CODING GUIDE FOR NATIONAL DATASET

The use of a common national coding guide will facilitate the pooling of data from screening programmes across the country to allow epidemiological analysis.

The Coding Guide for the National Dataset is divided into the same sections as the data collection forms and will allow a quick overview of the fields and section that the Audit aims to record.

The last section provides a list of fields that are essential for Audit purposes. Items in this list are essential because without them meaningful analysis of the data cannot be conducted. Items not on this list are still important and reasonable effort should be made to collect them because they provide a complete and in depth picture of the pathway to diagnosis.

Information for Section A, Section B.1 and Section B.2 is almost entirely included in the Exeter download and entering these data onto the forms might not be required (please follow QARC guidelines regarding this).

Section G (GP Notes) is no longer part of the audit, however if contacting the GP has been found to be useful this activity should continue. The Audit database still allows for GP data to be recorded. Section H (HPV tests) has been incorporated into Section B (Cytology history).

Section C (Colposcopy) has been divided in two parts, C.1 - colposcopy history and C.2 - colposcopy review

New codes do not overlap with previous codes, so data entered so far will not be affected by this upgrade.

Contents

Section A Personal and Cancer Details
Section B.1 Cytology History
Section B.2 Cytology Ceased or Postponed
Section C.1 Colposcopy history
Section C.2 Colposcopy review
Section D Histology
Section E Cytology Review
Section F Histology Review
Essential Fields
PERSONAL AND CANCER DETAILS

AJ-CRUK download
AJ-CRUK runs on the National Health Authority Information System ('NHAIS', also known as 'the Exeter system'). It downloads details on the screening histories of both cases and controls. The output can be automatically uploaded onto the Access database used to collate all Audit produced data regionally. AJ-CRUK has been updated and now includes the following fields: surname, forename, NHS number, postcode, date of birth, date of GP registration, cytology test date, cytology result, action code, reason, laboratory number, HPV infection marker, next test repeat in months and details of any episodes where women were ceased or postponed from the programme.

Study ID
Study ID is 16 or 17 characters long and is assigned automatically by AJ-CRUK at the same time that the controls are assigned to the case.

The Study ID had the following format TES/QT2/CCYY/NNNX
TES = HA cipher
QT2 = Q code of Case/Controls as of the date of diagnosis
CCYY = the year of the cases' diagnosis
NNN = a sequence number for the Qcode and the year of diagnosis
X = the Case/Control type identifier, where
  X = 1 indicates a Case
  X = 2 indicates a GP control
  X = 3 indicates a District (Health Authority) control
  X = 4 indicates an Adjusted Screened control
  X = 5 indicates an Abnormal control
  X = 6 indicates an Unadjusted Screened control

Postcode
It is essential that postcode is recorded in full. Postcodes are available from the AJ-CRUK electronic download. When uploaded into the Access database the postcode is used to assign an index of multiple deprivation for each woman.

Index of Multiple Deprivation
The index is calculated by the Office of the Deputy Prime Minister, it is based on geographical areas called Super Output Areas that include approximately 1,500 residents. We have ranked the index from least deprived to most deprived and divided them into deciles (0 most deprived to 9 least deprived).

Dates
All dates should be entered in the following format DD MM YYYY (e.g. May 7, 1992 becomes 07 05 1992)

Stage
Two boxes have been provided for stage (on the paper forms) to allow a preliminary staging on which the AJ-CRUK job can be run. The final FIGO stage can be entered at any time. Valid stage codes for AJ-CRUK are: 1A, 1B, 2, 2A, 2B, 3, 3A, 3B, 4, 4A, 4B, IN, 1B+, X. "X" should be used for unknown stage and "IN" or "1B+" if the tumour is known to be worse than micro invasive, but the full stage is not available.

