**NSW Pap Test Register Data Dictionary for Record Linkage**

NSW Cervical Screening Program

# Background

The NSW Pap Test Register (PTR or the Register) was established in 1996 in accordance with the NSW Public Health Act and is managed by the NSW Cervical Screening Program at the Cancer Institute NSW on behalf of the NSW Ministry of Health. The NSW Cervical Screening Program (NSW CSP or the Program) is a jointly-funded Commonwealth/State and Territory initiative under the National Healthcare Agreement. As part of the National Cervical Screening Program, the NSW CSP operates within the national cervical screening policies and guidelines; with a primary objective to implement an organised approach to cervical screening in NSW. The Australia-wide Cervical Screening guidelines are detailed in the National Health and Medical Research Council (NHMRC) publication "*Screening to Prevent Cervical Cancer: Guidelines for the Management of Asymptomatic Women with Screen Detected Abnormalities*" (2005).

The PTR is a centralised and confidential database of cervical cancer test results for NSW women. Within the PTR a person's cervical cancer tests are linked to a single PTR record, providing a comprehensive view of their cervical screening history.

# Coverage

The PTR was established in 1996 as a centralised and confidential database of cervical cancer test results for NSW women. 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 reported from 29th July 1996. Colposcopy results that are not linked to a laboratory record are not yet routinely reported to the PTR. The data does not include results for smears taken at other gynaecological sites (such as vault or vaginal smears). Histological data aims to exclude any coding for non-cervical sites, but coding of non-cervical sites (such as the uterus) may be included in the results of hysterectomies

The PTR collects cervical test data for persons residing in NSW at the time of their test, including from pathological laboratories in NSW and some interstate laboratories located in areas bordering NSW. Cervical test data includes all samples with a cervical component. All laboratories carrying out cervical cancer pathology testing in NSW are required to forward the results of tests on NSW women to the PTR under the NSW Public Health Act (2010). Interstate laboratories may forward the data of NSW women to the PTR on a voluntary basis.

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

The Register operates as an "opt-off" database, that is, all tests relating to cervical pathology will be included on the Register unless the person 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 PTR at the time of the test, or may withdraw their details from the Register at a later time. In this situation, the person's test results are retained on the Register but all identifying information is stripped from them, so that no tests may be linked to the person or to each other.

# Quality

Routine data quality control measures conducted 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 the NSW Electoral Roll, 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 and SNOMED coding conventions.

# NSW Pap Test Register Data Linkage

Data held by the NSW Pap Test Register contains the full cervical screening histories of persons 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 PTR 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 person's cervical screening history.

PTR 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.

PTR records available for analysis are non-identifiable details of the person (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 NSW Pap Test Register Data

**Definitions:**

* Client – The person 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 PTR collects a "test request date" variable, and it is assumed that this is the date of sample collection. In some cases however, the test request date supplied to the Register 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). All cytology coding held by the PTR, including results and recommendations prior to July 2006, have been mapped to the new codes. A mapping table of pre-2005 codes to post-2005 codes is available from the PTR Data Specialist if tests prior to July 2006 are requested.

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.

*The PTR 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 PTR by pathology laboratories. Histology results are stored using Systematized Nomenclature of Medicine (SNOMED) International terminology. Histology results contain up to 10 codes, including at least one cervical Topography code and at least one Morphology code related to the cervical component. Aetiology codes and Procedural codes are also accepted by the PTR.

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

The NSW Cervical Screening Program's Guide for Reporting Histology to the NSW Pap Test Register - SNOMED International is found at **Appendix 2**.

Notes:

* Histology Procedure codes are not consistently supplied to the PTR and should be treated as incomplete – so it is not always possible to identify the procedure that has been performed e.g. biopsy type, LOOP electro excision of cervix, curettage or hysterectomy.
* Information on margins of the sample is not comprehensively supplied to the PTR.

**Colposcopy information:** A colposcopy may take the form of a visual examination, or an examination with an associated biopsy. Biopsy results are routinely reported to the PTR by laboratories as part of the histology reporting process.The results of colposcopies where an associated laboratory report is not available are not yet routinely reported to the PTR. *Please contact the Data Specialist if you would like to discuss the analysis of colposcopy information.*

**HPV Test Results:** Cervical HPV test results are routinely provided to the PTR by pathology laboratories. HPV results are stored using a coding schedule developed in consultation with other jurisdictional Registers. HPV results contain information about the test type, test result and sampling method.

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

# NSW Pap Test Register Data Custodian

The Program Manager, Cervical and Bowel Screening, Cancer Institute NSW is the data custodian of NSW Pap Test Register data. The CHeReL organises data custodian sign-off for PTR 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 Pap Test Register data

Persons requesting Pap Test Register data for non-record-linkage purposes (e.g. for service provision or for planning) are directed to use the relevant forms at <http://www.cancerinstitute.org.au/data-and-statistics/cancer-registries/nsw-pap-test-register>

# Queries regarding Pap Test Register Dataset

Queries related the to NSW Pap Test Register dataset may be directed to the PTR Data Specialist, care of the NSW Pap Test Register nswpaptest@cancerinstitute.org.au or 02 8374 3610.

