



Minimal Dataset to obtain optimal registration data from Pathologists

www.kankerregister.org | www.registreducancer.org

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BWP 25/10/2014

INTRODUCTION



Law 13/06/2006

All malignancies have to be registered, using specific classifications and delivered with the complete protocol to the BCR

Law 19/05/2010

Also diagnoses in relationship with early cancer detection → BCR

Law 05/12/2011



Collaboration with BCR necessary to obtain/keep ratification of the lab

Structured file



Protocol file



Structured file

73133155939	19731331	2	ZHORBEY	ANNE	BE	9600	20130412	M-HPV+	13R01756	HOPITAL FICTIF BBB	#NS	#NS	#NS
73133155939	19731331	2	ZHORBEY	ANNE	BE	9600	20130412 T-EA563	M-67034	13R01756	HOPITAL FICTIF BBB	#NS	#NS	#NS
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95100533837	19951005	2	BLANCHART	SYLVIE	BE	5612	20131202 T-57400	M-00100	13A05613	HOPITAL FICTIF AAA	#NS	#NS	#NS

Data completely fictitious



Protocol file

394944

Nature du prélèvement + Renseignements cliniques :

Pap

Compte rendu :

Frottis composé de cellules pavimenteuses intermédiaires et parabasales.

Fond d'autolyse.

Pas vu d'épithélium endocervical.

Flore bactérienne non spécifique.

Particularités :

Présence d'altérations cellulaires dues à l'atrophie épithéliale.

Conclusion :

Formulation suivant le système de Bethesda :

Absence de lésion intraépithéliale ou de cellule suspecte de malignité : NILM

Qualité du prélèvement : optimale.

Recommandation : Aucune (dépistage de routine).

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395615

Nature du prélèvement + Renseignements cliniques :

A. Conisation : CIN II à 1 h.

B. Trois biopsies vaginales.

Vagin apparaît normal.

Compte rendu :

A. Pièce de conisation de 2x1,5x1,4 cm. Elle comporte un fil placé à 12 h. La marge de résection supérieure est tatouée à l'encre de chine noire et inférieure à l'encre de chine verte.

Cette pièce de conisation est incluse en totalité en 4 sections transversales (A1 à A4) prélevée de 9 à 3 h.

A l'histologie, cette pièce de conisation est le siège d'une lésion circonscrite située au niveau de la jonction et s'étendant tantôt vers l'endocol et plus rarement vers l'exocol. Elle se développe au dépens de l'épithélium malpighien métaplasique de surface. Elle se caractérise par des désordres architecturaux modérés associés à des atypies cytonucléaires modérées et des atypies koilocytaires. Cette lésion se situe au minimum à 3 mm de la marge de résection endocervicale et à 3 mm de la marge de résection exocervicale.

B. Trois biopsies incluses en totalité.

A l'histologie, ces biopsies intéressent de la muqueuse et de la sous-muqueuse vaginale. La muqueuse correspond à un épithélium malpighien bien différencié focalement parakératosique. On n'y observe pas de signe d'infection virale à HPV ni de signe de dysplasie.

Conclusion :

A. Conisation démontrant une lésion squameuse intra-épithéliale de haut grade (CIN II) et des signes d'infection virale à HPV.

Marges saines.

B. Biopsies vaginales : présence d'une zone de parakératose sans signe d'infection virale à HPV ni de signe de dysplasie.

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395150

Nature du prélèvement + Renseignements cliniques :

PAP

Compte rendu :

Frottis composé de cellules pavimenteuses superficielles et intermédiaires.

Fond leucocytaire.

Pas vu de cellules de la jonction pavimento-cylindrique*

Flore bactérienne de type Doderlein avec cytolysse.

Particularités :

Présence de cellules parakératosiques (parakératose).



**RESPECT FOR
DEADLINEs – DATASETs - FORMAT
USE OF SPECIFIC CLASSIFICATIONS**



**MORE TIME AVAILABLE FOR
QUALITY CONTROL and DATA
VALIDATION**

+/- 25 % registrations ask for investigation in depth (= 120,000/year)(2013)





Demanding and receiving data

Introducing data in the database allowing treatment of data



Correct/specified primary site ?

