

Metadata in the CRN - performing FAIR with ELVIS

Siri Larønningen

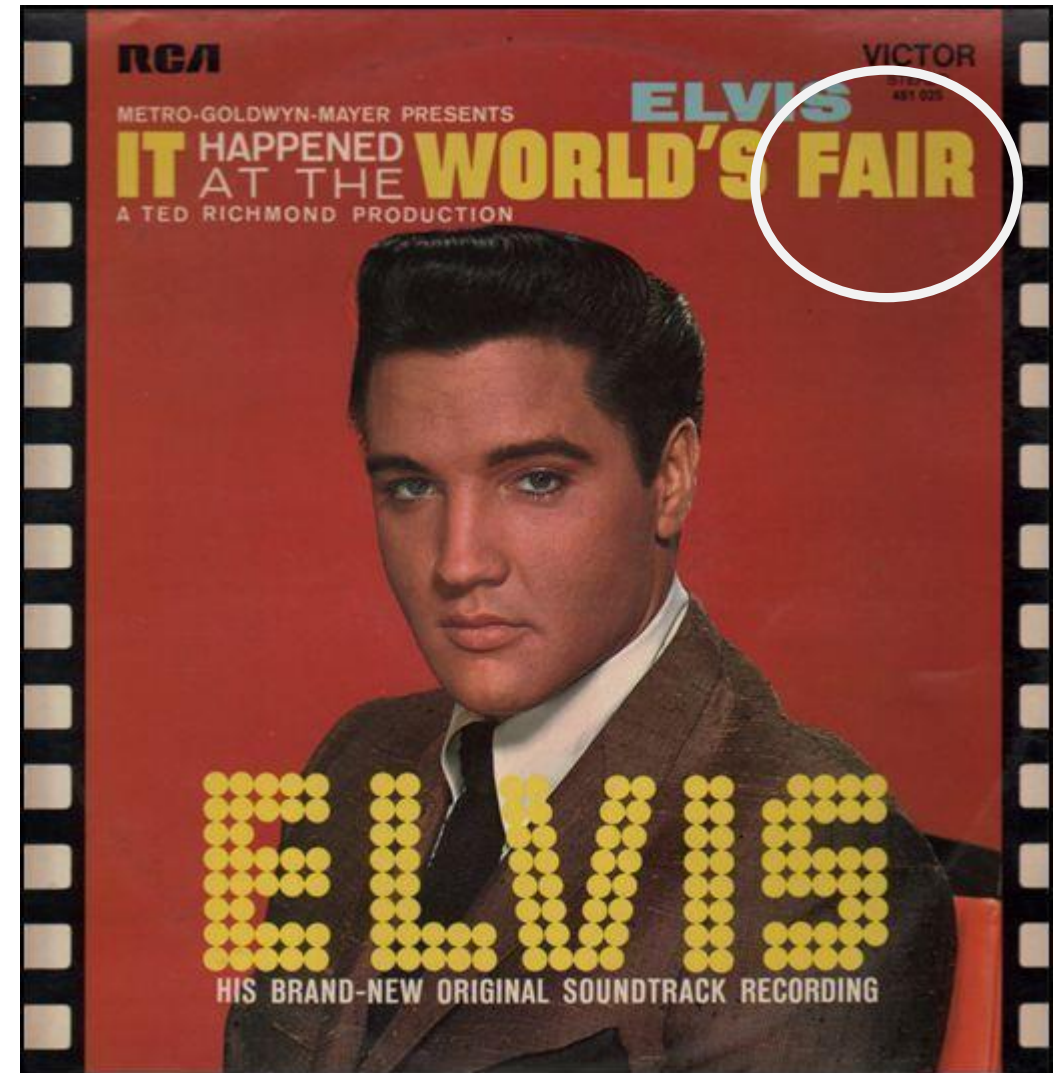
ENCR, 27.09.2018

GOAL: PERFORMING FAIR

- Findable
- Accessible
- Interoperable
- Re-usable

<https://www.force11.org/fairprinciples>

- → **ELVIS**: Electronic List of Variables In Systems



ELVIS RELEASES (DISCOGRAPHY)

- ELVIS internal (input and maintain)
- ELVIS public (browse and order)
- ELVIS coding manual (guidelines for structuring text to codes)

Registries ▾

Search

☐ Colorectal cancer

☐ Prostate cancer

☐ Breast cancer

☐ Malignant melanoma

☐ Lung cancer

☐ Childhood cancer

☐ Gyneacological cancer

☐ Lymphomas and lymphoid leu...

