



Data sources to collect information on treatment.

Terminology & cornerstones to describe radiotherapy.

Practical examples.

www.kankerregister.org | www.registreducancer.org

**Workshop treatment variables
IACR-ENCR Conference 2023**

**Lien van Walle
Belgian Cancer Registry**

Is your registry collecting data on treatment in a systematic way?

1. **No, we don't** collect any treatment data at the registry.
2. **We can** collect some treatment data, but **don't do it systematically**.
3. **Yes, we systematically collect** treatment data **for a selection of cancer sites**.
4. **Yes, we systematically collect** treatment data **for every** cancer diagnosis.

Does/can your cancer registry use a unique patient identifier?

1. **No, we don't** have any patient identification at the registry.
2. The registry has patient identification, but **we can't use it** for linkage with other databases.
3. **Yes, we have** and use patient identification at the registry.
4. **Other** situation.

National/regional data on treatment: data sources

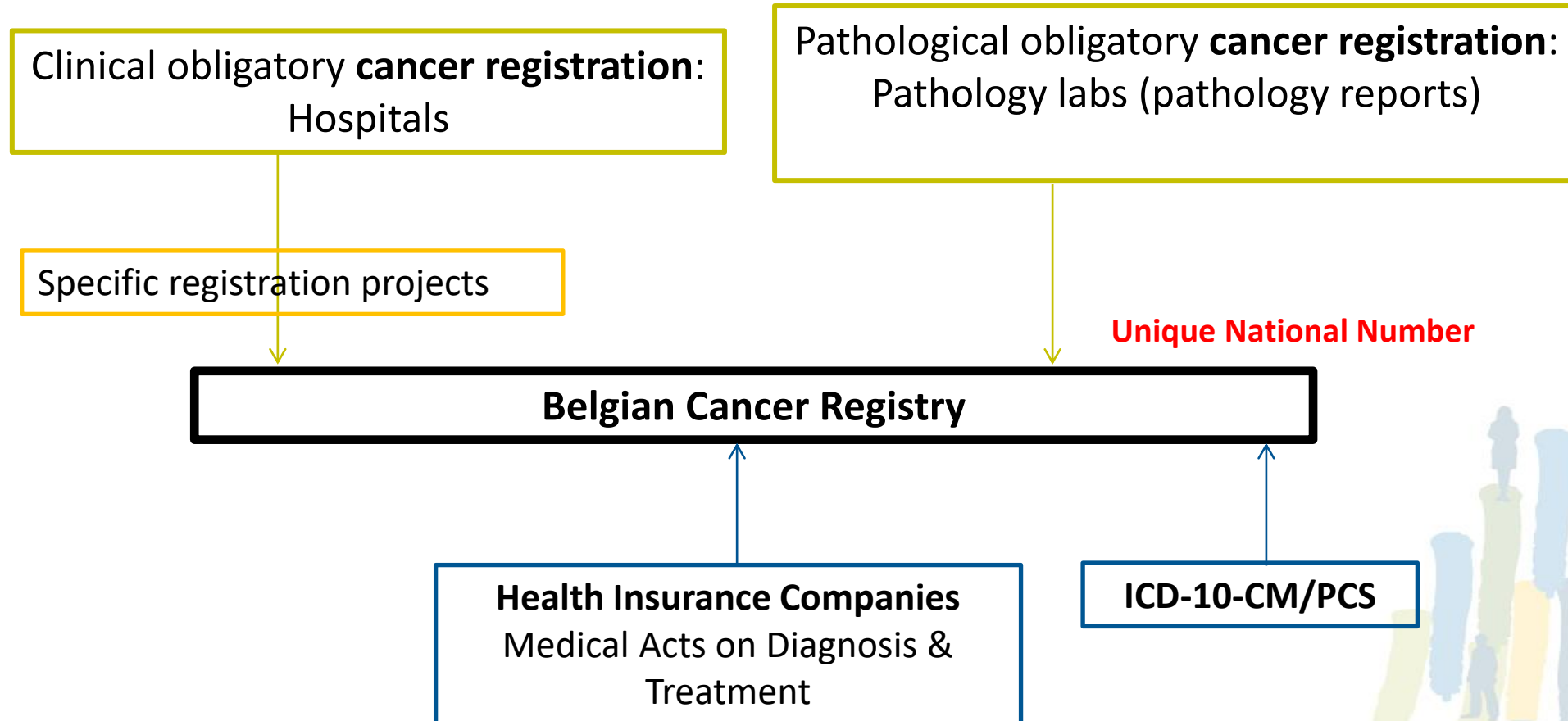
- Data through **standard cancer registration**
- Data through **specific registration projects**
- Data through **linkage** with **administrative database**

