



appendices

APPENDICES

CHARTER FOR WOMEN



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 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

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

The Histology Laboratory is responsible for: -

- Processing your samples
- Notifying the Colposcopy Clinic and the Programme Office with your results
- Maintaining your records.



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.

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.

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

Colposcopy	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 to women 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

Irish Cervical Screening Programme,
Top Floor, South West Wing, St. Joseph's Hospital, Mulgrave Street,
Freeport LK 407, Limerick.

CallSave: 1850 25 2 60 0
Tel: 061 461390
Fax: 061 481810
Email: icsp@mwfb.ie

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.

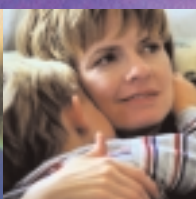
Right to Provide Feedback

- 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
Fax: +353 61 481810
Email: icsp@mwhb.ie



QUALITY POLICY STATEMENT OF THE IRISH CERVICAL SCREENING PROGRAMME



The purpose of our organisation is to support the provision of a high quality cervical screening service to women. Our organisation has as its core goal the continuous reduction of the incidence of and mortality from invasive cervical cancer.

We fully recognise that the success of our organisation depends on meeting the needs of women participating in the programme and therefore we aspire to quality at all levels of the ICSP.

The management of the ICSP is fully committed to this policy and has nominated a management representative to co-ordinate and monitor all activities in relation to ISO 9001/2000 as it relates to the ICSP coordination office, and Programme service providers according to their professional body accreditation and best practice standards.

The following relates specifically to the ICSP Coordination Office responsibilities.

We will endeavour to:

- Continually update the skills of all our employees with planned training and development programmes.
- Continually improve on the service we provide based on internal quality results and feedback from women.
- Promote continuous improvement methods and technologies used by all Programme service providers in line with international best practice.
- Monitor the quality performance of our service providers and assist them to improve their quality performance.

Marian O'Reilly

Dr Marian O'Reilly
Acting Director, Mid-Western Health Board
20 August 2003



ICSP-Q:Quality Policy:REV B:2003



IRISH CERVICAL SCREENING PROGRAMME - INFORMATION PACK

NATIONAL EXPERT ADVISORY GROUP, DECEMBER 1999 GUIDELINES

OBJECTIVE 1	STANDARD	METHOD	MEASUREMENT
All relevant information about the woman to be recorded on request form.	95% request forms fully completed.	Standardised request forms. Duplicate of form to be retained and logged in surgery recording system. Blocked lettering throughout the form and using tick boxes where possible. Training for Smeartakers about the importance of each item of information requested.	Total number of request forms received minus those returned with incomplete or illegible data.

OBJECTIVE 2	STANDARD	METHOD	MEASUREMENT
Effective sampling of the cervix.	90% smears considered "adequate" by laboratory, according to agreed standards in each participating laboratory.	Standardised method of smear taking, with standard equipment and technique (see appendix). Training for Smeartakers, which is subject itself to assessment and recording. Record if smear was difficult on patient's chart.	Six monthly report to each Smeartaker of smears sent, with breakdown of adequate/inadequate smears.

OBJECTIVE 3	STANDARD	METHOD	MEASUREMENT
Woman understands and is comfortable with the procedure.	<5% complaints to programme organisers.	Training of Smeartaker as above. Random consumer surveys-recording general impressions. Asking direct questions about each step of the process.	Review of complaint to central programme every three months. Consumer Surveys.



IRISH CERVICAL SCREENING PROGRAMME - INFORMATION PACK

OBJECTIVE 4	STANDARD	METHOD	MEASUREMENT
All smears taken recorded in full in woman's medical records and practice smear register.	100% all smears and smear reports recorded.	Training. All practices should have a register of smears, and a "suspended" register. Suspended = Those who have to defer their smear (e.g. pregnancy, illness etc).	Audit of register and sample patient records by practice nurse/doctor every year.
OBJECTIVE 5	STANDARD	METHOD	MEASUREMENT
Standardised delivery system of sample to laboratory.	>95% of samples to arrive intact.	Secure slide holder. Padded envelopes. Log date of posting in surgery. Laboratory to log date of receipt.	Audit of lost/broken slides using surgery and laboratory records.
OBJECTIVE 6	STANDARD	METHOD	MEASUREMENT
Each woman should fully understand the significance of her result, without generating unnecessary anxiety.	No standards have yet been developed.	Only "no abnormality detected" results can be discussed by phone, providing the doctor/nurse knows the woman and her level of understanding. Face to face consultation, for all other results, allowing adequate time for questions and explanations. Training as above.	Random surveys of patient satisfaction as per objective 3.
OBJECTIVE 7	STANDARD	METHOD	MEASUREMENT
All smears taken to be cross-checked with results received.	100% of smears to be reported and results seen and recorded by Smeartaker.	Practice register should be cross-checked against results received weekly/monthly.	Clinical audit.

