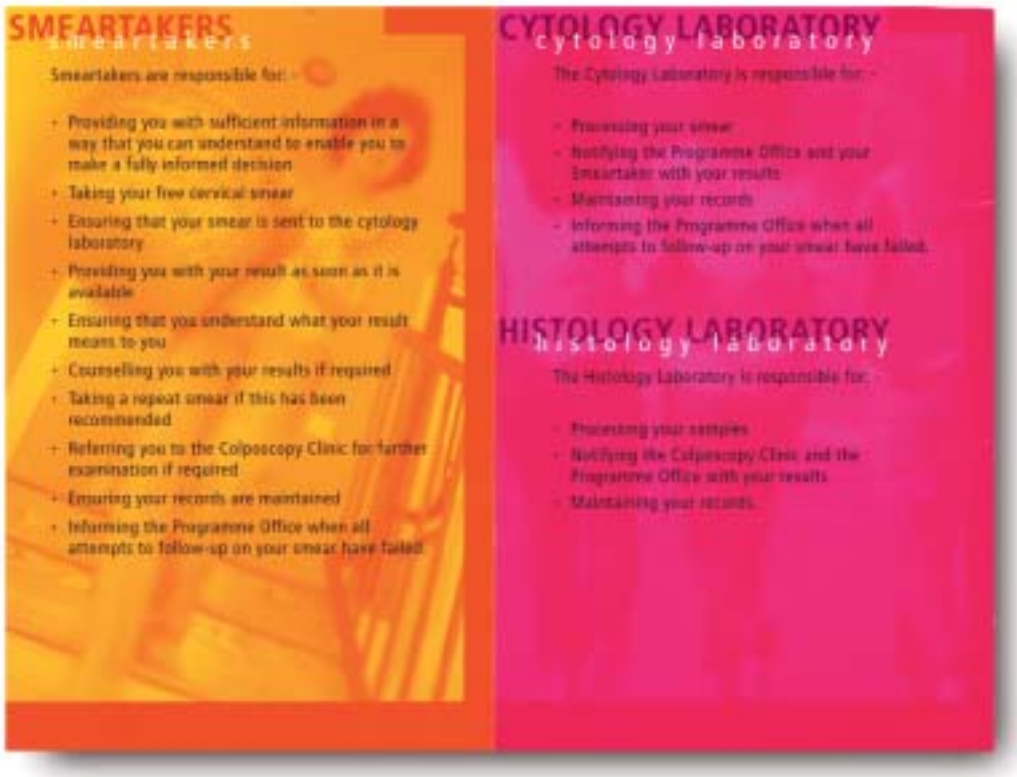
Appendix D *Continued*





Appendix E


CHARTER FOR WOMEN
charter for women
ICS P
IRISH CERVICAL SCREENING programme
The Irish Cervical Screening Programme (ICSP) commenced in October 2000 in the Mid-Western Health Board. Phase 1 is the first ever-organised approach to cervical screening in Ireland. The Irish Cervical Screening Programme aims to ensure that women aged 25 to 60 years will be invited by letter to attend for a free cervical smear test. A Register identifies the women to be invited for free cervical smear tests at 5 yearly intervals.
The Programme Office is responsible for the management, quality assurance and administration of the Programme. Each service involved in the programme process is responsible for their own participation and contribution to your care. The key services include the Smeartakers, the cytology laboratories, the colposcopy service and the histology laboratories.
This Charter outlines the standards of service, which you can expect from the Programme, and how you can assist in achieving and maintaining these standard.
The Irish Cervical Screening Programme key people and services include:


SMEARTAKERS
smeartakers
Smeartakers are responsible for: -
- Providing you with sufficient information in a way that you can understand to enable you to make a fully informed decision
- Taking your free cervical smear
- Ensuring that your smear is sent to the cytology laboratory
- Providing you with your result as soon as it is available
- Ensuring that you understand what your result means to you
- Counselling you with your results if required
- Taking a repeat smear if this has been recommended
- Referring you to the Colposcopy Clinic for further examination if required
- Ensuring your records are maintained
- Informing the Programme Office when all attempts to follow-up on your smear have failed
CYTOLOGY LABORATORY
cytology laboratory
The Cytology Laboratory is responsible for: -
- Processing your smear
- Notifying the Programme Office and your Smeartaker with your results
- Maintaining your records
- Informing the Programme Office when all attempts to follow-up on your smear have failed.
HISTOLOGY LABORATORY
histology laboratory
The Histology Laboratory is responsible for:
- Processing your samples
- Notifying the Colposcopy Clinic and the Programme Office with your results
- Maintaining your records