One of two different tumours for this patient ?

Treating data : Quality Control

Primary tumour or metastasis/recurrence ?

Correct patient ?

Correct/specified histology ?

Correct incidence date ?

+/- 25 % registrations ask for investigation in depth (= 120,000/year)

CLASSIFICATIONS

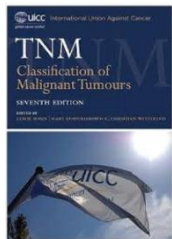
CODING OF ORGAN AND LESION

- **CODAP 2007** → derived from Leidse codes (Dutch) ; revised and adapted to the WHO-classification
- **SNOMED 3,5 VF** → by courtesy of the French government



*New Update of CODAP +
Shortlists per organ for CODAP and SNOMED*

*In
preparation*

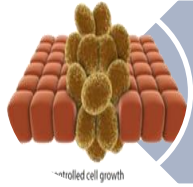


pTNM-CLASSIFICATION :

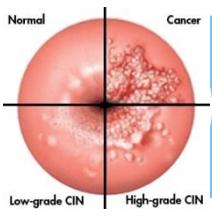
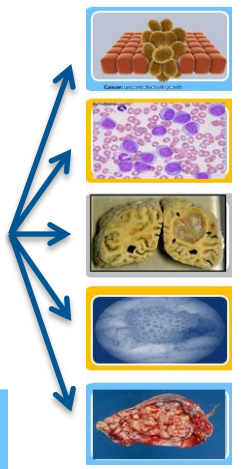
From 2010 onwards : TNM 7th edition of the **UICC** (all organs)



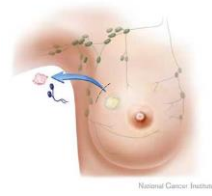
Data to deliver



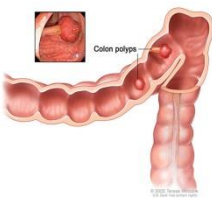
CANCER file (CLASSIC file)



PREVENTION FILE CERVIX



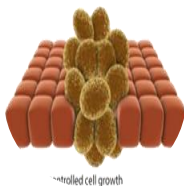
PREVENTION FILE BREAST



PREVENTION FILE COLON



DATASETS FOR THE DIFFERENT PROJECTS



- **CANCER-FILE** : dataset according to international guidelines for **cancer registries**

reception

validation of data

publication

By BCR

- Incidence
- Prevalence
- Trends
- Survival analyses
- Q-indicators
- Maps
- Support of research
-



DATASETS FOR THE DIFFERENT PROJECTS

- **PREVENTION-FILES** : dataset based on the needs of centers, responsible for organized cancer screening in Belgium
 - BREAST : Flanders (2001) – Brussels/Walloon region (2002)
 - COLON : Flanders (2013) - Brussels/Walloon region (2009)
 - CERVIX : Flanders (2013) – Brussels/Walloon region (----)

Data used to sustain :

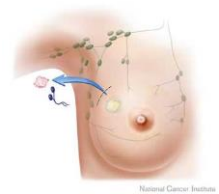


DATASETS FOR THE DIFFERENT PROJECTS

■ PREVENTION-FILES

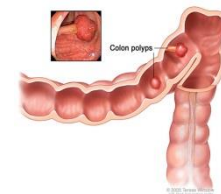
○ BREAST :

- What happened with + radiologic features ?
- Characteristics of interval cancers



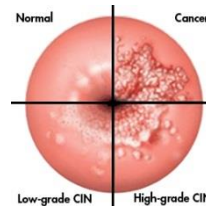
○ COLON :

- Consequences of a pos/neg iFOBT
- Characteristics of interval cancers



DATASETS FOR THE DIFFERENT PROJECTS

■ PREVENTION-FILES



○ CERVIX :

- Efficient call-recall invitation model → **Exclusion list** : exclusion of women who got a smear in recent history, reimbursed or not (+ ...)
- **Fail-Safe mechanism** : what happens after aberrant pap-result (INSU included) ?
- **Study** of efficacy of vaccination, effect on HPV-types,...
- Comparison of situation **before and after** the start of an organised screening program : Efficacy ? Results ?