National data
More detailed information
Registration burden

National data
No registration burden
Linkage possibility
Codes and classifications
No extra information

Belgian Cancer Registry: dataflow

Standard cancer registration



ADDITIONAL administrative databases

Data through standard cancer registration

- IACR Cancer Registration Principles & Methods (1991):

Table 1. Items of information collected by registries (from Jensen *et al.*, 1991)

Essential variables	
Personal identification	Names (in full) AND/OR unique personal identification number
Sex	Male or female
Date of birth	Day, month, year
Address	Usual residence (coded)
Incidence date	At least month and year
Most valid basis of diagnosis	
Topography (site) of primary	ICD-O
Morphology (histology)	ICD-O
Behaviour	ICD-O
Source of information	
Recommended variables	
Date of last contact	At least month and year
Status at last contact	(At least dead or alive)
Stage or extent of disease	
Initial treatment	

- Minimum dataset ENCR recommendation (2005):

Initial therapy (i.e. initiated within 4 month from incidence date) [A clear manual on what is included should be available form the registry for all treatment items]	As a minimum the registries should be able to present on a yes/no basis the treatment modalities used
<i>Surgery</i>	Any surgical procedure of curative or palliative nature
<i>Radiotherapy</i>	Any radiotherapy of curative or palliative nature
<i>Chemotherapy</i>	Any cancer chemotherapy of curative or palliative nature
<i>Endocrine (hormones)</i>	Exogenous therapy i.e. medication

Data through standard cancer registration

- Example dataset Belgian Cancer Registration:

11. DATUM START EERSTE BEHANDELING (DD-MM-YYYY) :.....	<ul style="list-style-type: none">Date start first treatment						
12. REEDS UITGEVOERDE BEHANDELINGEN : chronologisch invullen vanaf datum eerste behandeling	<ul style="list-style-type: none">Already finished treatment, chronologicallyPlanned treatment, chronologically						
<table border="1"><tr><td> </td><td> </td><td> </td><td> </td><td> </td><td> </td></tr></table>							
10 : heekunde 20 : externe radiotherapie/curietherapie 25 : concomitant chemoradiotherapie 40 : chemotherapie 80 : andere vorm van behandeling (invullen) :.....	15 : beenmergtransplantatie 30 : isotopen 50 : hormonale therapie 60 : Immunotherapie	70 : symptomatisch 90 : geen therapie 95 : weigering therapie 99 : onbekend					
13. VERDER BEHANDELINGSPLAN (intentie tot) codes chronologisch invullen zie punt 12							

- Treatment codes:
 - 10= surgery
 - 20= external radiotherapy
 - 25= concomitant chemoradiotherapy
 - 40= chemotherapy
 - 50= hormonal therapy
 - ...

*Example: patient with breast cancer;
- C50 M8500/3
- Treatment: 10 – 20 - 50*



Data through specific registration projects

- Online registration tool

The screenshot shows the top navigation bar with links: startpagina, gebruiksvoorwaarden, selecteer een ziekenfonds, contact, help. Below is the Belgian Cancer Registry logo and a welcome message: 'Welkom Nancy Van Damme', 'Bron: Onbekend'. The main section is titled 'Standard cancer registration' and shows 'Aantal bewaard: 0' with a 'Meer' link and several icons (plus, folder, envelope, star, chart).

Specific project registration

The screenshot shows a specific project registration module titled 'Innovative RT - APBI (Accelerated Partial Breast Irradiation) and Boost'. It includes a warning: 'By using this module you are not participating in the legally obliged registration of new...' and a 'Meer' link. It also shows 'Aantal bewaard: 0 ...' and 'Meer' link, along with the same set of icons as the standard registration section.

