

## APPENDIX 1

### GLOSSARY OF MEDICAL DEFINITIONS

#### for the assistance of lay people

(To be read in the context of this report)

#### ABNORMAL BLEEDING

- (a) Post-coital – after intercourse.
- (b) Intermenstrual – between menstrual periods.
- (c) Postmenopause – after menopause.
- (d) Haemorrhage

**ADENOCARCINOMA** Cancer of glandular epithelium (lining tissue).

**AETIOLOGY (etiology)** The cause of disease.

**ATYPIA** Deviation from the normal or typical state.

**BENIGN** Not harmful (or malignant) when applied to tumours or growths.

**BIOPSY** Removal and examination of tissue from the body.

**CANCER (Ca.)** A malignant cellular tumour.

**CANCER PRECURSOR** Precancerous.

**CC** Consultation (or Cancer) Clinic.

**CERVIX (Cx.)** The neck of the uterus.

**C.I.S.** Carcinoma in situ is a lesion located on the surface lining (epithelium). It is known as a cancer precursor or preinvasive disease which may invade or spread from the original surface location.

**CLINICAL** Matters relating to the health and care of patients.

**COITUS** Sexual intercourse.

**COLPOSCOPY** The procedure of studying epithelial surfaces by means of a magnifying instrument (colposcope).

**CONE BIOPSY, CONIZATION** The removal of a cone of tissue from the mouth of the cervix, designed to encompass the whole area of abnormality detected, in order to provide tissue for examination. Also used for treatment.

**CONSERVATIVE TREATMENT** (in gynaecology) Management of a patient which is designed to conserve as much of her genital tract as possible and/or to avoid more radical surgical procedures.

**CRYOTHERAPY (CRYOSURGERY)** Destruction of a lesion by the application of extreme cold.

**CYTOLOGY** The study of cells.

- (a) positive cytology (smear) – an indicator of the presence of disease.
- (b) negative cytology (smear) – an indicator of the absence of disease.

**CYTOPATHOLOGY** The science of the study of diseased cells.

**DIAGNOSIS** Identification of disease.

**DIAGNOSTIC TEST** A test used when a patient presents with symptoms, or following a positive screening test, to determine the exact nature of the disease.

**DIATHERMY** High frequency electrical current used to destroy lesions.

**DIFFERENTIATION** The process by which abnormal or immature cells are distinguished by individual characteristics which are attributes of normal cell types.

**DYSPAREUNIA** Difficult or painful coitus (sexual intercourse) in women.

**DXR** Deep x-ray therapy.

**EMBOLI** Material, most commonly blood clots, obstructing the circulation, but which may be other substances such as air or fragments of tumour.

**ENDOMETRIUM** The specialised lining of the uterus which is shed at menstruation.

**EPIDEMIOLOGY** The study of the distribution and causes of diseases and events in populations and the application of this study to the control of health problems.

**EPITHELIUM** The cellular covering of internal and external surfaces of the body.

**EROSION** A shallow or superficial ulceration.

**EUA** Examination under anaesthetic.

**EXFOLIATION** Shedding of surface epithelial cells.

**HISTOLOGY** The study of the minute structure, composition and function of tissues.

**HISTOPATHOLOGY** The science of the study of diseased tissues.

**HYPERTROPHY** Increase in volume of a tissue or organ caused by enlargement of existing cells.

**HYSTERECTOMY** Surgical removal of the uterus. This may be through an abdominal incision – abdominal hysterectomy, or through the vagina – vaginal hysterectomy.

**INCIDENCE** The number of new cases of a specified disease which are diagnosed or reported during a defined period of time in a given population.

**INCOMPLETE EXCISION**

- (a) intentionally removing only part of a lesion by surgery or biopsy.
- (b) Unintentionally removing only part of a lesion that has been confirmed either by histological report or by positive cytology (smear tests) following its removal.

**INTRACAVITARY RADIATION** Radiation treatment provided by sources inside the uterus.

**LASER THERAPY** A device used in localised surgery to destroy a lesion by application of an intense beam of light.

**LIBIDO** Sexual drive.

**MALIGNANCY** A condition which if unchecked usually develops into serious illness and may cause premature death. When applied to tumours, may be described as an uncontrolled growth of cells.

**MANAGEMENT** The complete care of a patient including advice, information, treatment and follow-up treatment or monitoring of a condition.

**MENORRHAGIA** Excessive amount and/or duration of menstruation.

**MENSTRUATION** Period, or regular monthly bleeding.

**METASTASIS** Disease which has spread from one organ to another (often known as 'secondaries' in cancer).

**METASTASIZE** (verb of metastasis)

**MICROINVASION** Carcinoma (of the cervix) which has invaded underlying tissue from 1-5mm. Known as preclinical invasive disease or Stage 1A carcinoma.

