**ACT Cervical Screening Register Data Dictionary for Record Linkage**

ACT Cervical Screening Program

# Background

The ACT Cervical Screening Register (CSR or the Register) was established in 1995 in accordance with the ACT Public Health Act Regulations 2000 and is managed by the ACT Cervical Screening Program, Health Improvement Branch, ACT Health.

The ACT Cervical Screening Program (ACT CSP or the Program) is a jointly-funded Commonwealth/State and Territory initiative under the National Healthcare Agreement. It aims to implement an organised approach to cervical screening in the ACT. The ACT CSP is part of the National Cervical Screening Program and operates in line with national cervical screening policies and guidelines.

# Coverage

The CSR was established in 1995 as a centralised and confidential database of cervical cancer test results for ACT women. Within the CSR a person's cervical cancer tests are linked to a single cervical screening record, providing a comprehensive picture of their cervical screening history. Cervical cancer tests collected include cytology tests (such as Pap tests), histology tests (such as biopsy results and the results of hysterectomies), and human papilloma virus (HPV) tests. Data on cervical cancer tests and histology tests are available from 29 July 1996. Data on HPV tests are available from 2006.

Colposcopy results are not yet routinely reported to the CSR. The data does not include results for smears taken at other gynaecological sites (such as vault or vaginal smears). Some coding of non-cervical sites (such as the uterus) may be included in the results of hysterectomies.

The CSR collects cervical test data for women residing in the ACT at the time of their test from pathological laboratories in the ACT and some interstate laboratories. All laboratories carrying out cervical cancer pathology testing in the ACT are required to forward the results of tests performed on NSW women to the CSR under the ACT Public Health Regulations 2000 (Section 3). Interstate laboratories may forward the data of ACT women to the CSR on a voluntary basis.

Data collected by the CSR includes personal identifiers and demographic information, the date and result of any cervical cancer tests, information about the provider performing the test, and information about the laboratory that processed it. Information is supplied electronically from pathology laboratories typically within 30 days of the sample being processed.

The Register operates as an ‘opt-off’ register; that is, all tests relating to cervical pathology will be included on the Register unless the woman who has the test explicitly opts off. A woman who has a cervical cancer test may elect to have their identifying particulars withheld from the CSR at the time of the test, or may withdraw their details from the Register at a later time. In this situation, the woman's test results are retained on the Register but all identifying information is removed, so that no tests can be linked to the woman or to each other.

# Quality

Routine data quality control measures conducted by the CSP include: monitoring data transmission rates to ensure that all cervical cancer tests are received by the Register from laboratories, data matching validation checks and cross checks of data items, identity verification using ACT Health Patient Administration System (CTPAS), regular checks of result coding accuracy and reliability using the text of pathology reports, reconciliation of information from multiple sources, examination of multiple registrations, collaboration with test providers, pathologists and other medical experts, and the use of NHMRC coding conventions.

# ACT Cervical Screening Register Data Linkage

Data held by the ACT Cervical Screening Register contains the full cervical screening histories of women who have consented to be on the Register. Each person's record contains full personal identifiers at the time of the most recent cervical cancer test, their identifiers at the time of previous tests, as well as the results of any cervical cancer test for that individual. De-identified tests cannot be linked to any individual or to any other tests.

The CHeReL links CSR records to create an ID number for each person. Data for each person can be linked to any external (with sufficient identifiers) or Master Linkage Key data collection, with the corresponding ID attached. This gives researchers the opportunity to investigate outcomes in relation to a woman's cervical screening history.

CSR data within the CHeReL Master Linkage Key is updated periodically. The data supplied to CHeReL is therefore subject to change, as quality assurance exercises occur.

CSR records available for analysis are non-identifiable details of the women’s records (excluding ethnicity), and the dates and results of cervical cancer tests (cytology, histology and HPV tests). Non-identifying details of test providers are also available. Details of the laboratory that processed the test are not available for linkage due to commercial confidentiality.

# Special Notes for using ACT Cervical Screening Register Data

**Definitions:**

* Client – The woman that has had a cervical cancer test
* Provider – The health practitioner that took the cervical cancer test, or the health practitioner by or on whose behalf the relevant pathology request form was submitted
* Cervical Test Data – This includes all samples with a cervical component, not just those collected as part of the cervical screening pathway. It includes cervical cancer pathology.

**Date of cervical test:** The CSR collects a ‘test\_date’ variable, and it is assumed that this is the date of sample collection. In some cases however, the ‘test \_date’ supplied to the CSR by laboratories is the date the test request form was supplied to the patient. This may not necessarily be the date of collection of the sample.

**Cervical Cytology results:** Cytology test results are coded by the laboratory to the Cytology Coding Schedule (NHMRC 2005) and sent to the PTR. The Coding Schedule was developed by the National Cervical Screening Program based on the Australian Modified Bethesda System 2004 for reporting cervical cytology, and introduced along with revised guidelines for the management of asymptomatic women with screen-detected abnormalities on 1 July 2006 (NHMRC 2005). The guidelines *Screening to Prevent Cervical Cancer: Guidelines for the Management of Asymptomatic Women with Screen Detected Abnormalities* can be found here: <https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/wh39_screening_to_prevent_cervical_cancer_150610.pdf>.