Example data collection:

Tumour characteristics

Indication

Radiotherapy **details**: Start and end date; Planned total dose; Effectively delivered total dose; Number of fractions; Radiotherapy technique

Surgery **details**: Date of surgery; surgical technique

...

Example: patient with breast cancer; C50 M8500/3

- Treatment:

- lumpectomy with sentinel ('10')

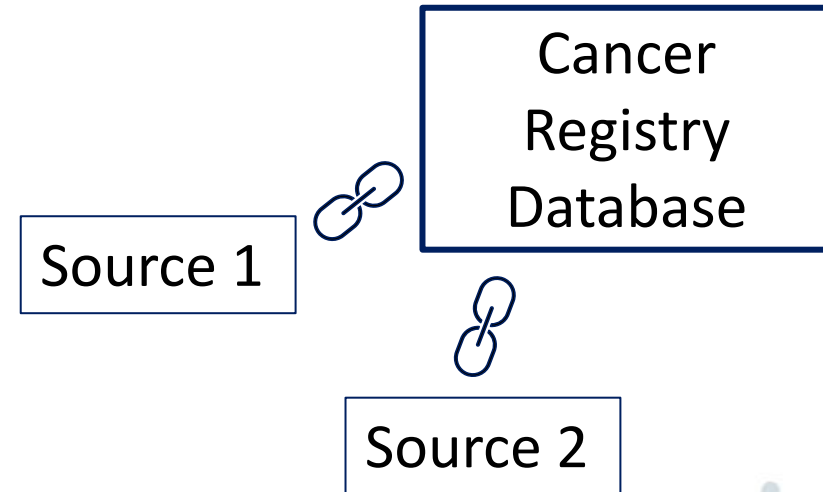
- external beam RT of the breast 42,5Gy 16 fractions

+ boost ('20')

- start Tamoxifen ('50')

Data through linkage with administrative databases

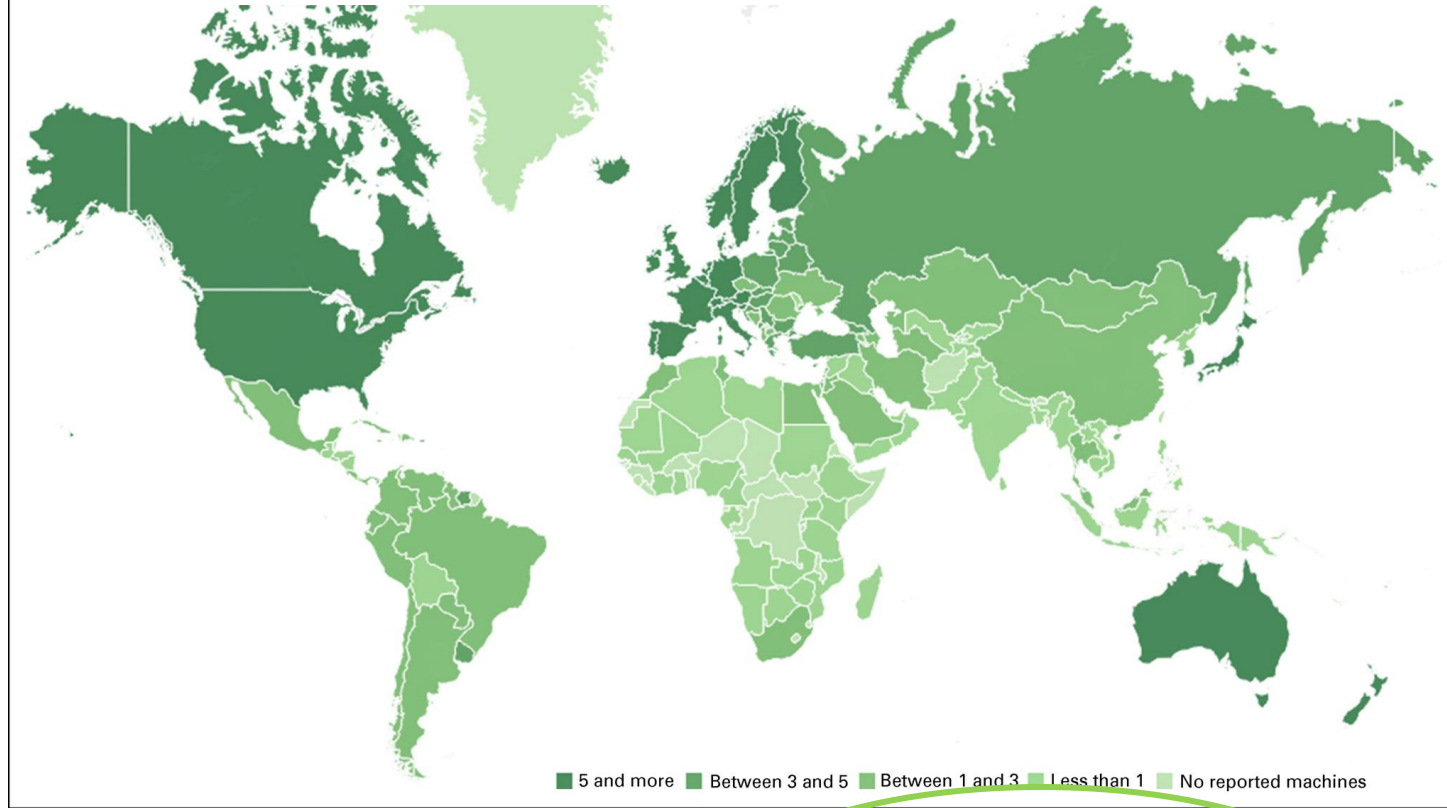
- **Unique patient identifier**
- **Administrative databases**
 - Reimbursed treatment data
 - Hospital discharge data
 - Medical record data
 - ...
- **Used classification system**
 - **International** standard classification systems (ICD)
 - **National/regional** classification systems
 - Nomenclature coding from healthcare insurance