**MYOMETRIUM** The middle layer of the wall of the uterus, composed of smooth muscle.

**NATURAL HISTORY** The stages of progression, remission and the final outcome of a disease which has not been treated.

**NEONATE** Newborn infant.

**OCCULT CANCER** Hidden disease which is not obvious on examination of the patient.

**PAPANICOLAOU TEST (SMEAR)** A simple painless test used to detect CIS or cancer of the genital tract. Often called Pap smear or test.

**PATHOLOGY** The study of the essential nature of disease, particularly changes in body tissues and organs which are caused by disease.

**'PILL' CERVIX** A microscopic change seen in the glands of the cervix in some women treated with oral contraceptives.

**PRECANCEROUS** Disease which has not invaded tissue outside the original site. In the context of this Inquiry, it refers to changes confined to the epithelium or lining tissue.

**PRECLINICAL** Before disease becomes recognisable by symptoms or appearance.

**PREMALIGNANT DISORDER** Precancerous.

**PREVALENCE** The number of cases of a specified disease in a given population at a designated time.

**PROGNOSIS** Forecast of the probable course and outcome of a disease including prospects of recovery.

**RADICAL TREATMENT OR SURGERY** Aims to eradicate the lesion or cure the disease by a method which requires very extensive treatment.

**RADIOTHERAPY** The use of x-rays or radiation from radioactive substances in the treatment of cancer

**RADIUM** A highly radioactive material used in the treatment of malignant diseases.

**RECTUM** The terminal portion of large intestine leading to the anus through which faeces are eliminated.

**RECURRENCE** The return of symptoms after a period during which they have disappeared or reduced in intensity, or the reappearance of overt disease.

**SCREENING** The routine search for unsuspected disease (or medical investigation which does not arise from a patient's request for advice for a specific complaint).

**SCREENING TESTS** Tests which sort apparently well women who probably have a disease from those who probably do not. Screening is an initial examination only; those with a positive test require a more definitive diagnostic examination.

**SENSITIVITY OF A TEST** The proportion of all people who have the disease who are correctly identified as such by the test.

**SMEAR TEST** See Papanicolaou test

**SPECIFICITY OF A TEST** The proportion of all people who do not have the disease who are correctly identified as such by the test.

**STAGING** When invasive cancer of the genital tract is diagnosed the stage or the extent of the disease is established. This enables a decision to be made as to the best method of treatment. There are international criteria for staging known as FIGO classification (1976 modification). Prior to 1976 Stage Ia included all cases not detectable clinically, ie, microinvasive and occult invasive cancers.

**Pre-invasive carcinoma**

Stage 0                      Carcinoma in situ, intraepithelial carcinoma. Cases of Stage 0 should not be included in any therapeutic statistics for invasive carcinoma.

**Invasive carcinoma**

Stage I                      Carcinoma strictly confined to the cervix (extension to the corpus should be disregarded).

## CERVICAL CANCER REPORT

Stage	Ia	Microinvasive carcinoma (early stromal invasion) less than 5 mm.
	Ib	All other cases of Stage I occult cancer should be marked "occ".
	II	The carcinoma extends beyond the cervix, but has not extended on to the pelvic wall. The carcinoma involves the vagina, but not the lower third.
	IIa	No obvious parametrial involvement.
	IIb	Obvious parametrial involvement.
	III	The carcinoma has extended on to the pelvic wall. On rectal examination there is no cancer-free space between the tumour and the pelvic wall. The tumour involves the lower third of the vagina. All cases with a hydronephrosis or non-functioning kidney should be included, unless they are known to be due to another cause.
	IIIa	No extension to the pelvic wall.
	IIIb	Extension on to the pelvic wall and/or hydronephrosis or non-functioning kidney.
	IV	The carcinoma has extended beyond the true pelvis or has clinically involved the mucosa of the bladder or rectum. A bullous oedema as such does not permit a case to be allotted to Stage IV.
	IVa	Spread of the growth to adjacent organs.
	IVb	Spread to distant organs.

**STROMA** The tissue beneath the surface layer (epithelium) of an organ.

**SQUAMOCOLUMNAR JUNCTION** The site at which the epithelium (or skin) covering the outside of the cervix meets the glandular lining of the cervical canal.

**SQUAMOUS CARCINOMA** Cancer arising in the squamous epithelium identifiable microscopically by its scaly or plate-like appearance.