IRISH CERVICAL SCREENING PROGRAMME - INFORMATION PACK

OBJECTIVE 8	STANDARD	METHOD	MEASUREMENT
Appropriate action taken for those with other than normal smears.	Action plan arranged and logged in patient's chart, practice register and central register for all "other than normal" smear results within 2 weeks of receipt of result by the doctor.	Other than normal results to be dealt with as per recommendations in Laboratory QA document.	Audit of results and action taken each quarter.

OBJECTIVE 9	STANDARD	METHOD	MEASUREMENT
Prompt referral for colposcopy.	90% of women to be referred to colposcopy clinic within 4 weeks of receipt of a smear result that is not normal. 100% to be referred within 8 weeks.	An administrative system within the practice to generate referrals, i.e., practice referral. Rapid access to Colposcopy Clinic. Priority given to those with high grade lesions.	Record date of result received and referral sent.

OBJECTIVE 10	STANDARD	METHOD	MEASUREMENT
Adequate medical and psychological support for women while undergoing colposcopy surveillance and treatment.	>90% of reports about treatment to be sent to the woman's Doctor within 2 weeks of her having attended the Colposcopy Clinic.	See Colposcopy QA document.	Audit of date of OPD visit and date of report reaching the surgery.

OBJECTIVE 11	STANDARD	METHOD	MEASUREMENT
Failsafe Procedure: Smartakers will ensure that all repeat/not normal results are followed up as directed.	80% of smears which need repeating, are done within 4 months of the repeat date and 95% within 6 months.	Cross-check repeat smears performed quarterly with the recall list from Central Register Office. Notify register of those women who have failed to respond to invitation to repeat smear or who are unsuitable for repeat (pregnant, ill, etc.).	See Failsafe Procedure Document.



General Cervical Screening Programme Terminology

Abnormal Smear	Smears showing cervical cell abnormalities called dyskaryosis, but not benign changes such as infection or hormonal influences.
Adequate Smear	A smear that the laboratory, on examination, deems to contain adequate squamous (outer) and endocervical (inner) cells for screening purposes.
Biopsy	Removal of a sample of tissue from the body, for examination under a microscope.
Cervical Intraepithelial Neoplasia (CIN)	Cervical Intraepithelial Neoplasia is not cancer. It is a histological (examination of a tissue biopsy) diagnosis. It describes varying degrees of abnormality of the cells within and confined to the epithelium (cervical lining or 'skin'). There are three grades of CIN: I, II, III.
Cervical Cancer	Cancer of the cervix. Cancer cells have spread beyond the natural basement membrane boundary of the cervical skin. The very great majority (circa 95%) of cervical cancer is of the squamous (skin) variety.
Cervical Cytology	A microscope examination of cells scraped from the surface of the skin of the cervix.
Cervical Ectropian	Occurs when the inside of the cervical cells (columnar) come out on to the surface of the cervix. A red roughened appearing area on the cervix. A normal hormonally influenced change.
Cervical Smear Test	A screening test where a sample of the surface cells are taken from the skin of the cervix or vagina/vault, preserved immediately and sent to the laboratory for microscope examination.
Colposcope	A binocular like instrument on a tall stand which allows the specialist (called a colposcopist) to examine the cervix & vagina.
Colposcopy	A low power magnification, light illuminated diagnostic examination of the cervix and vagina looking for abnormalities of the tissue.
Cone Biopsy	A surgical removal of a cone-shaped section of the cervix to remove abnormal cells. The procedure is diagnostic but may be curative as well.
Coverage	The number, percentage, or proportion of women screening by a screening programme.
Cytology	The study of cells. The cells are examined under a microscope for signs of abnormality.
Diagnostic Smear	A smear taken outside of the normal screening interval as a part of the diagnostic assessment of a woman who has signs and symptoms which might indicate cervical cancer.
Dyskaryosis	Term used in cytology to describe nuclear abnormalities in cervical cells. Dyskaryotic cells are classified as mild, moderate and severe and correlate with CIN I, CIN II and CIN III.
Effectiveness	The extent to which an established screening programme meets its defined objectives.