Cancer treatment variables : 3 broad categories

Surgery – **Radiotherapy** – Systemic treatment

Access to radiotherapy worldwide per million population



High Income Countries

62	4,304	9,012	8,574	335	96
Countries	RT centers	Equipment	Linear accelerators	Radionuclide therapies	Particle therapies

Middle/Low Income Countries

89	3,047	5,465	3,711	1,742	10
Countries	RT centers	Equipment	Linear accelerators	Radionuclide therapies	Particle therapies

Belgian Cancer Regist



Global radiotherapy: current status and future directions – White Paper. May Abdel-Wahab, Soehartati S. Gondhowiardjo, Arthur Accioly Rosa, Yolande Lievens, Noura El-Haj, Jose Alfredo Polo Rubio, Gregorius Ben Prajogi, Herdis Helgadottir, Eduardo Zubizarreta, Ahmed Meghazifene, Varisha Ashraf, Stephen Hahn, Tim Williams, and Mary Gospodarowicz; JCO Global Oncology 2021 :7, 827-842

Documentation of treatment with radiotherapy: why is it important?

Interests of the clinician:

- Cancer-specific outcome (LRR, DFS, OS)
- Early toxicity
- Late toxicity ! Importance of follow-up !
 - Oncological (radiation induced cancers)
 - Non-oncological (neurological, cardial, ...)
- Assessment of possibility to re-irradiate

Interests of the epidemiologist:

- Research real-world data
 - Cancer-specific outcome on population level
 - Implementation of guidelines
 - Comparison between regions/countries/continents...
- Public health organization
 - Reimbursement of treatment
- Late toxicity ! Importance of follow-up !
 - Oncological
 - Non-oncological

Direct Attack

- **Basic principles radiotherapy – overview parameters:**

- Overall treatment time
- Treatment setting
- Treatment intent
- Fractionation & number of fractions
- Technique & used particle/isotope