DATASET FOR CODAP users

	VARIABLES FOR CODAP users	DATASET FOR CANCER DIAGNOSES	DATASET FOR BREAST AND COLON PREVENTION FILE	DATASET FOR CERVIX PREVENTION FILE
		following international guidelines for cancer registries	According to the need of the Centers for Cancer Detection in Belgium	
1	National Social Security Number (INSZ/NISS)	C	C	C
2	Last name	O/C	O/C	O/C
3	First name	O/C	O/C	O/C
4	Sex	C	C	C
5	Date of birth	C	C	C
6	Date of death	O	O	O
7	Zip code = postal code	C	C	C
8	Country code	C	C	C
9	Specimen number	C	C	C
10	Date specimen was taken	C	C	C
11	Requesting hospital	O	O	O
12	RIZIV/INAMI number of the demander of the test		C	C
13	Quality of the specimen			C
14	Organ	C	C	C
15	Lesion	C	C	C
16	pT	O/C*		
17	pN	O/C*		
18	pM	O/C*		
19	Degree of certainty	O	O	O
20	HPV high risk test results			C if HPV test performed
21	HPV high risk types detected			O
22	Nomenclature number(s)		O	O

O = Optional C = Compulsory O/C = Compulsory if INSZ/NISS unknown O/C* = Compulsory if applicable

O = New proposal of 25/10/2014



DATASET FOR SNOMED users

	VARIABLES FOR SNOMED USERS	DATASET FOR CANCER DIAGNOSES	DATASET FOR BREAST AND COLON PREVENTION FILE	DATASET FOR CERVIX PREVENTION FILE
		following international guidelines for cancer registries	According to the need of the Centers for Cancer Detection in Belgium	
1	National Social Security Number (INSZ/NISS)	C	C	C
2	Last name	O/C	O/C	O/C
3	First name	O/C	O/C	O/C
4	Sex	C	C	C
5	Date of birth	C	C	C
6	Date of death	O	O	O
7	Zip code = postal code	C	C	C
8	Country code	C	C	C
9	Specimen number	C	C	C
10	Date specimen was taken	C	C	C
11	Requesting hospital	O	O	O
12	RIZIV/INAMI number of the demander of the test		C	C
13	Quality of the specimen			C
14	Diagnostic procedure	O or HR	O or HR	HR
15	Organ	C	C	C
16	Lateralization	O	O	
17	Morphology	C	C	C
18	Differentiation level	O		
19	pT	O/C*		
20	pN	O/C*		
21	pM	O/C*		
22	Degree of certainty	O	O	O
23	HPV high risk test results			C if HPV test performed
24	HPV high risk types detected			O
25	Nomenclature number(s)		O	O

O = Optional C = Compulsory O/C = Compulsory if INSZ/NISS unknown O/C* = Compulsory if applicable
 HR = highly recommended **O = New proposal of 25/10/2014**



VARIABLES OF THE DATASET

- **PATIENT IDENTIFICATION : INSZ/NISS**
 - If missing : last/first name, sex, date of birth, postal code
 - Allows linkage of data from different sources
- **COUNTRY CODE** : only patients with Belgian residence are included in incidence numbers for Belgium ; questions never asked for non-BE
- **PROTOCOL NUMBER** : to link protocol and structured data
- **DATE SAMPLE WAS TAKEN/(RECEIVED)** : to establish
 - incidence date in case of cancer
 - date of screening examination



VARIABLES OF THE DATASET

- **REQUESTING HOSPITAL (optional)**

- BCR can contact applicant to provide extra information (eg real incidence date in case of sample on recurrence)
- Useful in fail-safe system