☐ Oesophagus and stomach ca...

☐ Sarcomas

Variables

Search for Variables

Q

Valid from

Valid to

Filters

✓

↺

Found: 194

Name ↕	Information level ↕	Valid from ↕	Tech Name ↕	Filters	+ New
Other treatment Information about other treatment.	Case	01.01.1953	annenBeh	⌵	✎
Other treatment Information about other types of treatment	Message	01.01.1953	annenBeh	⌵	✎
Other imaging of primary tumor Is other imaging performed on the primary tumor?	Message	01.01.1953	annetBilddiagnostikk	⌵	✎
Other imigaing of primary tumor specified Freetext field for indication of other imaging type of primary tumor	Message	01.01.1953	annetBilddiagnostikkSpesifiser	⌵	✎
Other cell/tissue sample of primary tumor specified Freetext field for indication of other type of cell/tissue sample of primary tumor.	Message	01.01.1953	annetVevsproverSpesifiser	⌵	✎
Other cell/tissue sample of primary tumor Indicates if another type of cell/tissue sampling than biopsy or TUR-P is done	Message	01.01.1953	annetVevsprover	⌵	✎
Number of biopsies right Number of biopsies taken from right side of prostate.	Message	01.01.1953	AntBiopsierH	⌵	✎
Number of biopsies right not given The coder has the possibility to check "not given" in the pathology message if number of biosies taken from right side of prostate is not mentioned in the pathology report.	Message	01.01.1953	AntBiopsierHlkkeAngitt	⌵	✎
Number of biopsies with tumor tissue right Number of biopsies with tumor tissue taken from right side of prostate.	Message	01.01.1953	AntBiopsierTumorH	⌵	✎
Number of biopsies with tumor tissue right not given	Message	01.01.1953	AntBiopsierTumorHlkkeAngitt	⌵	✎

Categories ▾

Search

☐ Patient

☐ Medical history

☐ Institution

✓

☒ Diagnostics

☒ Diagnostic methods

☐ Tumor characteristics and ex...

✓

☐ Treatment

☐ Neoadjuvant therapy

☐ Surgery

☐ Radiotherapy

☐ Medical/other treatment

☐ Complications/evaluation afte...

☐ Inclusion in clinical trial

☐ Follow-up

☐ PROMs

☐ CRN administration

Variables

Search for Variables

Q

Valid from

Valid to

⌵ Filters

✓

↺

Cancer sites 1 ▾

C61 Prostate ✕

Clinical registries 1 ▾

Prostate cancer ✕

☐ Include variables not in use

☐ My Variables

Found: 6

Name ⬆	Information level ⬆	Valid from ⬆	Tech Name ⬆	⌵ Filters	+ New
psa					
PSA at the time of diagnosis PSA value at the time of diagnosis.	Case	01.01.1953	psaDiagnose	⌵	✎
PSA before radiotherapy PSA value before radiotherapy.	Case	01.01.1953	psaPreStralebeh	⌵	✎
PSA before surgery PSA value before surgery.	Case	01.01.1953	psaPreoperativt	⌵	✎
PSA-value unknown The clinician can check the box if it is unknown whether or not the PSA-level is measured.	Message	01.01.1953	PSAVerdiUkjent	⌵	✎
PSA-value not measured The clinician can check the box if the PSA-level is not measured	Message	01.01.1953	PSAVerdiIkkeTatt	⌵	✎
PSA-value PSA-value at time of diagnosis.	Message	01.01.1953	PSAVerdi	⌵	✎