# NSW Pap Test Register – Data Structure

Data held by the NSW Pap Test Register contains the full cervical screening histories of persons 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.

A sample view of a single client's screening history may be seen below:

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Client Details at Time of Test | DOB | Residential Postcode at Time of Test | Test Date | Test Type | Result Group | Test Result Codes | Provider Postcode Information |
| Jane Doe | 01/01/1961 | 2070 | 12/05/2009 | Cytology | NEG | A1 B1 S1 E0 O1 R2 | 2010 |
| Jane Doe | 01/01/1961 | 2067 | 10/08/2012 | Cytology | HSIL | A1 B1 S5 E1 O1 R6 | 2012 |
| Jane Doe | 01/01/1961 | 2067 | 03/10/2012 | Histology | High Grade | T83200 M67017 | 2010 |
| Jane Doe | 01/01/1961 | 2067 | 17/01/2013 | Histology | High Grade | T83200 M67017 P183420 | 2010 |
| Jane Doe | 01/01/1961 | 2067 | 06/07/2013 | Cytology | NEG | A1 B1 S1 E1 O1 R4 | 2010 |
| Jane Doe | 01/01/1961 | 2067 | 06/07/2013 | HPV | HPV DNA Negative | D4 H0 M1 | 2010 |

# NSW 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 their cervical test.  | YY |
| **Cervical Test Data** |
| Date of Test/Test Request Date | Date of test as provided on test request form. Available for Cytology, Histology and HPV tests | DD/MM/YYYY |
| Overall Cytology Result  | The overall result group for the Cytology result as defined by the NHMRC 2005 guidelinesA mapping table of the combination of individual cytology results to an overall result group is available on request. | AC AdenocarcinomaAENDO Atypical endocervical cellsAGLAN Atypical glandular cellsAIS Endocervical adenocarcinoma-in-situCNOS Carcinoma not otherwise specifiedECAC Endocervical adenocarcinomaEMAC Endometrial adenocarcinomaHSIL High-grade squamous intraepithelial lesionLSIL Low-grade squamous intraepithelial lesionN/A Not applicableNEG NegativePHGL Possible high-grade glandular lesionPHSIL Possible high-grade squamous intraepithelial lesionPLSIL Possible low-grade squamous intraepithelial lesionSCC Squamous cell carcinomaUNSAT Unsatisfactory |
| Test Type Code | Code indicating test type | C = CytologyH = HistologyP = HPV DNA |
| Cytology Type Code | Cytology test results are coded by the laboratory to the Cytology Coding Schedule (NHMRC 2005) and sent to the PTR. All cytology coding held by the PTR, 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 evaluation e.g. poor cellularity, poor preservation, cell detail obscured by inflammation/ blood/ degenerate cellsS1 = Cell numbers and preservationsatisfactory. No abnormality or only reactive changesS2 = Possible low-grade squamousintraepithelial lesion (LSIL)S3 = Low-grade LSIL (HPV and/or CIN 1)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 significance E3 = Possible high-grade endocervical glandular lesionE4 = Adenocarcinoma-in-situE5 = Adenocarcinoma-in-situ with possible microinvasion/ invasionE6 = Adenocarcinoma |
| Cytology Other/non-cervical 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 specialist |
| Overall Histology Result  | The overall histology result determined from the most serious Morphology code.  | 0 Diagnosis not applicable (diagnosis not related to cervical screening)1 Negative, benign2 Atypical/Abnormal not otherwise specified3 HPV effect alone4 CIN/Dysplasia not graded5 CIN 1 +/- HPV7 High grade intra-epithelial abnormality +/- HPV8 Microinvasive cancer9 Cervical cancer |
| Histology Codes | Histology results sent from laboratories are stored in the Pap Test Register as SNOMED International codes. Histology results contain a mandatory cervical Topography code and at least one Morphology code. Up to 10 histology codes are stored for each histology result. | The SNOMED International format used in the PTR is a 6-character expression XNNNNN, where X = "T","M","L" or "P", and N is a number. T-code - The topography code indicates the anatomical site of the test, with cervical codes prefixed with T832nn. (mandatory)M-code – Morphology code (mandatory)L-code – Living Organism (Aetiology) code (optional)P-code – Procedural code (optional)Refer to **Appendix 1** for the NSW Cervical Screening Program's Guide to Reporting Histology - SNOMED International- for a list of codes commonly used when reporting cervical histology. Please contact the PTR Data Specialist if definitions are required for other codes. |
| HPV Test Type code |  | D1 DigeneD2 Amplicor HPV (PCR)D3 Linear Array HPV (PCR)D4 PCR Not Otherwise Specified (NOS)DZ Unspecified test type |
| HPV Test Result Code |  | H0 HPV DNA NegativeH1 HPV DNA detected – High RiskH2 HPV DNA detected – Low RiskH3 HPV DNA detected – Both High Risk & Low Risk |
| HPV Sampling Method Code |  | M1 LBC sampleM2 Digene samplerM3 Self collectM4 Other sampler |

# Appendix 1 –SNOMED International Codes commonly used when reporting Cervical Histology