- **RIZIV/INAMI NUMBER OF APPLICANT OF TEST**

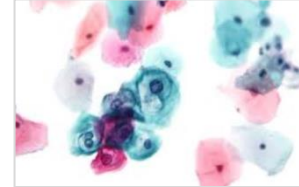
(compulsory for prevention files)

- Useful in fail-safe system



VARIABLES OF THE DATASET

- **DIAGNOSTIC PROCEDURE**



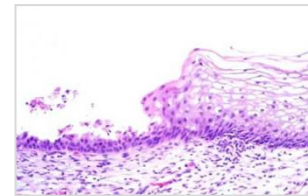
- **CYTOLOGY or HISTOLOGY?**

- Indicator of certainty

- Most important for cervix-file :

- **Fail-safe system** : aberrant pap-result followed by a biopsy ?

- **Monitoring** : which cytological results triggered a biopsy ?



VARIABLES OF THE DATASET

- **DIAGNOSTIC PROCEDURE**

CODAP :

To deliver the diagnostic procedure, one can choose one of the following possibilities:

- **within organcode**

- **Cytology** : 64**CY** (65 CY)

- **Histology** : 64CE, 64JU, 64PO, **64HI (new !)**



VARIABLES OF THE DATASET

▪ DIAGNOSTIC PROCEDURE

CODAP :

- *Within nomenclature code for cervix*
- *Also possible : new variable in new field :*

Specific BD-code (BD = Basis for Diagnosis)

- 1 Autopsy
- 2 Histology primary tumour
- 3 Histology metastasis
- 4 Cytology



VARIABLES OF THE DATASET

- **DIAGNOSTIC PROCEDURE**

CODAP :

IMPORTANT :

At BCR : **if** diagnostic procedure is not clearly provided by means of organcode, nomenclature or BD-variable

64, 64NS and 64XX (non-existing codes) → considered as **CYTOLOGY** since most frequent



VARIABLES OF THE DATASET

▪ DIAGNOSTIC PROCEDURE

SNOMED : one can chose one of following possibilities :

- **Within organcode** = T-code (eg T-EA559: cervical smear)
- *Within nomenclature code (cervix)*
- **Specific field :**
 - **P-code** eg P3-45600/P3-45260 (cervical) smear
P1-03100 biopsy

- **Specific BD-code**

- 1 Autopsy
- 2 Histology primary tumour
- 3 Histology metastasis
- 4 Cytology



VARIABLES OF THE DATASET

- **DIAGNOSTIC PROCEDURE**

Not feasible : **Within Protocol-number**

Eg 14-F-12546 : F=Frottis

Eg 14-H-14578 : H=Histology

Eg 14-C-98765 : C=Cytology

Eg 14-B-25896 : B=Biopsy

- Format of protocolnb different for all sources (manual work)
- What if > 1 sample type described in 1 protocol ?



VARIABLES OF THE DATASET

- **ORGAN CODE (mandatory)**

- Code of the sample in which diagnosis is made
 - **invasive cancer and for in situ (high grade dysplasia) lesions** : as specific as possible (skin/colon/...)
 - **for benign lesions** : less specificity is OK
- **CODAP** : organcode ; 4 characters are preferred
- **SNOMED** : T-axis

Creation of prevention files based on ORGAN CODE

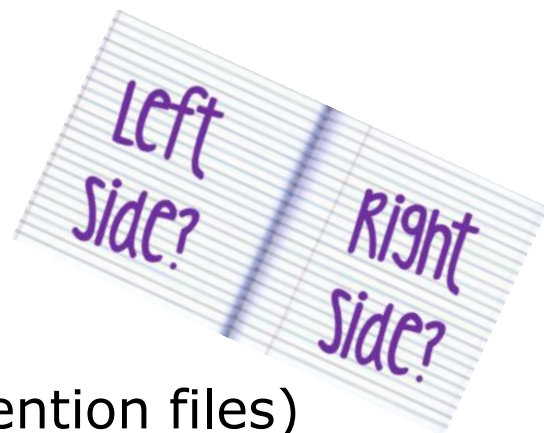


VARIABLES OF THE DATASET

▪ LATERALITY

- Important for paired organs (cancer/prevention files)
- **CODAP** :
 - sometimes included in organ code of 4 characters (eg 69LI)
 - If not : different possibilities are offered
 - make 2 registrations (eg 80BB 91MG and 06BR 91MG)
 - add LI/RE (6 characters) (eg 80BBRE 91MG)
 - add new variable : laterality (**new**)