Indirect Attack

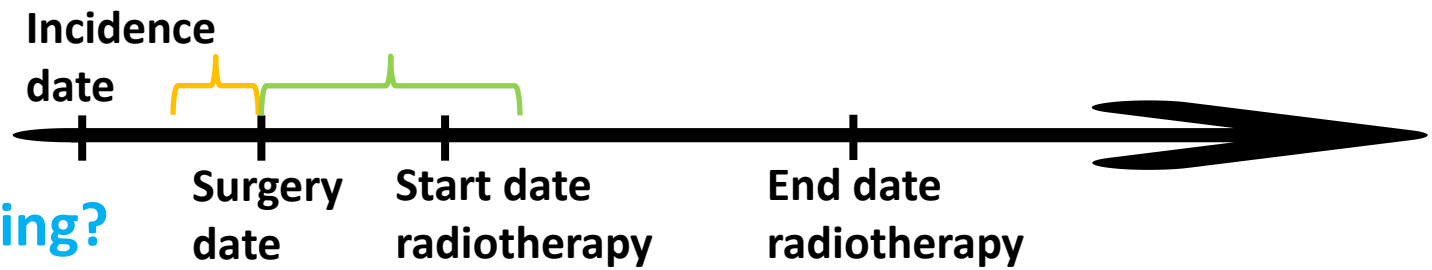
Overall treatment time

- **Start date** of radiotherapy – **end date** of radiotherapy
→ Use to determine the treatment setting

Treatment setting

- Radiotherapy can be delivered in multiple 'settings':
 - As **monotherapy**
 - As part of **multimodal** treatment
 - Before/during/after **surgery** of primary tumour
 - neoadjuvant/adjuvant setting
 - intra-operative setting
 - Before-after/together with **chemotherapy/targeted therapy**
 - sequential/concomitant setting

Treatment setting



■ Identification of treatment setting?

A. Treatment **setting registered** through standard cancer registration?

B. Use **linkage** with other data sources

■ **Aim = reconstruct timeline of treatments** with respect to incidence date

■ **In practice**

■ **Collect dates of different treatments**

- **Start date** of radiotherapy – **end date** of radiotherapy
- **Date** of surgery/chemotherapy/targeted therapy

■ **Define timeframes** around incidence date and/or surgery date

- Ex. **Neoadjuvant** [-1 mo; date of surgery]
- Ex. **Adjuvant** [date of surgery; +3 mo]

■ Sometimes treatment **setting is incorporated** in used classification

- Ex. Intraoperative radiotherapy coded in ICD-9/10

Treatment intent

- Radiotherapy can be delivered with **curative/radical** or **palliative/supportive** intent
 - Curative/radical
 - primary tumour** directed and/or **oligometastases** directed
 - Ex. Adjuvant whole breast RT, Oligometastatic prostate RT
 - Palliative/supportive
 - primary tumour** directed and/or **metastases** directed
 - Ex. Haemostatic bladder RT, Pancreatic RT

Treatment intent

■ Identification of treatment intent?

A. Treatment intent **registered** through standard cancer registration?

B. Use **linkage** with other data sources

- **Aim** = distinguish first line (multimodal) treatment from palliative intended radiotherapy

■ In practice

- Collect dates of radiotherapy delivery

- Apply timeframes

- Treatment intent incorporated in used classification?

- Ex.: health insurance reimbursement code with description of palliative intent

- ICD-10-CM/PCS

Fractionation & number of fractions

- Radiotherapy can be delivered using different fractionation-schemes and a variable number of fractions
 - **Standard** fractionation
 - **Hyperfractionation**
 - **Hypofractionation**
- **Identification of fractionation/number of fractions?**
 - A. Type of fractionation-scheme **registered** through standard cancer registration?
 - B. Use **linkage** with other data sources
 - **Aim** = distinguish different radiotherapy-schemes
 - **In practice**
 - Collect dates of radiotherapy delivery
 - Type of fractionation-scheme **incorporated** in used classification?
 - Ex. health insurance reimbursement code with description of fractionation

Technique & used particle/isotope

- Radiotherapy can be delivered using different **techniques**:
 - Conventional external beam (3D-CRT)
 - Rotating (IMRT)
 - Imaging on board (IGRT)
 - Stereotactic (S(B)RT)
 - Brachytherapy (interstitial versus intra-cavity)
- Radiotherapy can be delivered using different **particles/isotopes**:
 - Standard photons or electrons
 - Heavy particles: protons, carbon ions, neutrons
 - Gamma emitting isotopes for brachytherapy: iodine, iridium, cesium, ...

