European Network of Cancer Registries

ENCR Working Group on Treatment Data Harmonisation: Overview of First Recommendations

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ENCR Recommendations

Marked differences in practice exist between cancer registries, for example, with respect to data sources, definitions and processing methods.

To make cancer registry data comparable, which is one of the main aims of the Network, it is important that common rules and definitions are used.

Standard dataset	Published 2023 Previous version 2005	EN ES FR
Basis of Diagnosis	Published 2022 Previous version 1999	EN ES FR RO DE
Cancer cases in migrant population	Published 2022	EN FR ES
Recording and Reporting of Urothelial Tumours	Published 2022	EN ES FR RO
Incidence Date	Published 2022 Previous versions 1995, 1997	EN ES FR DE RO

ENCR Working Group on Treatment Data Harmonisation

June 2021: set up of the WG

- Bring together European experts in cancer registration, epidemiology and from the clinical field
- Discuss and draft **guidelines for improved data collection and harmonisation of treatment data among European cancer registries**.
- Key step to provide **cross-comparisons** between European regions and countries,
- contributing to **design** actions to ensure better integrated and comprehensive cancer care and
- addressing unequal **access to optimal care**.

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Cancer treatment data available in European cancer registries: Where are we and where are we going?

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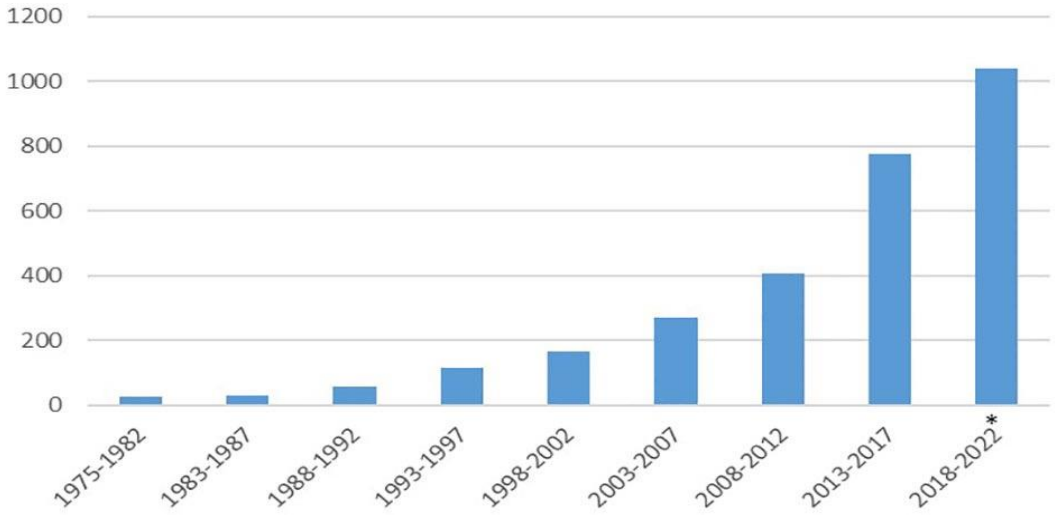
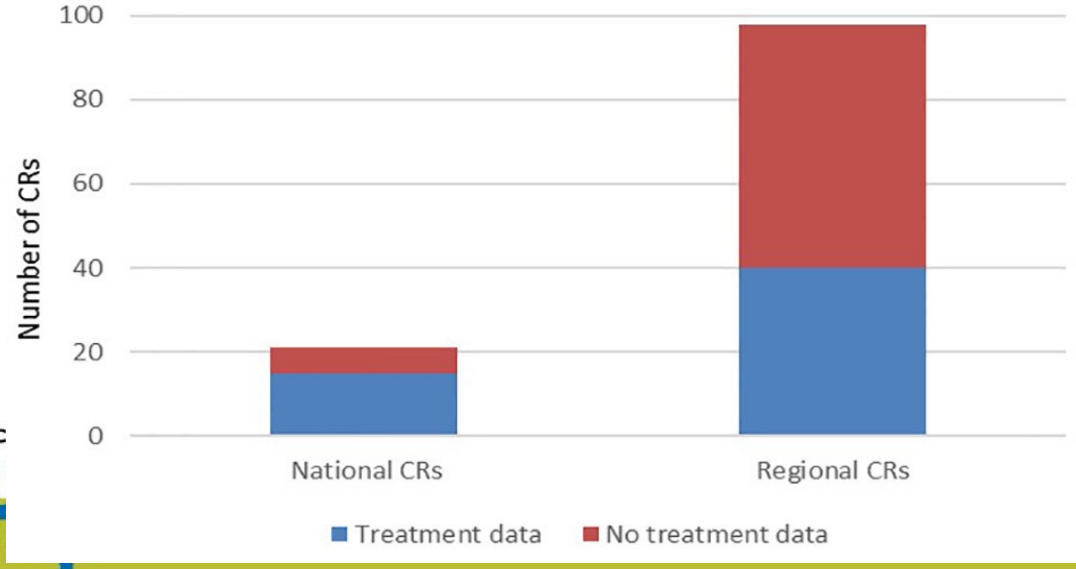
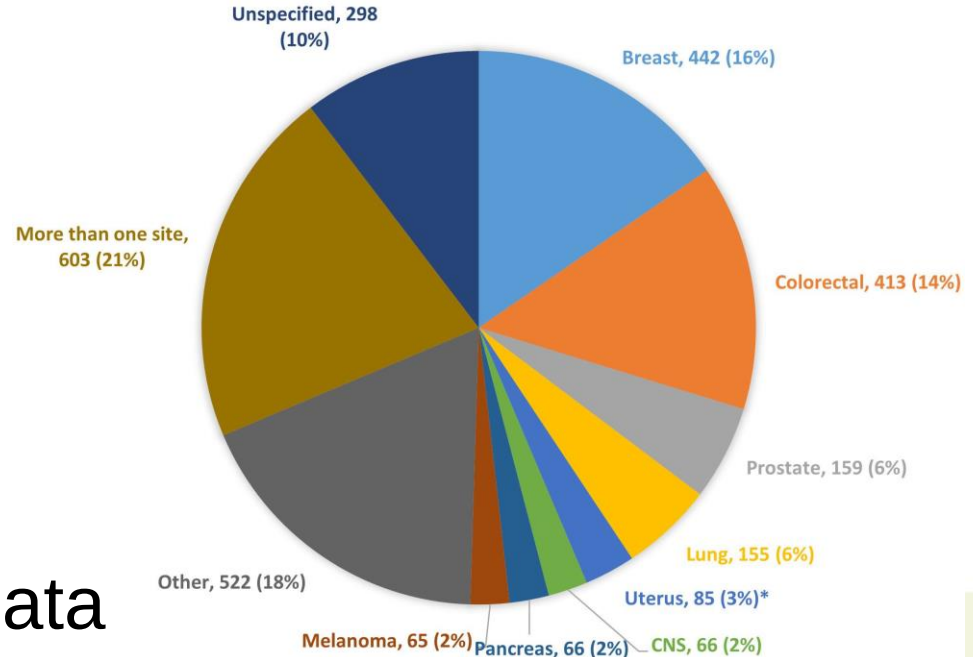
Literature Review