1 = Left
2 = Right



VARIABLES OF THE DATASET

- **LATERALITY**

- Important for pare organs

- **SNOMED** :

- sometimes included in T-axis (eg T-04030 = sein gauche)
- If not : laterality can be added in separate field



1 = left		G-A101 = left
2 = right	or	G-A100 = right



VARIABLES OF THE DATASET

▪ LESION CODE (mandatory)

- **CODAP** : Lesioncode (4 characters)
- **SNOMED** : M-code
- **#NS or #NA** if only additional test performed without histological dx (KRAS, HPV, EGFR, FISH,...) → these registrations will not be included in Cancer file

Creation of CANCER file based on LESION CODE

#NS = Not stated/Not present

#NA = Not applicable



VARIABLES OF THE DATASET

- **DIFFERENTIATION GRADE (optional)**

- **CODAP :**

- sometimes included in lesioncode
eg 93GG : well differentiated adenocarcinoma
- can** also be delivered in separate field (**NEW !**)

- **SNOMED :**

- sometimes included in M-code
eg M-83313 : well differentiated follicular adenocarcinoma
- can also be delivered in separate field



VARIABLES OF THE DATASET

- **pTNM-VARIABLES (if applicable)**

- Presence in protocol = ok but not sufficient
 - Textual recognition = possible if standardised format but loss of Q
- *Important in analyses of quality of care*
- *Important in survival studies...*

- **CERTAINTY OF DIAGNOSIS (optional)**

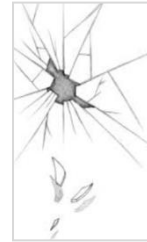
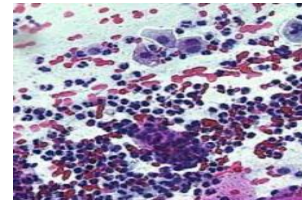
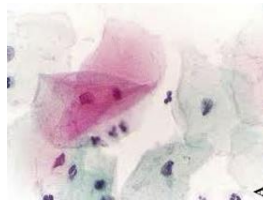
1=uncertain
2=differential problem
3=certain



VARIABLES OF THE DATASET

- **QUALITY OF SPECIMEN (CERVIX-file)(compulsory)**

SUF or INSU*



→ Important in **fail-safe system** : do all patients with a smear not allowing an evaluation, get the adapted care (i.c. new sample) ?



**RIZIV/INAMI number
of Applicant of test**

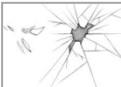
* liquid-based cytology has reduced the inadequate rate from around 10% to 2.7%.



VARIABLES OF THE DATASET

- **HPV high risk TEST RESULTS (only for CERVIX-file)**

HPV+, HPV-, HPV_i (only for molecular tests / not for immunohist. tests)

- Test performed, no HPV → **HPV-**
- Test performed, HPV detected but only HPV low risk → **HPV- !!!**
- **Test performed, HPV detected and HPV high risk → HPV+**
- Test performed, no analyse of result possible  → **HPV_i**

High risk HPV : 16,18,31,33,35,39,45,51,52,56,58,59,(68) (IARC)

- Test performed, HPV detected but low/high risk ? → **HPV_i !**
- Test performed, HPV-types detected are HR-types + HPV 66 → **HPV+**
unless if subtyping only revealed HPV66 → **HPV-**