Technique & used particle/isotope

- **Identification of radiotherapy technique/used particle?**
 - A. Type of technique **registered** through standard cancer registration?
 - B. Use **linkage** with other data sources
 - **Aim** = distinguish different radiotherapy-techniques
 - **In practice**
 - Type of technique **incorporated** in used classification?
 - Ex. health insurance reimbursement code with description of technique or particle/isotope
 - Ex. used code in ICD-9/10

Practical tools: where to start? Tiers-system

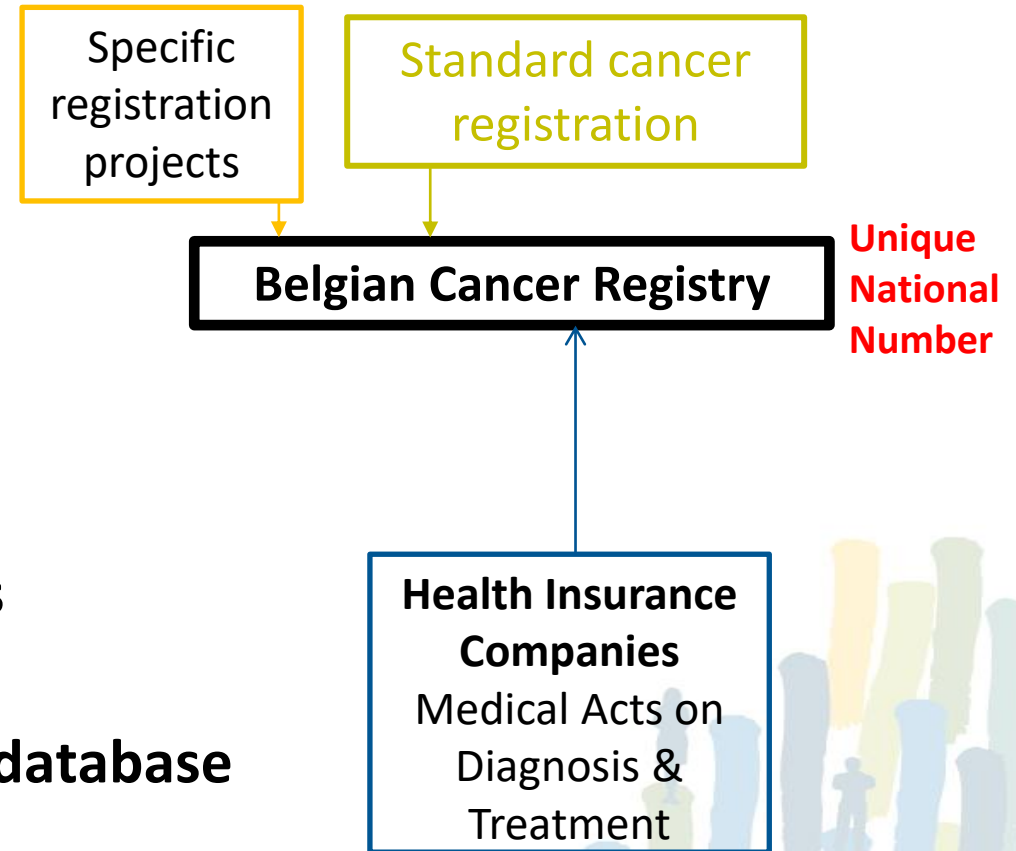
Start with the essence, build up if possible.

Tier 1: yes/no

Tier 2/3:

- Treatment setting & intent: timing in oncology care path, curative/palliative
- Fractionation
- Complexity (technique & used particle/isotope)

2 practical examples



- Data through **standard cancer registration**

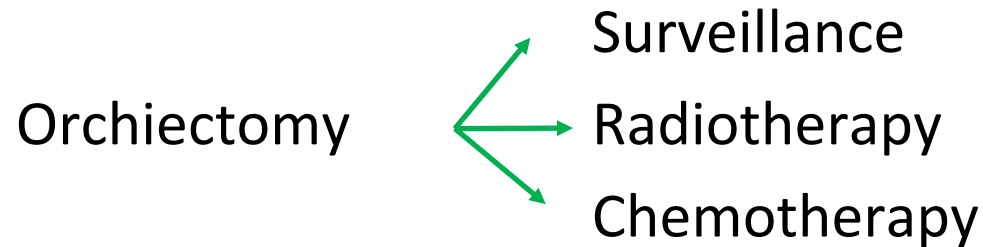
Example 2 ▪ Data through **specific registration projects**