All cytology coding held by the CSR, including results and recommendations prior to July 2006 have been mapped to the new codes.

The Cytology Coding Schedule summarises a cytology/Pap test report to 6 alpha-numeric codes, covering the test type, site of test, squamous cell result, endocervical cell result, other non-cervical cells, and the recommendation made by the laboratory around further testing if the current test is ‘R6’ or ‘R7’. All other Rec codes are generated by the CSR system based on result codes so that Rec codes reflect NHMRC guidelines (2005)

*The CSR is able to supply the overall cytology result group or the individual cytology codes on request.*

**Cervical Histology Results:** Cervical histology tests are routinely provided to the CSR by pathology laboratories. Histology results are stored using National Cervical Screening Program Data dictionary (Histology) terminology. Histology results contain up to 7 code fields, including at least one cervical topography code related to the cervical component. Aetiology codes and procedural codes are also accepted by the CSR.

*The CSR is able to supply the overall histology result group or individual histology codes on request.*

Histology results are supplied to the Register in plain text and coded by Registry staff

Notes:

* Histology procedure codes are consistently supplied to the CSR and should be treated as complete – so it is always possible to identify the procedure that has been performed e.g. biopsy type, LOOP electro excision of cervix, curettage or hysterectomy.

**Colposcopy information:** Results are not yet reported to the CSR.

**HPV Test Results:** Cervical HPV test results are routinely provided to the CSR by pathology laboratories as part of the ‘test of cure’. HPV results are stored using a coding schedule developed in consultation with other state and territory cervical screening registers. HPV results contain information about the test type, test result and sampling method.

**HPV Vaccination status:** The CSR does not yet routinely collect information about HPV vaccination status.

# ACT Cervical Screening Register Data Custodian

The ACT Chief Health Officer is the data custodian of ACT Cervical Screening Register data. The CHeReL organises data custodian sign-off for CSR on behalf of the researcher. To arrange sign-off, please contact:

Centre for Health Record Linkage

Cherel.mail@moh.health.nsw.gov.au or 02 9391 9924

# Non-record-linkage requests for Cervical Screening Register data

Persons requesting CSR data for non-record-linkage purposes (e.g. for service provision or for planning) are directed to [submit](file:///C%3A%5CUsers%5Cpeter%20couvee%5CAppData%5CLocal%5CMicrosoft%5CWindows%5CTemporary%20Internet%20Files%5CContent.Outlook%5CDA7F5LD4%5Csubmit) a request in writing citing planned usage of the data to:

Chief Health Officer

ACT Health

GPO Box 825

CIVIC ACT 2601

# Queries regarding Cervical Screening Register Dataset

Queries related the to Cervical Screening Register dataset may be directed to the

Program Manager

ACT Cervical Screening Register

GPO Box 825

CIVIC ACT 2601

cervical.screenin@adct.gov.au

(02) 62051955.

# ACT Pap Test Register - Variable Information

| **Variable** | **Description/Notes** | **Data Values/Codes** |
| --- | --- | --- |
| **Client Data** |
| Date of Birth | Client's date of birth | DD/MM/YYYY |
| Age at Test | A calculated field that is the age in years that the person was when they had the test.  | YY |
| Date of Test | Date of test as provided by the pathology laboratory. | DD/MM/YYYY |
| Type of Test |  |