Categories ▾

Search

☐ Patient

☐ Medical history

☐ Institution

☒ Diagnostics

☒ Diagnostic methods

☒ Tumor characteristics and extent of disease

☐ Treatment

☐ Follow-up

☐ PROMs

☐ CRN administration

Variables

Search for Variables 🔍

Valid from

Valid to

⌵ Filters

✓

↺

Found: 101

Name ⬆	Information level ⬇🔤	Valid from ⬆	Tech Name ⬆	⌵ Filters	+ New
Gleason score before surgery Gleason score before surgery is the sum of gleason grade 1 and gleason grade 2.	Case	01.01.1953	gleasonScorePreop	⬆	✎
Clinical registries: Prostate cancer		Source: Cancer Registry of Norway		Datatype: String	
Cancer sites: Prostate		Registration Method: Generated		Data size: 2	
Category: Tumor characteristics and extent of disease		Deliverable: Yes		xPath:	
Basis of diagnosis Det most reliable method used to confirm the diagnosis for the cancer case. The value is set based on basis-values for the messages in the case and rules for which basis have the highest priority within the period of diagnosis.	Case	01.01.1953	Basis	⬆	✎
Clinical registries: All clinical registries		Source: Cancer Registry of Norway		Datatype: Nchar	
Cancer sites: All cancer sites		Registration Method: Generated		Data size: 2	
Category: Diagnostic methods		Deliverable: Yes		xPath:	
pN Pathological N-stage	Case	01.01.1953	pN	⬆	✎
Clinical registries: All clinical registries		Source: Pathology reports		Datatype: Varchar	
Cancer sites: All cancer sites		Registration Method: Generated		Data size: 10	
Category: Tumor characteristics and extent of disease		Deliverable: Yes		xPath:	
cM Clinical N-stage	Case	01.01.1953	cM	⬇	✎
cN Clinical N-stage	Case	01.01.1953	cN	⬇	✎



Metastasis **Draft**

Actions

Send for approval

Mark as unused

[Return to usage](#)

Overview

Cancer sites

Clinical registries

Message types

Values

References

Detail

Quality

Name: Metastasis

TechName: met

Description: Metastasis at time of diagnosis.

Data size: 1

Required: Yes

Category: Tumor characteristics and extent of disease

Information level: Case

Datatype: Nchar

Registration Method: Generated

Source: Cancer Registry of Norway

History:

- Created by krei on 17.08.2018
- Last Updated by krei on 03.09.2018

Latest Version

ChangeLog





History:

- Created by krej on 17.08.2018
- Last Updated by krej on 03.09.2018

Latest Version

ChangeLog

Metastasis

Draft

Actions ▾

Overview

Cancer sites

Clinical registries

Message types

Values

References

Detail

Quality

Name ▴▾	Valid from ▴▾	Valid to ▴▾	 Filters	 New
C00 Lip	01.01.1953		 	
C01 Base of tongue	01.01.1953		 	
C02 Other and unspecified parts of tongue	01.01.1953		 	
C03 Gum	01.01.1953		 	
C04 Floor of mouth	01.01.1953		 	
C05 Palate	01.01.1953		 	
C06 Other and unspecified parts of mouth	01.01.1953		 	
C07 Parotid gland	01.01.1953		 	
C08 Other and unspecified major salivary glands	01.01.1953		 	
C09 Tonsil	01.01.1953		 	
C10 Oropharynx	01.01.1953		 	





Metastasis

Draft





Actions ▾

- Overview
- Cancer sites
- Clinical registries
- Message types
- Values
- References
- Detail
- Quality

Name ↕

Valid from ↕

Valid to ↕

Filters

+ New

Colorectal cancer



Breast cancer



Malignant melanoma



Lung cancer



Lymphomas and lymphoid leukaemias



Childhood cancer



Oesophagus and stomach cancer



Sarcomas



Prostate cancer



Gyneacological cancer



History:

- Created by krej on 17.08.2018
- Last Updated by krej on 03.09.2018

Latest Version

ChangeLog

Metastasis

Draft

Actions

Overview

Cancer sites

Clinical registries

Message types

Values

References

Detail

Quality

Value	Description	Valid from	Valid to	Filters	New
0	No direct tumor growth in neighbouring tissue or organs, no node metastasis, no organ metastasis	01.01.1993			
1	Metastasis to lymph node(s) within same body section	01.01.1993			
2	Metastasis to lymph node(s) in other body sections	01.01.1993			
3	Organ metastasis within same body section	01.01.1993			
4	Organ metastasis to a different body section	01.01.1993			
5	Microscopical tumor growth in neighbouring tissue	01.01.1993			
6	Macroscopical tumor growth in neighbouring tissue (all diagnostic methods)	01.01.1993			
7	Metastasis confirmed, but unknown where	01.01.1993			
8	Microinvasive growth, carcinoma with beginning infiltration	01.01.1993	31.12.2015		
9	Unknown tumor metastasis at time of diagnosis	01.01.1993			
A		01.01.1953	31.12.1985		





Metastasis

Draft



Actions

History:

- Created by krej on 17.08.2018
- Last Updated by krej on 03.09.2018

Latest Version

ChangeLog

Overview

Cancer sites

Clinical registries

Message types

Values

References

Detail

Quality

Dataset	Display Name	Table name	TechName	Datatype	Filters	New
DBQ	Met	MELDING	METASTASE	Nchar		





Metastasis

Draft





Actions ▾

History:

- Created by krej on 17.08.2018
- Last Updated by sla on 24.09.2018

[Latest Version](#)

[ChangeLog](#)

[Overview](#) [Cancer sites](#) [Clinical registries](#) [Message types](#) [Values](#) [References](#) **Detail** [Quality](#)

Status: Draft

Example: 4

Reason for change:

Help text in form:

Background information for variable:

Exists for primary: Yes

Valid for data extraction: Yes

Data extraction comment:

Valid from: 01.01.1953

Variable name synonyms: [Met](#)

xPath:

Snomed CT:

Reason for no longer registering the variable:

Question text in form:

Exists for recurrence: No

Valid to:





History:

- Created by kre on 17.08.2018
- Last Updated by sla on 24.09.2018

Latest Version

ChangeLog

Metastasis

Draft



Actions ▾

OverviewCancer sitesClinical registriesMessage typesValuesReferencesDetailQuality

High quality. Existing for all cancer cases. Low level of unknown (value 9).

T-stage given by pal

History:

- Created by kre on 05.09.2018
- Last Updated by kre on 05.09.2018

Latest Version

ChangeLog

Overview Cancer sites Clinical registries

 Reply  Reply All  Forward  IM



man 24.09.2018 15:40

kg.apps@gmail.com

ELVIS feedback: I have some problems understand

To  Gintaras Pikelis;  Siri Larønningen

 If there are problems with how this message is displayed, click here to view it in a web browser.

Action Items

I have some problems understanding the meaning of the attribute "Data type" in this variable. Can you help me?

Sent by Larønningen

On 24-39-2018

[Active page](#)

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Feedback

Tell us your opinion.
Let us know if something is not working as expected or missing.
Leave us a message and ELVIS team will contact you.



Edit

Name

Metastase

English name

Metastasis

TechName

met

Description

Sykdommens utbredelse ved diagnosetidspunkt.

English description

Metastasis at time of diagnosis.

Category

Tumor characteristics and extent of disease

Information level

Case

Registration Method

Generated

Datatype

Nchar

☐ Clinical notifications

☐ Pathology reports

☐ National registry

☐ Cause of Death Registry

☐ Norwegian Patient Registry

☐ Radiation therapy machines

☐ CSAM Cytodose

☐ Chemotherapy Managem...