Example 1 ▪ Data through **linkage with administrative database**

Example 1: Evaluate the implementation of guidelines

■ Adjuvant treatment testisseminoma stage I

- Standard treatment *before ESMO guidelines 2013*:

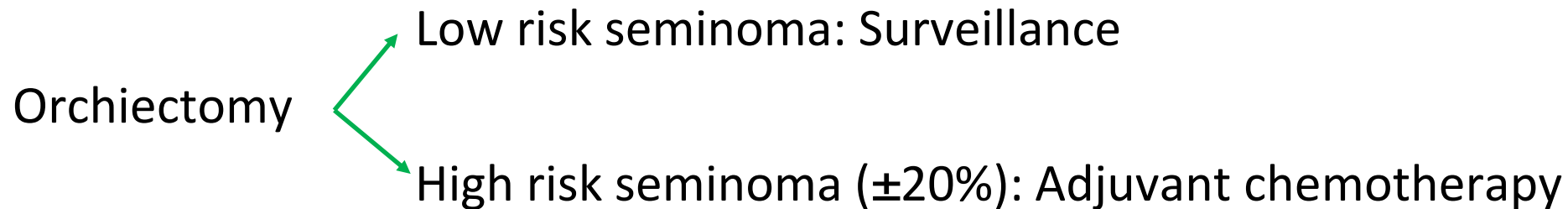


- Clinical practice guideline ESMO 2013:

clinical practice guidelines Annals of Oncology 24 (Supplement 6): vi125-vi132, 2013
doi:10.1093/annonc/mdt304

Testicular seminoma and non-seminoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up[†]

J. Oldenburg¹, S. D. Fosså¹, J. Nuver², A. Heidenreich³, H-J Schmolli⁴, C. Bokemeyer⁵, A. Horwich⁶, J. Beyer⁷ & V. Kataja⁸, on behalf of the ESMO Guidelines Working Group*