Histology
The following histological coding must be used to run AJ-CRUK and should only be used in reference to this output

S. Squamous
A. Adenocarcinoma
B. Adeno-squamous carcinoma
U. Undifferentiated
O. Other
U. Unknown

Treatment
Only one treatment option can be recorded for each woman. Please record the most severe treatment received by the woman.
### CYTOLOGY HISTORY

*(all fields provided by AJ-CRUK, except where noted)*

<table>
<thead>
<tr>
<th>No Cytology Reason</th>
<th>Result Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>(not provided by AJ-CRUK)</em></td>
<td>1 Inadequate</td>
</tr>
<tr>
<td>1 Not on Exeter System</td>
<td>2 Negative</td>
</tr>
<tr>
<td>2 Invited but did not attend</td>
<td>N Negative (HPV)</td>
</tr>
<tr>
<td>3 Not yet called</td>
<td>3 Mild Dyskaryosis</td>
</tr>
<tr>
<td>4 Ceased</td>
<td>M Mild (HPV)</td>
</tr>
<tr>
<td>5 Unclear</td>
<td>4 Severe Dyskaryosis</td>
</tr>
<tr>
<td></td>
<td>5 ? invasive cancer</td>
</tr>
<tr>
<td></td>
<td>6 ? glandular neoplasia of endocervix</td>
</tr>
<tr>
<td></td>
<td>7 Moderate dyskaryosis</td>
</tr>
<tr>
<td></td>
<td>8 Borderline changes in squamous cells</td>
</tr>
<tr>
<td></td>
<td>9 Borderline changes in endocervical cells</td>
</tr>
<tr>
<td>Source</td>
<td>E Borderline changes in endocervical cells (HPV)</td>
</tr>
<tr>
<td><em>(not provided by AJ-CRUK)</em></td>
<td>0 ?Glandular (non cervical)</td>
</tr>
<tr>
<td>1 GP</td>
<td>G ?Glandular (non cervical) (HPV)</td>
</tr>
<tr>
<td>2 NHS Community Clinic</td>
<td>2 NHS Hospital (Colp)</td>
</tr>
<tr>
<td>3 GUM clinic</td>
<td>4 Moderate dyskaryosis</td>
</tr>
<tr>
<td>4 NHS Hospital (Colp)</td>
<td>5 Unclear</td>
</tr>
<tr>
<td>5 Private</td>
<td>6 Age</td>
</tr>
<tr>
<td>6 Other</td>
<td>7 Absence of cervix</td>
</tr>
<tr>
<td>7 Unknown</td>
<td>8 Informed Choice</td>
</tr>
</tbody>
</table>

### CYTOLOGY CEASED OR POSTPONED

<table>
<thead>
<tr>
<th>Postponement Reason</th>
<th>Ceased Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Recent Test</td>
<td>6 Age</td>
</tr>
<tr>
<td>2 Current Pregnancy</td>
<td>7 Absence of cervix</td>
</tr>
<tr>
<td>3 Patient wish to defer</td>
<td>8 Informed Choice</td>
</tr>
<tr>
<td>4 Under treatment relevant to screening</td>
<td>9 Other</td>
</tr>
<tr>
<td>5 Administrative reason</td>
<td>99 Mental Capacity Act (Best interests)</td>
</tr>
<tr>
<td>10 Practice Invitation</td>
<td></td>
</tr>
</tbody>
</table>
AUDIT OF INVASIVE CERVICAL CANCER  
March 2013

**COLPOSCOPY HISTORY**

<table>
<thead>
<tr>
<th>Attendance Type</th>
<th>TZ Type</th>
<th>Colposcopist</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Yes</td>
<td>0. Not Recorded</td>
<td>1 Consultant</td>
</tr>
<tr>
<td>2 No</td>
<td>1. Fully Visible (ectocervical)</td>
<td>2 Medical Non-consultant</td>
</tr>
<tr>
<td>3 Not Recorded</td>
<td>2. Fully Visible (endocervical)</td>
<td>3 Nurse</td>
</tr>
<tr>
<td>4 DNA (Did not attend)</td>
<td>3. Not Fully Visible</td>
<td>4 Trainee</td>
</tr>
<tr>
<td>5 Hospital Cancellation</td>
<td>4. Unsatisfactory Exam</td>
<td></td>
</tr>
<tr>
<td>6 Patient Cancellation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Colp Impression**