**TEACHING HOSPITAL** A hospital which has attached to it, doctors or other health professionals whose duties include both treatment of patients and teaching students. Patients entering a teaching hospital may be invited to take part in teaching procedures.

**TREATMENT/THERAPY** Management or care of a patient in combating a disease or disorder.

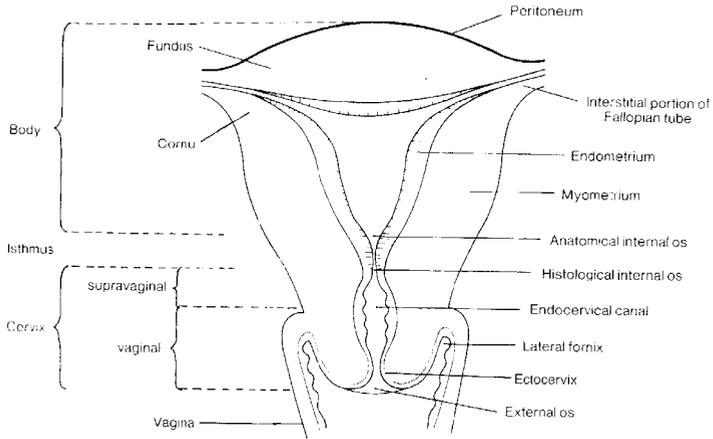
**UTERUS (WOMB)** The hollow muscular organ in which the fertilized egg normally becomes embedded and in which the developing embryo/fetus is nourished. The uterus is a pear-shaped organ consisting of the body of the uterus (or corpus) which narrows to form the cervix or neck of the womb. The uterine or Fallopian tubes enter the uterus at its upper outer aspect, and at its lower end the cervix opens into the vagina or front passage.

**URETER** The tube through which urine passes from the kidney to the bladder.

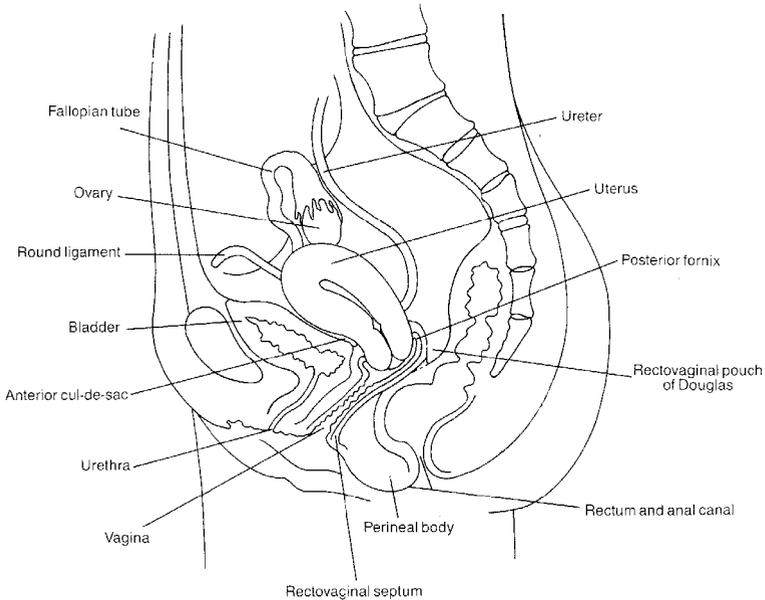
**VAGINAL VAULT** The upper part of the vaginal cavity into which the cervix projects.

**WEDGE BIOPSY** A surgically-excised, wedge-shaped piece of tissue (larger than the punch biopsy) taken for examination by the pathologist.

**Coronal (transverse) section of the uterus, cervix and upper vagina**



**Sagittal (longitudinal) section of the pelvis**



## APPENDIX 2

### PROCEDURE FOR THE INQUIRY

Following publication of an article in the June 1987 issue of 'Metro' magazine, the then Minister of Health, the Honourable Michael Bassett, appointed District Court Judge Silvia Cartwright as a Committee of Inquiry to inquire into the treatment of cervical cancer at National Women's Hospital and into other related matters.

Judge Cartwright was appointed by warrant dated 10 June 1987, and the various matters into which she was directed to inquire were extensively set forth in nine Terms of Reference. The majority of those Terms of Reference contained multiple issues specific to National Women's Hospital in Auckland, but also having a wider application to the medical profession at large. In particular, the importance of patients' rights and their protection was emphasised in a number of the Terms of Reference.

The Minister of Health, in his press release accompanying the Judge's warrant, had himself stressed that "the rights of the patient must be fully upheld".