☒ Cancer Registry of Norway

☐ Patient reported

Valid for data extraction

Yes

Source 1

All



- Tasks12
- Users
- Lookup Tables
- Categories
- Forms
- Message types
- Clinical registries
- IARC List
- Sources
- Datasets
- Cancer sites
- Information level
- Datatypes
- Registration Methods
- Classifications
- Variable Orders

Categories

Name	English name	Description	English description	+ New	Sortering
Pasient	Patient	Informasjon om hver enkelt person som er registrert i Kreftregisteret, ikke knyttet til en spesifikk kreftdiagnose. Eksempel på informasjon er fødselsdato og nåværende bosted, kjønn og alder.	Information about each single person registered in the Cancer Registry, not linked to a specific cancer diagnosis. Examples of information are date of birth and current residence, sex and age.		
Behandling	Treatment	Informasjon om hvilke typer behandling pasienten har gjennomgått for den spesifikke kreftdiagnosen	Information about which types of treatment the patient has undergone for that specific cancer diagnosis		
Oppfølging/tiltak	Follow-up	Informasjon om planlagt oppfølging og tiltak videre i pasientforløpet for den spesifikke kreftdiagnosen.	Information about planned follow-up for the patient related to the specific cancer diagnosis.		
Diagnostikk	Diagnostics	Informasjon om utredning av den spesifikke kreftdiagnosen og resultat av utredningen.	Information about the diagnostic workup of that specific cancer diagnosis and the result of the diagnostics		
Institusjon	Institution	Informasjon om helseinstitusjoner som har vært involvert i utredning, behandling og oppfølging av den spesifikke kreftdiagnosen.	Information about health institutions involved in diagnostics, treatment and follow-up of the specific cancer diagnosis		
Diagnostiske metoder	Diagnostic methods	Informasjon om hvilke diagnostiske metoder som er benyttet i utredningen av den spesifikke kreftdiagnosen.	Information about which diagnostic methods are used in relation to that specific cancer diagnosis.		
PROMs	PROMs	Pasientrapportert informasjon knyttet til en spesifikk kreftdiagnose	Patient reported information related to the specific cancer diagnosis.		
KRG Administrasjon	CRN administration	Informasjon som kun benyttes til intern administrasjon i Kreftregisteret	Information only used for administration within the Cancer Registry of Norway.		
Sykehistorie	Medical history	Informasjon om symptomer, tegn, funn og plager pasienten har hatt før han/hun fikk sin kreftdiagnose og som er relevant for den spesifikke diagnosen.	Information about symptoms, signs, findings and afflictions the patient had before his/her cancer diagnosis and which are relevant for that specific diagnosis.		



Tasks 12

Users

> Lookup Tables

🛒 Variable Orders

Users



Username ↕	First name ↕	Last name ↕	Email	Roles	#
ansk	Anna	Skog	Anna.Skog@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver	
edas	Edrun	Andrea Schnell	Edrun.Andrea.Schnell@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver	
gipi	Gintaras	Pikelis	Gintaras.Pikelis@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver, IT Administrator	
one-more-gipi	Gintaras	Pikelis	pikelis@gmail.com	User	
krei	Kristin	Eik	Kristin.Eik@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver	
muha	Muhammad	Hammad	Muhammad.Hammad@kreftregisteret.no	User, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver, IT Administrator, Administrator	
qigu	Qingbao	Guo	Qingbao.Guo@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver, IT Administrator	
sla	Siri	Larønningen	Siri.Laronningen@kreftregisteret.no	User, Administrator, Coder, Coding Manual updater, Coding Manual approver, Metadata updater, Metadata approver	
stau	Steinar	Auensen	Steinar.goytil.Auensen@kreftregisteret.no	User	



- Cancer sites ▾
- Search
- > ☐ Lip, oral cavity and pharynx
 - > ☐ Digestive organs
 - > ☐ Respiratory and intrathoracic org...
 - > ☐ Bone and articular cartilage
 - > ☐ Melanoma and skin
 - > ☐ Mesothelial and soft tissue
 - > ☐ Breast
 - > ☐ Female genital organs
 - > ☐ Male genital organs
 - > ☐ Urinary tract
 - > ☐ Eye, brain and central nervous sy...
 - > ☐ Thyroid and other endocrine glands
 - > ☐ Ill-defined and unknown
 - > ☐ Lymphoid, haematopoietic and re...