<table>
<thead>
<tr>
<th>Surgical Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leave blank if the woman is NOT pregnant. Write &quot;NK&quot; if NOT KNOWN</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Surgical Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leave blank if unknown. Write 99 if patient was discharged</td>
</tr>
</tbody>
</table>

**Pathological Diagnosis (in this section, if the sample has multiple diagnosis, please enter most severe diagnosis only)**

0. Normal (include, cervicitis, infection, inflammatory changes)

X. Inadequate

1. HPV Changes

2. CIN - not otherwise specified
   2.1 CIN1
   2.2 CIN2
   2.3 CIN3

3. CGIN - not otherwise specified
   3.1 Low grade CGIN
   3.2 High grade CGIN
   3.3 HGCIN and CGIN
   3.5 SMILE (Stratified mucin-producing intraepithelial lesions)

4. Squamous carcinoma - not otherwise specified
   4.1 Squamous Keratinizing
   4.2 Squamous non-keratinizing
   4.3 Squamous basaloïd
   4.4 Squamous verrucous
   4.5 Squamous warty
   4.6 Squamous papillary
   4.7 Squamous lymphoepithelioma
   4.8 Squamous squamous-transitional
   4.9 Squamous small cell

5. Adenocarcinoma - not otherwise specified
   5.1 Adeno mucinous
     5.11 Adeno mucinous endo
     5.12 Adeno mucinous intestinal
     5.13 Adeno mucinous signet-ring
     5.14 Adeno mucinous minimal deviation
     5.15 Adeno mucinous villoglandular
   5.2 Adeno endometrioid
   5.3 Adeno clear cell
   5.4 Adeno serous
   5.5 Adeno mesonephric
Both these sections are based on the RCPath minimum dataset. We allow for up to three pathological diagnosis to be entered to allow for all possible combinations.

### Type of Specimen

<table>
<thead>
<tr>
<th>Type of Specimen</th>
<th>FIGO Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cervix Biopsy</td>
<td>1A 1B 2 3 4</td>
</tr>
<tr>
<td>2. Polyp</td>
<td>1A1 1B1 2A 3A 4A</td>
</tr>
<tr>
<td>3. LLETZ (loop)</td>
<td>1A2 1B2 2B 3B 4B</td>
</tr>
<tr>
<td>4. Laser excision/cone</td>
<td></td>
</tr>
<tr>
<td>5. Knife Cone</td>
<td></td>
</tr>
<tr>
<td>6. Trachelectomy</td>
<td></td>
</tr>
<tr>
<td>7. Hysterectomy</td>
<td></td>
</tr>
<tr>
<td>8. Other complete cervical excision</td>
<td></td>
</tr>
</tbody>
</table>

### Excision status

<table>
<thead>
<tr>
<th>Excision status</th>
<th>Excision margin</th>
<th>Margin involved by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete</td>
<td>1. Ectocervical</td>
<td>2. CIN</td>
</tr>
<tr>
<td>Incomplete</td>
<td>2. Endocervical</td>
<td>3. CGIN</td>
</tr>
<tr>
<td>Not applicable</td>
<td>3. Deep lateral/radial</td>
<td>4. SMILE</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5. NA</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Invasive Cancer</td>
</tr>
</tbody>
</table>

### Additional features

This is an open field. You can make a note of the following if applicable: TEM, endometriosis, micro glandular hyperplasia, diathermy artefact, epithelial stripping, fragmented, small focus of tumour, tumour necrosis/haemorrhage.