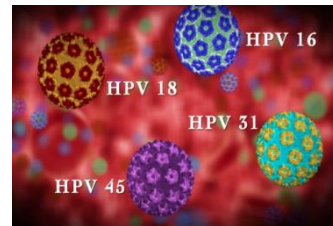


VARIABLES OF THE DATASET

- **HPV high risk TYPES DETECTED (CERVIX-file)(optional)**

HP16

HP16,HP31



- Not appl. if no search for specific HPV subtypes (only range)
- Only to fill out when search for specific **high risk** subtype of HPV is done
- *Importance : evaluation of vaccination of young girls*
 - *Period before and after start of vaccination program*
 - *Changes in HPV-subtypes, responsible for cancer ?*



VARIABLES OF THE DATASET

- **HPV high risk TEST RESULT AND TYPES DETECTED**

WHO HAS TO DELIVER THE INFORMATION ?

*BCR PROTOCOL : the lab who performs test **AND** the lab who asks for the test ... seems too strict + lots of effort*

NEW GUIDELINE : *the lab who performs test **OR** the lab who asks for the test ... : mutual consent between labs → applicant of test has to guarantee the information reaches the BCR ('3 questions'...)*



VARIABLES OF THE DATASET

- **NOMENCLATURE ...**

- **For cervix files : data used to**

- Δ Cytology versus histology
 - Δ Screening versus follow up
 - Δ First exam or second reading
 - Get a first idea of amount of non-reimbursed exams



VARIABLES OF THE DATASET

- **NOMENCLATURE ...**

- Is never used :

- To communicate to external partners with link to certain laboratory
 - For analyses per lab (sampling is not responsibility of pathologist)



VARIABLES OF THE DATASET

- **NOMENCLATURE ... (→ cervix file)**



- **PROBLEMS :**

- Information can be inaccurate :
 - Lab does not always know sample history of patient
 - Corrections by IMA follow later on (after delivering data to BCR)
- Information not always present in application used by the pathologist
 - problem when lab wants to use webservice
- some pathologists reluctant to deliver the information



VARIABLES OF THE DATASET

- **NOMENCLATURE ... (→ cervix-file)**

- **SOLUTION(S) ?**

- Condition : all analyses remain possible**

- Partial Solution 1 :**

- Some analyses can be done with IMA-data and will be executed at a later moment*

- *Screening versus follow up*

- *First exam or second reading*

- *Amount of non reimbursed samples*



VARIABLES OF THE DATASET

- **NOMENCLATURE ... (→ cervix-file)**

- **Partial Solution 2 : variable becomes optional**

- Delivering remains possible

- If not (longer) delivered, it is obligatory to indicate very clearly the **difference between CYTOLOGY and HISTOLOGY**

- **DIAGNOSTIC PROCEDURE OF UPMOST IMPORTANCE**

- **CODAP** : in organcode, (new) BD-variable

- **SNOMED** : in organcode, P-axis, BD-variable



REIMBURSEMENT OF THE PATHOLOGIST

- Data 2013 (delivered in 2013 or 2014) :
RIZIV : **603,609 €** → **BCR** → **all labs who delivered data**
- Amount/lab depending on adherence to guidelines for the datasets, necessity of extra manipulations by BCR and “size of the lab” (≈ amount of unique notifications)
- Quality indicators elaborated eg
 - Deadline respected ?
 - Protocols anonymised ?
 - Official classifications (CODAP/SNOMED) ?
 - pTNM delivered in structured file ?
 -



REIMBURSEMENT OF THE PATHOLOGIST

- **Problem** : some central labs have different activity centers (AC)
 - One big file, gathering all registrations (with link to AC)
 - Multiple smaller files of all different AC
- **Solution** : from data delivered for 2014 onwards : reimbursement per ratification-number according to RIZIV/INAMI, independent of amount of delivered files



(NEAR) FUTURE

- OPTIMALISATION OF BCR-PROTOCOL
- NOMENCLATURE FOR CERVIXFILE → **optional variable**
IF diagnostic procedure is delivered !!!
- DATASETS WILL REMAIN AS STABLE AS POSSIBLE
(new proposals for variables remain *optional* eg
laterality/differentiation grade/diagnostic procedure for CODAP
sources)