Variables

Search for Variables  Valid from Valid to   

Found: 202

Name	Information level	Valid from	Tech Name	
Deregistered	Case	01-01-1953	avregistrert	
A case is deregistered when new information disproves diagnosis.				
Municipality at time of registration	Case	01-01-1953	kommunereg	 
Municipality of residence at time of registration of the cancer case.				
Surgery	Case	01-01-1953	Kirurgi	 
Most comprehensive surgery done as primary treatment for the cancer case. The value is set based on surgery-values for the messages in the case and rules for which surgery have the highest priority within the period of diagnosis.				
Certainty of diagnosis	Case	01-01-1953	DS	 
How reliable the diagnosis of the cancer case is. The value is set based on DS-values for the messages in the case and rules for which DS have the highest priority within the period of diagnosis				
Topography	Case	01-01-1953	Topografi	 
Origin of primary tumor. Rules decide which topography is generated for the cancer case if the messages have different topographies.				
Localisation	Case	01-01-1953	Lok_ICD7	 
Origin of primary tumor. Rules decide which localisation is generated for the cancer case if the messages have different localisation.				
Morphology	Case	01-01-1953	Morfologi	 
Tumor-type of the cancer case, the histopathological classification of tumor. Mainly coded by ICD-O-2, but also ICD-O-3, WHO and some internal codes are used. Tumor-type is given in the first four digits and tumor behaviour in the fifth digit. For data deliveries, the differentiation of tumor is often included as the sixth digit. Rules decide which morphology is generated for the cancer case if messages have different morphology.				
Histology	Case	01-01-1953	Hist_MOTNAC	 
Tumor-type of the cancer case, the histopathological classification of tumor. Coded after MOTNAC (Manual of tumor nomenclature and coding). Differentiation of tumor is given in the fourth digit. Cases with date of diagnosis after 31.12.1991 has the value 9999. Rules decide which histology is generated for the cancer case if messages have different histology.				
Topography_ICDO3	Case	01-01-1953	Topografi_ICDO3	 

Municipality at time of registration 

Surgery 

Certainty of diagnosis 

Topography 

Localisation 

Morphology 

Check out 



Checkout

Name	Description	TechName	#
Municipality at time of registration	Municipality of residence at time of registration of the cancer case.	kommunereg	
Surgery	Most comprehensive surgery done as primary treatment for the cancer case. The value is set based on surgery-values for the messages in the case and rules for which surgery have the highest priority within the period of diagnosis.	Kirurgi	
Certainty of diagnosis	How reliable the diagnosis of the cancer case is. The value is set based on DS-values for the messages in the case and rules for which DS have the highest priority within the period of diagnosis	DS	
Topography	Origin of primary tumor. Rules decide which topography is generated for the cancer case if the messages have different topographies.	Topografi	
Localisation	Origin of primary tumor. Rules decide which localisation is generated for the cancer case if the messages have different localisation.	Lok_ICD7	
Morphology	Tumor-type of the cancer case, the histopathological classification of tumor. Mainly coded by ICD-O-2, but also ICD-O-3, WHO and some internal codes are used. Tumor-type is given in the first four digits and tumor behaviour in the fifth digit. For data deliveries, the differentiation of tumor is often included as the sixth digit. Rules decide which morphhology is generated for the cancer case if messages have different morphology.	Morfologi	

Checkout

ELVIS performance

- Frontstage
 - Java platform
 - Javascript libraries
- Backstage
 - Storage: MySQL database
 - Interoperability: Restful APIs
 - Security: LDAP authorization, HTTPS and SSL-certificates

ELVIS v1.0 Tour

- ELVIS v1.0 Tour
 - Autumn 2018: Metadata update and approval (internal use)
 - Autumn 2018: Variable overview, search and order (public use)
 - Autumn 2018: Export of metadata to other systems
 - Christmas 2018: Coding manual
- Special performances
 - Autumn 2018: Duet with GURI (in-house rule engine)
 - Winter 2019: Duet with BioByte (external system for biobanks)

ELVIS future career

- Statistics on data quality
- Fans requests



To the ELVIS working
group

THANKS!!

Gintaras Pikelis

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