### Pathological Diagnosis

Pathological Diagnosis (in this section, if the sample has multiple diagnosis, you can enter up to three diagnosis for each specimen)

*Full coding can be found in the colposcopy section (page 3) of this document*

0. Normal (include, cervicitis, infection, inflammatory changes) 3. CGIN - not otherwise specified
4. Squamous carcinoma - 3.1 Low grade CGIN
5. Adenocarcinoma 3.2 High grade CGIN
6. Adenosquamous 3.3 HGCIN and CGIN
7. Carcinoma cervix other type 3.5 SMILE (Stratified mucin-producing intraepithelial lesions)
8. Benign squam cell lesions
9. Non-cervical malignancy (including secondary tumours)
NK. Not known
AUDIT OF INVASIVE CERVICAL CANCER

March 2013

CYTOLOGY REVIEW

Test Type
1 Routine Screening
2 Repeat (following abnormal)
3 Surveillance (following Colp)
4 Symptomatic
5 Colposcopy
6 Other

Cytology Type
1 Conventional
2 LBC (SurePath)
3 LBC (ThinPrep)
4 LBC (Other)

Result Codes
1 Inadequate
2 Negative
N Negative (HPV)
3 Mild Dyskaryosis
M Mild (HPV)
4 Severe Dyskaryosis
5 ? invasive cancer
6 ? glandular neoplasia of endocervix
7 Moderate dyskaryosis
8 Borderline changes in squamous cells
B Borderline changes in squamous cells (HPV)
9 Borderline changes in endocervical cells
E Borderline changes in endocervical cells (HPV)
0 ?Glandular (non cervical)
G ?Glandular (non cervical) (HPV)

Not available for review, reasons
Not Found
Not Released
Not Suitable

Reviewed at
1 Local
2 Training Centre
3 Consensus

Reviewer Type
Consultant Pathologist
Consultant BMS
Assistant Director
Training Centre Manager
Medical Director

Potential False Positives
A Normal Endometrial Cells
B Endometriosis/tubo-endo metaplasia
C LUS Endometrial Sampling
D Histiocytes
E Follicular Lymphocytic cervicitis
F IUCD Effect
G Other (Specify)

Potential False Negatives
1 Small Cell Dysk
2 Pale Cell Dysk
3 Microbiopsies
4 Small Keratinized cells
5 Sparse Dysk (<200 cells)
6 Other (Specify)

If inadequate, details
1 Insufficient material
2 Not properly stained
3 Cytolitic
4 Obscured

Technical features
1 Fixation adequate
2 Artefact/contaminant present
3 Staining adequate
**ESSENTIAL FIELDS**

*Study ID is required for all sections*

**SECTION A**

**Personal and Cancer Details**
- Date of Birth
- Date of Diagnosis
- Stage of Tumour (FIGO)
- Histology
- Treatment
- Index of Multiple Deprivation

**SECTION B.1 & B.2**

**Cytology History**
- Reason for no cytology
- Date test was taken
- Result of the cytology test
- HPV result

**SECTION C.1 & C.2**

**Colposcopy History**
- Number of colposcopic appointment
- Date of colposcopy
- Attendance Type
- Colposcopist
- Surgical Procedure

**Colposcopy Review**
- All fields should be completed

**SECTION D1**

**Histology Cancer Diagnosis**
- Date of specimen
- Type of specimen
- Pathological diagnosis
- FIGO stage

**SECTION D2**

**Histology Specimen History**
- Date of specimen
- Type of specimen
- Pathological diagnosis
- Excision status

**SECTION E**

**Cytology review**
- Slide ID
- Cytology Type
- Date of original cytology
- Result of original cytology
- Reviewed at
- Review result
- Original result NFR (no further review)

**SECTION F**

**Histology Review**
- Specimen ID
- Date of original specimen
- Pathological diagnosis of original specimen
- Evidence of TZ sampling
- Reviewed at
- Review pathological diagnosis
- Excision status