Efficacy	Is the extent to which an intervention/programme produces a beneficial result under ideal conditions. Ideally the determination of efficacy is based on the results of a randomised controlled trial.
Efficiency	Is the measure of the result achieved in terms of money, resources and time expended on a procedure of known efficacy and effectiveness.
Eligible For Screening	Those women aged 25-60 yrs for whom the ICSP recommends and funds screening according to national policy.
Failsafe	The action taken by the clinically responsible doctor to ensure a smear result is appropriately followed-up. Laboratories and ICSP support primary care failsafe as well.
False Negative	The screening test reports a negative (normal) finding although the person being screened has the condition.
False Positive	The screening test reports a positive (abnormal) finding although the person being screened does not have the condition.
Histology	The microscopic study of the structure and composition of body tissue.
HPV	Human Papilloma Virus a group of wart viruses, of which a high proportion are sexually transmitted.
Hysterectomy	The surgical removal of the uterus (womb) – called total if it includes the cervix or subtotal / partial if the cervix is not entirely removed.
Incidence (rate)	The number of new cases of a disease or happening that occurs in a given period in a specified population.
Informed Consent	The giving of all the necessary information by a provider to fully explain the procedure and choices to the deciding person on whom the procedure will be performed. For the ICSP informed consent covers the smear, participation in the ICSP, limitations of screening, results, associated tests and treatment.
Intraepithelial Neoplasia	Abnormal cells in the epithelium of the lower genital track. See Dyskaryosis, VAIN, VIN.
Liquid Base Cytology	The placement of harvested cervical cells into a special transport solution for sending to the laboratory, where the slide is made ready for examination.
LLETZ	Large Loop Excision of the Transformation Zone is a diagnostic &/or treatment method to remove the cervical areas of abnormality or concern.
Local Destructive Techniques	Laser, cryocautery, cold coagulation and radical diathermy are treatment methods to destroy the cervical areas of abnormality or concern.
Morbidity	The number of cases of a specific disease during a defined period of time in a given population.
Mortality	The number of deaths from a specified disease during a defined period of time in a given population.



terminology

Negative predictive value	The proportion of test-negative women who do not have precancerous cervical abnormality. It is a measure of the likelihood that someone with a negative test is actually disease free.
Normal Smear	A smear result, which is reported to be within normal limits.
Opportunistic Smear	A smear done when the opportunity presents irrespective of the woman's ICSP eligibility or screening requirements. Refer self refer.
PAP Test	This is another name for a 'smear test'. Papanicolau was the man who invented the process of staining cells on a slide in preparation for examination under a microscope.
Policy	National cervical screening policy as defined in the 'Report of the Department of Health Cervical Screening Committee' 1996 document, guides the national requirements for the ICSP. A statement of intended direction developed for the purpose of guiding present and future actions and decisions.
Positive predictive value	Is the proportion of test-positive women who are truly positive. It can be considered a measure of the likelihood that a woman with a positive test truly has a precancerous cervical abnormality.
Prevalence (rate)	May refer to have precancerous cervical abnormality or cancer. It is the total number of women who have a cervical precancerous lesion or cancer at a particular time (or during a particular period) divided by the population at risk of having a cervical precancerous lesion or cancer at this point in time or midway through the period.
Screening Programme	An organized approach of managing a population of people to be screened to determine the likelihood of the disease, or not, that is being screened for.
Self Referral Smear	When a woman presents to an ICSP registered smearer and at the smearer's discretion has her first smear test for entry into the ICSP without having a prior invitation to do so.
Sensitivity	The proportion of truly diseased persons in a screened population who are identified as diseased by a screening test. It is a measure of the probability that any given case will be identified by the test. A test with 100% sensitivity will detect every subject with the disease state among those tested. The sensitivity of the cervical smear test is defined as the proportion of women with cervical intraepithelial neoplasia (CIN) whose smear tests are interpreted as positive.
Short Interval Screening	When a smear is done before a smear is due according to the woman's screening requirements and national policy. Refer opportunistic.
Smear Episode	The entire smear process includes the taking of a smear, informing the woman of the result, providing support and counseling as required and referring for follow-up as appropriate.
Smeartaker Provider	A doctor or nurse who meets all the ICSP registration requirements.
SNOMED Codes	Systematised Nomenclature of Medicine – a coding system for recording histological diagnosis.