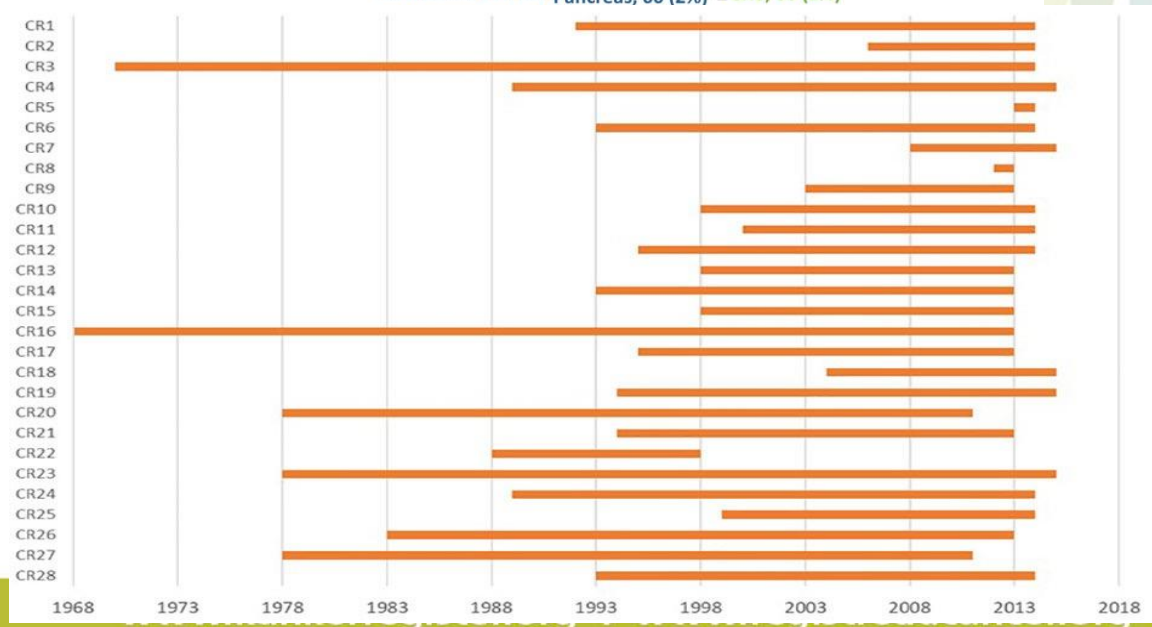


Questionnaire



Data





Belgian C

Treatment Data Recording (phase I)