WOMEN
women
Women are responsible for: -
- Registering with the Irish Cervical Screening Programme
- Informing your chosen Smeartaker in advance if you have special needs (interpreter services and access requirements)
- Responding to your invitation to attend for a free smear test by making an appointment with your chosen Smeartaker (check that they are registered with the Programme) for your cervical screening
- Reading the information sent to you by the Programme Office
- Attending for your free smear test
- Ensuring that you understand your smear result
- Informing your Smeartaker if you require further information to understand what your result means to you
- Following your Smeartakers recommendations
- Attending for repeat smear tests as recommended
- Attending for further examination (colposcopy) as recommended
- Informing us if you change your name and/or address
- Informing us if you do not wish to have your smear test
- Providing us with feedback
GLOSSARY
glossary
Colposcope
Colposcopy means looking at the cervix with a microscope. This is carried out in the same way as your smear test. The microscope does not touch you or go inside you, it just provides magnification so that any abnormal areas can be seen more clearly.
Cytology
The study of cells in a laboratory using a microscope
Histology
The study of body tissues in a laboratory using a microscope
Informed Consent
Obtaining signed consent after giving information about the smear test, the test accuracy, the register and the programme in general in a manner which they can understand.
Programme Office
This is the single central point of co-ordination for the Irish Cervical Screening Programme
Register
This is a computerised record of women in the eligible age group (25 - 60 years).
Smeartaker
A doctor or nurse registered with the Irish Cervical Screening Programme
CONTACT DETAILS
contact details
Irish Cervical Screening Programme,
Top Floor, South West Wing, St. Joseph's Hospital, Mulgrave Street,
Freepost LK 407, Limerick.
LoCall: 1850 25 2 60 0
Tel: 061 461390
Fax: 061 401870
Email: icsp@hse.ie
THE PROGRAMME OFFICE
the programme office
The Irish Cervical Screening Programme Office is responsible for: -
- Establishing the quality standard for the Irish Cervical Screening Programme
- Working in partnership with the key people involved (Women, Smeartakers, cytology laboratories, histology laboratories and Colposcopy Clinics) to continually improve the service
- Establishing a Register of women aged between 25 and 60 years, for the purposes of cervical screening
- Updating your records on our information system with results from the laboratories (cytology and histology) and Colposcopy Clinics
- Ensuring that you and all women who have registered with the Programme are invited to attend for cervical screening
- Ensuring that you are sent letters to invite you for your free smear test at the appropriate times
- Notifying you about your results
- Following up on women who are not in compliance with the recommendations for repeat smears and/or further examinations.
COLPOSCOPY CLINIC
colposcopy clinic
The Colposcopy Clinic is responsible for: -
- Ensuring that you are sent an appointment for further examination following referral
- Providing you with sufficient information about the examination in a way that you can understand
- Carrying out the colposcopy examination
- Ensuring you receive advice following colposcopy
- Ensuring that your sample is sent to the histology laboratory
- Providing you with your result as soon as it is available
- Ensuring that you understand what your result means to you
- Following up on your result
- Repeating the examination if necessary
- Providing you with information on colposcopy treatments if required
- Referring you for further examination or treatment if required
- Ensuring your records are maintained
- Informing your nominated General Practitioner about your colposcopy, any recommendations and follow-up advice
- Informing the Programme Office when all attempts to follow-up on your colposcopy have failed.


WOMEN'S RIGHTS...
women's rights
Right to be Fully Informed
• Before making a choice or giving consent, you have the right to the information that is needed to make an informed choice or give informed consent including:
(a) An explanation of the procedure; and
(b) The explanation of the options available, including an assessment of the expected risks, limitations, side effects, benefits and costs of each option; and
(c) Advice of the estimated time within which the results will be provided.
• You have the right to honest and accurate answers to questions relating to cervical screening.
Right to Make an Informed Choice and Give Informed Consent
• Cervical Screening may be provided only if you make an informed choice and give informed consent.
• You must be capable of making an informed choice and giving informed consent.
• You have the right to refuse services and to withdraw consent to services.
• You have the right to express a preference as to who will provide your services and have that preference met where practicable.
Right to Effective Communication
• You have the right to effective communication in a form, language, and manner that enables you to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.
• You have the right to an environment, which enables and encourages communication.
Right to be Treated with Respect
• You have the right to be treated with respect.
• You have the right to a service that takes into account the values, and beliefs of different cultural, religious, social, and ethnic groups.
• You have the right to have your privacy respected.
Right to Support
• You have the right to have a support person of your choice present.
Right to Freedom from Discrimination, Coercion, Harassment, and Exploitation
• You have the right to be free from discrimination, coercion, harassment, and sexual, financial or other exploitation.
Right to Dignity and Independence
• You have the right to have services provided in a manner that respects your dignity and independence.
Right to Confidentiality
• Your confidentiality will always be respected.
Right to Services of an Appropriate Standard
• You have the right to have services provided with reasonable care and skill.
• You have the right to have services provided that comply with the Irish Cervical Screening Programme standards.
• You have the right to have services provided in a manner consistent with your needs.
Right to Provide Feedback
• If you are satisfied...
If you are pleased or satisfied with the Irish Cervical Screening Programme, please let us know as it gives us the opportunity to recognise excellent service by our staff.
• If you are dissatisfied...
If you are dissatisfied with any aspect of the delivery of our services or our policies, please tell us, as we want to identify any problems or areas where changes could be made so that we can improve our services. If you feel you have grounds for complaint about our services, please let us know. This will help us to put things right for you or to prevent the same thing happening to others. We take your complaints seriously and have a formal complaints process so we can respond to you quickly.
Enquiries/Complaints/Suggestions Contact:
Administrator, Irish Cervical Screening Programme,
Top Floor, South West Wing, St. Joseph's Hospital,
Mulgrave Street, Freepost LK 407, Limerick, Ireland.
CallSave: 1850 25 2 60 0
Tel: +353 61 461390
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ICSP
IRISH CERVICAL SCREENING programme

The **Women's** Health Council
Comhairle Shláinte na mBan