In accordance with usual practice, legal counsel was appointed to assist Judge Cartwright in the running of the Inquiry. The tasks of such counsel included advising the Commission on its powers, the scope of its Inquiry and generally as to the legal aspects of the Commission's work; assembling and briefing evidence and other material for presentation to the Commission; assisting individuals and organisations in the preparation and presentation of their statements; attending the hearings of the Commission and examining and cross-examining witnesses.

A preliminary hearing was held on 18 June 1987. At this, a number of lawyers instructed by interested bodies or people attended and sought party status on behalf of their clients. Other individuals and groups also attended and sought party status for themselves or their organisations. Several important matters were raised and argued at this hearing, including the question of medical privilege and to what extent relevant patient files could be made available to the Inquiry.

Other matters raised were amendments to some of the Terms of Reference already promulgated by the Minister, the identity of expert witnesses to be called before the Inquiry, the logistics of organising the hearings, the production of exhibits and the procedures to be adopted.

Judge Cartwright indicated that, as far as possible, the Inquiry would be conducted in an inquisitorial manner, with counsel assisting the Commission calling the evidence and conducting the examination and cross-examination of witnesses, but that where appropriate, cross-examination by counsel or parties would be allowed on application. Briefs of evidence and submissions were asked to be submitted in writing at least 24 hours beforehand.

Judge Cartwright also ruled that certain amendments to the Terms of Reference sought by counsel and parties would be recommended to the Minister by her, but that others would not.

On the question of any medical privilege which may or may not have applied to patient files, and the patient confidentiality which must necessarily be preserved, Her Honour considered the various arguments presented and reserved her decision until 25 June 1987, when a second preliminary hearing was scheduled to take place.

At the second hearing on 25 June 1987, Judge Cartwright announced that party status was

granted to all those who had sought it, that she was informed by the Minister that amendments to the Terms of Reference as recommended by her would be made by way of gazette notice and that, by way of further gazette notice, disclosure of medical information contained in the files of any present or former patient of National Women's Hospital would be made to her, counsel assisting or her medical adviser, Dr Paul, if that information were required for all or any of the purposes of the Commission of Inquiry.

The Judge further addressed the purpose for which she would need to have access to relevant patient files, viz that certain Terms of Reference required her to consider the adequacy or otherwise of patients' treatment at National Women's Hospital and whether there was a need to urgently contact any patient for follow-up treatment.

The decision to seek access to patient files by Ministerial gazette notice was taken on the grounds of expediency, because of the urgent nature of Term of Reference Three. Nevertheless, every effort was also made to write to patients, former patients or their next of kin, where it was considered that those patients may be at risk under Terms of Reference One and Three.

Public notices were placed in the newspapers on three occasions to notify the public of hearing dates, to invite interested persons and organisations to make submissions in writing and, where anybody so wished, to attend the hearings in support of those submissions and to give evidence. Most importantly, however, these public notices also stated that provision would be made for people to give evidence in private and that such evidence would be treated confidentially. These public notices also appeared in Maori and Samoan.

Judge Cartwright herself, also announced at a preliminary stage of the hearings, that she was anxious to hear from patients and that contact with them was to be her province alone.

As a result, the Commission received many letters from patients, former patients or their families. In addition, many of the patients listed by the late Dr McIndoe as "Group 2" patients were personally written to by Judge Cartwright. A member of the Commission's staff who had specialist training in counselling skills, was appointed to deal with patient queries and to co-ordinate private interviews with Judge Cartwright.

In all, nearly 1200 patient files were requested and received from National Women's Hospital, as well as a small number from Auckland Hospital, where patients had undergone associated treatment there.

At a further preliminary hearing, Judge Cartwright heard arguments from parties and counsel on whether access to patient files should be allowed them and their medical advisers for the purposes of examination and cross-examination of witnesses at the Inquiry. Although argument opposing this was presented by counsel for the Auckland Hospital Board, Judge Cartwright placed a wide interpretation upon the phrase "for all or any of the purposes of the Inquiry" contained in the Ministerial gazette notice and ruled that patients, parties, their counsel and/or medical advisers should have access to information in the patient files for the purpose of preparing examination and cross-examination. The signing of an appropriate undertaking not to use the information obtained in this way for any purpose other than that of the Inquiry would be required in each case. No appeal was taken from this ruling.

After the preliminary hearings and before the hearing of the evidence began, a research assistant was employed to put information retrieval systems into place, as it was clear that the Inquiry would receive a great deal of documentation in the form of exhibits, patient files, submissions and other.