Specificity	Is the proportion of truly non-diseased persons who are so identified by the screening test. It is a measure of the probability of correctly identifying a non-diseased person with a screening test. A test with 100% specificity will correctly identify as normal all those subjects who do not have the disease being assessed. The specificity of the cervical smear test is defined as the proportion of women without CIN whose smear tests are interpreted as negative.
Squamo-Columnar Junction (SCJ)	The area of the cervix where the squamous cells covering the outside skin of the cervix (ectocervical), meets the columnar cells, which line the inner cervical canal (endocervical). It is this area that is most at risk of change and so requires to be smeared.
Squamous	A type of multi-layers cells, which line the vagina and outer layer of the cervix.
Squamous Cell Carcinoma / Cancer	The most common form of cervical cancer.
Standard	Is a minimum requirement upon which performance can be measured.
Systematic Screening	Where the target population is invited to have a cervical smear at regular intervals.
Transformation Zone	The region of the cervix where the columnar cells of the inner cervix have or are changing to outer squamous cells. The process of change is call metaplasia. It is the area most at risk of abnormal change.
Unsatisfactory / Inadequate Smear	A smear that cannot be safely read and reported by the laboratory. Causes include obscuring by blood or exudates, insufficient cells, destruction of cells due to air-drying or mishandling, broken slide.
VAIN	Vaginal intraepithelial neoplasia.
Validity	The accuracy of the screening test in distinguishing those who do have the disease being searched for and those who do not, in the asymptomatic population.
Vault Smear	A smear taken from the top of the vagina after a total hysterectomy.
VIN	Vulval intraepithelial neoplasia.



Register Specific Terminology List

Active	Meets ICSP criteria for inclusion to all ICSP services, as required, in accordance with policy and screening history.
Call	The ICSP request to a women to attend for her first smear OR subsequent routine smear having previous had an ICSP recorded normal smear result and management recommendation (P2, R2 or R3) Refer recall.
Eligible	Women aged 25 to 60 years inclusive, or women over 60 yrs who have no previous smear history, with a residential address within the ICSP defined area and attending an ICSP registered smeartaker.
Defer	The delaying of a smear call or recall date to another future date due to temporary reasons: woman pregnant; under other medical treatment; unavailable; on holiday; smear taken but not CSR received etc.
Failsafe	The action taken by the ICSP following the non-response of a woman &/or her clinically responsible doctor to a recall for a recommended repeat smear after a previous 'not normal' smear result &/or management recommendation. (R4/5/6/7/8)
Inactive	A temporary change in the woman's ICSP participation status due to the client being under age; smear date deferred until another date; no longer residing within the ICSP defined area; referred to colposcopy; lost to follow-up; overseas. In the event that a smear is received the woman's status will be amended as appropriate. Inactive women will not be invited or recalled for screening.
Opt-off	For whatever reason the woman has personally chosen to withhold or withdraw her consent for any future participation in the ICSP.
Participation	An eligible women who in attending a ICSP registered smeartaker consents for the purpose of having a Programme paid smear, registration onto the ICSP register for the receipt of call, recall, result, reminder, failsafe letters and future cervical screening care.
Permanently Inactive	A permanent change to the woman's Register eligibility status due to woman's choice (opt-off); client being over age; confirmed death; confirmed total benign hysterectomy; confirmed sex change. No further Programme contact will be made. Women can choose to re-enter the Programme.
Payee	A ICSP registered GP to whom payment is made for eligible smears and in accordance with the ICSP laboratory screening recommendations.
Recall	An ICSP written request to a woman to have a repeat smear following the receipt of a previous 'not normal' management recommendation. (R4/5/6/7/8)



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