Version 28-06-2023

Contents

Treatment definition

- For the purpose of the recommendations, anticancer treatment is defined as
- **first course procedures**, given within a fixed time frame after diagnosis.
- The definition **excludes**:
  - diagnostic procedures,
  - interventions that do not a have (potential) effect on the tumour,
  - second line (disease progression) and further courses of therapy (e.g. interventions for recurrence after disease free interval).

Treatment types

- Following the **latest Call for Data protocol for European Population-Based cancer registries**, organised by JRC and ENCR, treatment types (modalities) are divided between:
  - surgery,
  - radiotherapy,
  - systemic therapies
    - chemotherapy,
    - targeted therapy,
    - immunotherapy,
    - hormone therapy,
    - other - such as corticosteroids - or unspecified.

Surgery

Table 1. *Surgery (all cancer entities): variables description, format, missing/unknown values and coding schema.*

Variable description	Format	Missing/ unknown	Coding
Surgery	F	9	0→No 1→Yes, not specified 2→Yes, local surgery only 3→Yes, 'operative' surgery
Day of surgery	F	99	Range of allowed values: From 1 to 31
Month of surgery	F	99	Range of allowed values: From 1 to 12
Year of surgery	F	9999	≥ Year of incidence
Hospital of surgery	A	9	National coding system

F: Numeric variable A: Alphanumeric variable

Radiotherapy

Table 2. *Radiotherapy (all cancer entities): variables description, format, missing/unknown values and coding schema.*

Variable description	Format	Missing/	Coding
Day of radiotherapy start	F	99	Range of allowed values: From 1 to 31
Month of radiotherapy start	F	99	Range of allowed values: From 1 to 12
Year of radiotherapy start	F	9999	≥ Year of incidence
Day of radiotherapy stop	F	99	Range of allowed values: From 1 to 31
Month of radiotherapy stop	F	99	Range of allowed values: From 1 to 12
Year of radiotherapy stop	F	9999	≥ Year of incidence
Radiotherapy centre	A	9	National coding system
Radiotherapy in relation to systemic therapy			therapy 3 → Yes, sequential use to systemic therapy

Systemic therapy

Day of systemic therapy end	F	99	Range of allowed values: From 1 to 31
Month of systemic therapy end	F	99	Range of allowed values: From 1 to 12
Year of systemic therapy end	F	9999	≥ Year of incidence
Systemic therapy type	A	9	Condensed systemic therapy type 1→ Chemotherapy 2→ Targeted therapy (including monoclonal antibodies) 3→ Immunotherapy (excl. monoclonal antibodies) 4→ Hormone therapy 5→ Other or unspecified
Systemic therapy centre	A	9	National coding system
Year of systemic therapy start	F	9999	≥ Year of incidence

Anatomical Therapeutic Chemical (ATC) Codes, Generic and Trade Names

Chemotherapy Targeted therapy

	ATC code	Generic name	Trade name	
L01A	L01XC02	Rituximab	MABTHERA	
			BLITZIMA	
			RITEMVIA	
			RITUZENA	
			RIXANTHON	
			RIXATHON	
			RIXIMYO	
			TRUXIMA	
L01A			TUXELLA	
	L01XC03	Trastuzumab	HERCEPTIN	
			HERZUMA	
L01A			KADCYLA	
			KANJINTI	
			ONTRUZANT	

Stem cell transplantation

Table 4. *Stem cell variable description.*

Variable description	Format	Missing/ unknown	Coding
Stem cell transplantation (SCT)	F	9	0 → No 1 → Yes
Day of SCT	F	99	Range of allowed values: From 1 to 31
Month of SCT	F	99	Range of allowed values: From 1 to 12
Year of SCT	F	9999	≥ Year of incidence

Reason for no treatment

Table 5. *Reason for no treatment variable description.*

Variable description	Format	Missing/ unknown	Coding
Reason for no anticancer treatment	F	9	1 → Watchful waiting 2 → Active surveillance 3 → Refusal 4 → Symptomatic treatment only 5 → Unspecified 6 → Patient's death

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