Three medical advisers were retained to assist and advise Judge Cartwright and counsel assisting. Their names were announced at a special press conference on 8 July 1987.

## CERVICAL CANCER REPORT

The three medical advisers were Professor E V MacKay, Professor of Obstetrics and Gynaecology, University of Queensland, Dr Charlotte Paul, Epidemiologist, University of Otago Medical School, and Dr Linda Holloway, Pathologist, of the University of Otago Wellington School of Medicine.

The public hearings of the Inquiry commenced on 3 August 1987 and were finally completed on 27 January 1988. There were a total number of 68 sitting days. Evidence was heard from 59 witnesses, including medical experts from the USA, UK, Australia, Japan and Norway. Two further medical experts, who were familiar with Dr Green's writings and his work with CIS during the relevant period, were interviewed before Judge Cartwright in Sydney and counsel and parties were afforded the prior opportunity of notifying matters which they wanted put to these experts. The evidence of one witness was submitted at the hearings in written form only, as no cross-examination of him was required. In addition, twelve patients or former patients (including "Ruth" from the 'Metro' article) and two relations of patients gave evidence 'in camera', ie in the absence of the public and the media, at the hearings.

In total, 5657 pages of transcript of evidence were recorded at the public hearings and were made available to counsel, parties and the media on a daily basis. At the conclusion of the evidence Judge Cartwright heard three days of closing submissions from counsel and parties. In addition, written submissions had been received from 31 individuals or organisations and were available to counsel and parties for their perusal.

The scope of the evidence and submissions was wide-ranging and included theoretical expert opinion on treatment standards pertaining in the 1960s, the 1970s and at the present time; evidence in respect of the treatment actually given to patients and former patients of the National Women's Hospital during those periods of time; the development of the doctrine of informed consent during those periods of time; the efficacy of smear testing both as a diagnostic technique and as a national screening procedure; and the cultural implications of gynaecological treatment for different ethnic groups.

During the course of the hearings, no application to cross-examine witnesses by parties or counsel for parties was refused, but the requirement that the right to cross-examine would only be granted upon application did avoid unnecessary or extraneous cross-examination being conducted by persons either not represented or not having party status.

In addition to the evidence given at the public and 'in camera' hearings, Judge Cartwright heard evidence privately from a further 70 patients, four nurses, two general practitioners and the daughter of a former special duties sister. These private interviews were taken on oath and were recorded. All patients who gave evidence either privately or 'in camera' were afforded the opportunity to discuss their patient files with Professor MacKay, if they so wished. Transcripts of the private interviews were made available to counsel and parties but were edited so as to remove any identifying details. All patients were referred to throughout by their Hospital File number only and/or the initial of their surname.

446 exhibits were formally produced during the course of the hearings, including 226 patients' files. In addition, many other documents were submitted or referred to the Inquiry.

During the course of the Inquiry, the Commission's medical advisers carried out an analysis and review of patient files received by the Inquiry and as the results of this came to hand, Judge Cartwright reported on an interim basis to the Minister of Health pursuant to Term of Reference Three.

There were six interim reports in total and they included the names of 123 patients deemed to require tracing and follow-up treatment.

From the time of the first preliminary hearing on 18 June 1987, until the last day of public hearings on 27 January 1988, the news media maintained a constant and vigilant presence.

At times there were television and film cameras present as well as journalists. Because the forum was that of a public inquiry and not a court of law, the Commission had no power to exclude the media, but Judge Cartwright set ground rules at an early stage which required members of the media to be as unobtrusive and as sensitive as possible. Her Honour warned the media about the necessity of preserving strict confidentiality in respect of both patients' names and also the names of doctors who were not already named in the 'Metro' article, were not parties to the Inquiry or were not appearing as witnesses before the Inquiry.

However, on three later occasions during the course of the Inquiry Her Honour had occasion to warn all concerned that there should be no public comment made through the news media concerning any matter which was before the Inquiry, until such time as she had finally reported to the Minister of Health.

In early 1988, it became necessary to recall two witnesses because of unforeseen issues which had been raised during the hearings. These concerned the taking of vaginal smears of neonates, the collection of fetal cervixes and clinical photography of anaesthetised women. One of these witnesses was recalled on the basis that he had commented outside the Inquiry on the neonatal smear issue. The other was recalled to give further necessary information to the Inquiry.

At the conclusion of the public hearings on 27 January 1988, Judge Cartwright thanked all those who had participated in what had proved to be a lengthy and difficult Inquiry. In particular, she paid tribute to the patients who had come forward to help the Inquiry and whose health, treatment and rights were central to the issues facing her.