DATASET FOR CODAP users dd 25/10/14

	VARIABLES FOR CODAP users	DATASET FOR CANCER DIAGNOSES	DATASET FOR BREAST AND COLON PREVENTION FILE	DATASET FOR CERVIX PREVENTION FILE
		following international guidelines for cancer registries	According to the need of the Centers for Cancer Detection in Belgium	
1	National Social Security Number (INSZ/NISS)	C	C	C
2	Last name	O/C	O/C	O/C
3	First name	O/C	O/C	O/C
4	Sex	C	C	C
5	Date of birth	C	C	C
6	Date of death	O	O	O
7	Zip code = postal code	C	C	C
8	Country code	C	C	C
9	Specimen number	C	C	C
10	Date specimen was taken	C	C	C
11	Requesting hospital	O	O	O
12	RIZIV/INAMI number of the applicant of the test		C	C
13	Quality of the specimen			C
14	Diagnostic procedure	O / HR	O /HR	O / HR
15	Organ	C	C	C
16	Laterality	O / HR	O / HR for breast	
17	Lesion	C	C	C
18	Differentiation grade	O		
19	pT	O/C*		
20	pN	O/C*		
21	pM	O/C*		
22	Degree of certainty	O	O	O
23	HPV high risk test results			C if HPV test performed
24	HPV high risk types detected			O
25	Nomenclature number(s)		O	O

O = Optional C = Compulsory HR = Highly Recommended O/C = Compulsory if INSZ/NISS unknown O/C* = Compulsory if applicable



DATASET FOR SNOMED users dd 25/10/14

	VARIABLES FOR SNOMED USERS	DATASET FOR CANCER DIAGNOSES	DATASET FOR BREAST AND COLON PREVENTION FILE	DATASET FOR CERVIX PREVENTION FILE
		following international guidelines for cancer registries	According to the need of the Centers for Cancer Detection in Belgium	
1	National Social Security Number (INSZ/NISS)	C	C	C
2	Last name	O/C	O/C	O/C
3	First name	O/C	O/C	O/C
4	Sex	C	C	C
5	Date of birth	C	C	C
6	Date of death	O	O	O
7	Zip code = postal code	C	C	C
8	Country code	C	C	C
9	Specimen number	C	C	C
10	Date specimen was taken	C	C	C
11	Requesting hospital	O	O	O
12	RIZIV/INAMI number of the applicant of the test		C	C
13	Quality of the specimen			C
14	Diagnostic procedure	O / HR	O / HR	HR
15	Organ	C	C	C
16	Laterality	O / HR	O / HR for breast	
17	Morphology	C	C	C
18	Differentiation grade	O		
19	pT	O/C*		
20	pN	O/C*		
21	pM	O/C*		
22	Degree of certainty	O	O	O
23	HPV high risk test results			C if HPV test performed
24	HPV high risk types detected			O
25	Nomenclature number(s)		O	O

O = Optional C = Compulsory O/C = Compulsory if INSZ/NISS unknown O/C* = Compulsory if applicable HR = highly recommended



(NEAR) FUTURE

- REIMBURSEMENT PER RATIFICATION NUMBER
- CODAP update 2014/2015 (including new codes eg 64HI)
- SHORTLISTS FOR CODAP / SNOMED for all organs INCLUDING TOPO/MORPHO (following blue books – WHO)
- WEBSERVICES for continuous delivery of data



VERY NEAR FUTURE

centers for cancer screening need the (analyses on)
prevention data earlier



**NEXT CALL FOR DATA WILL ARRIVE IN JANUARY
WITH DEADLINE FOR DELIVERY : 15/02/2015**

F/B : CERVIX T3-2014 + COLON 2014 + BREAST 2014 + CANCER 2014

W : CERVIX 2014 + COLON 2014 + BREAST 2014 + CANCER 2014

*Note : when extraction of data near deadline : most data will be validated
→ less risk of missing data for a given period*



Thank you for your collaboration !



Belgian Cancer Registry



Belgian Cancer Registry



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