|  |
| --- |
| C = Cytology |
| D = HPV DNA |
| H = Histology |

 |
| Overall Result | The overall result group for the Cytology result as defined by the NHMRC 2005 guidelines.A mapping table of the combination of individual cytology results to an overall result group is available on request. | C1 = NormalC2 = Possible LGEA/LGEAC3 = Possible HGEAC4 = HGEAC5 = MalignantCU = Unsatisfactory PapD0 = HPV NegativeD1 = HPV PositiveDU = Unsatisfactory HPVH- = Endocervical PolypH0 = Unsatisfactory BiopsyH1 = NormalH2 = Reactive InflammatoryH3 = LGEA CIN1 +/HPV or HPV+/CIN1H4 = HGEA CIN2/3 +/-HPV AIS, CIN 1-2 Pre malignant endometrial cellsH5 = Invasive Malignancy HP = Possible High Grade |
| **Cervical Test Data** |
| Cytology Type Code | Cytology test results are coded by the laboratory to the Cytology Coding Schedule (NHMRC 2005) and sent to the SCR. All cytology coding held by the CSR, including results prior to July 2006, have been mapped to the codes introduced in 2006. | AØ = Not statedA1 = Conventional smearA2 = Liquid based specimenA3 = Conventional and liquid based specimen |
| Cytology Site Code |  | BØ = Not statedB1 = CervicalB2 = VaginalB3 = Other gynaecological site |
| Cytology Squamous Cell Code |  | SU = Unsatisfactory for evaluationS1 = Cell numbers and preservation satisfactory. No abnormality or only reactive changesS2 = Possible low-grade squamous intraepithelial lesion (LSIL)S3 = Low-grade LSIL (HPV and/ or CIN I)S4 = Possible high-grade squamous intraepithelial lesion (HSIL)S5 = High-grade squamous intraepithelial lesion (HSIL) (CIN II/ CIN III)S6 = High-grade squamous intraepithelial lesion (HSIL) with possible microinvasion/ invasionS7 = Squamous carcinoma |
| Cytology Endocervical Code |  | EU = Due to the unsatisfactory nature of the smear, no assessment has been madeE- = Not applicable: vault smear/ previous hysterectomyE0 = No endocervical componentE1 = Endocervical component present. No abnormality or only reactive changesE2 = Atypical endocervical cells of uncertain significanceE3 = Possible high-grade endocervical glandular lesionE4 = Adenocarcinoma-in-situE5 = Adenocarcinoma-in-situ with possible microinvasion/ invasionE6 = Adenocarcinoma |
| Cytology Other Code |  | OU = Due to the unsatisfactory nature of the smear, no assessment has been madeO1 = No other abnormal cellsO2 = Atypical endometrial cells of uncertain significanceO3 = Atypical glandular cells of uncertain significance - site unknownO4 = Possible endometrial adenocarcinomaO5 = Possible high-grade lesion – non-cervicalO6 = Malignant cells - uterine bodyO7 = Malignant cells - vaginaO8 = Malignant cells – ovaryO9 = Malignant cells – other |
| Cytology Recommendation Code |  | R0 = No recommendationR1 = Repeat smear 3 yearsR2 = Repeat smear 2 yearsR3 = Repeat smear 12 monthsR4 = Repeat smear 6 monthsR5 = Repeat smear 6 – 12 weeksR6 = Colposcopy/ biopsy recommendedR7 = Already under gynaecological managementR8 = Referral to specialistR9 = Other management recommendedRS = Symptomatic - clinical management required |
| **Histology Test Data** |
| Histology Specimen Code |  | 0 = Not disclosed1 = Colposcopy only2 = Punch biopsy of the cervix3 = Endocervical Curettage4 = Large Loop excision of TZ5 = Cone biopsy6 = Endometrial curettage7 = Total hysterectomy8 = Vaginal biopsy9 = Other pelvic tissue10 = Metastatic sites11 = Manchester repair12 = Endocervical polyp13 = Sub-total hysterectomy |
| Histology Squamous Code |  | 0 = Not applicable (or information not available)1 = Native squamous epithelial; squamous metaplasia;immature squamous metaplasia with or without inflammatory or reactive changes; atrophy2 = Atypia Atypical immature squamous metaplasia; hyperkeratosis/parakeratosis3 = HPV Effect4 = Mild dysplasia (CIN1)5 = Moderate dysplasia (CIN2)6 = Severe dysplasia / CIS (CIN3)7 = Microinvasive squamous cell carcinoma8 = Invasive squamous cell carcinoma |
| Histology HPV Code |  | 0 = N/A no squamous tissue collected1 = Absent2 = Suggestive, possible3 = Definite, consistent |
| Histology Endocervical Code |  | 0 = Not applicable1 = Normal; inflammatory or reactive changes; endocervical polyp2 = Mild nuclear changes (probably reactive)3 = Endocervical dysplasia4 = Adenocarcinoma insitu5 = Microinvasive adenocarcinoma6 = Invasive adenocarcinoma7 = Adenosquamous carcinoma (cervix)8 = Carcinoma of cervix (other) |
| Histology Endometrial Code |  | 0 = Not applicable1 = Benign endometrial cell changes2 = Pre Malignant endometrial cell changes3 = Malignant endometrial cell changes |
| Histology Other Code |  | 0 = Not applicable1 = Normal vaginal tissues; inflammatory, reactive or hormonal changes2 = HPV effect in vaginal tissues3 = Vaginal intraepithelial dysplasia (VAIN1/2/3)4 = Vulval neoplasia in-situ or invasive (VIN)5 = Vaginal squamous cell carcinoma6 = Vaginal adenocarcinoma7 = Ovarian Carcinoma (all types)8 = Metastatic tumour from outside female genital tract9 = Other malignancy (mesenchymal; trophoblastic; germ cell; unknown origin) |
| **HPV Test Data** |
| HPV Test Type code |  | HP1 = Digene (Hybrid Capture Test and Hybrid Capture II Test)HP2 = PCR (Polymerase Chain Reaction)HP3 = Non-amplified techniquesHP9 = Not stated |
| HPV Test Result Code |  | H0 = No high risk types of HPV DNA presentH1 = High risk types of HPV DNA present  |
| **Test Provider data** |
| Referring Practitioner Postcode | Postcode of the individual health practitioner requesting the relevant pathology request form was submitted | nnnn |