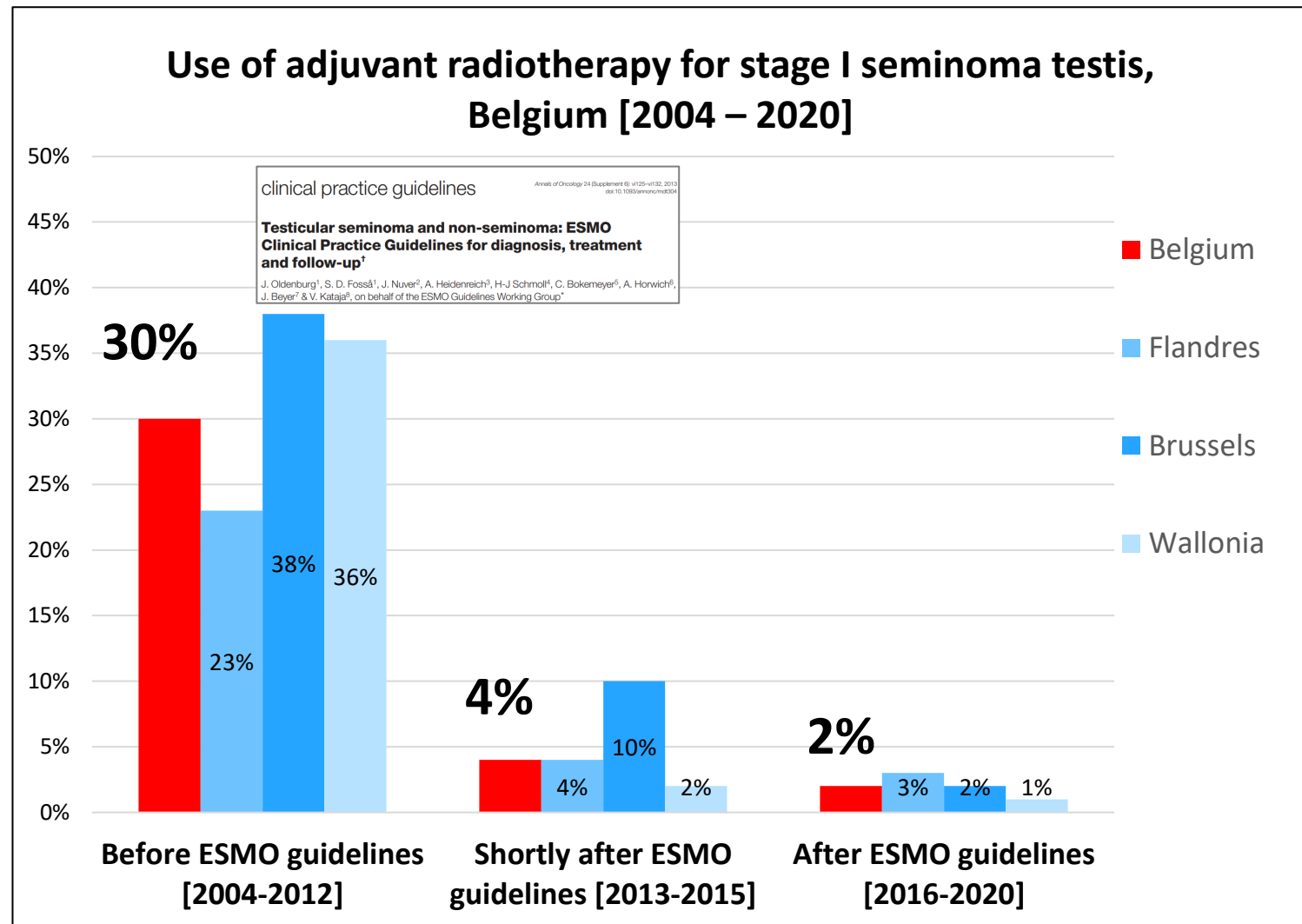


Alternative: radiotherapy

Implementation of guidelines

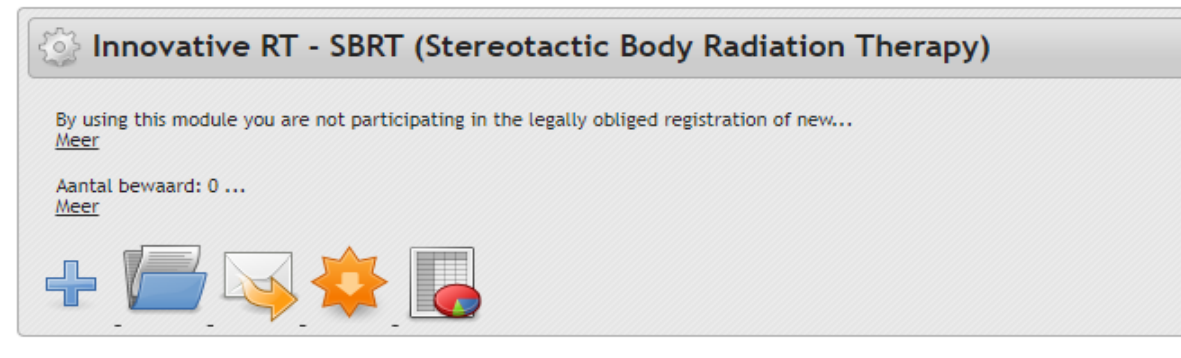
- **Adjuvant treatment testisseminoma stage I**
 - **Data source 1:** Belgian Cancer Registry:
 - Testis seminoma [2004-2020], stage I
 - **Data source 2:** Administrative data national health insurance:
 - Orchiectomy
 - Define selection of surgery codes
 - Definition timeframe [-1; 6 months] around incidence date
 - Adjuvant radiotherapy
 - Define selection of radiotherapy codes
 - Definition timeframe [date orchiectomy; +3 months]

Implementation of guidelines



Example 2: guidance of reimbursement

- **Guidance reimbursement of Stereotactic Body RadioTherapy (SBRT) in Belgium**
 - suggested by Belgian Knowledge Centre (KCE)
 - close collaboration of Belgian Cancer Registry (BCR)
Belgian National Institute for Health and Disability Insurance (NIHDI)
Belgian College for Physicians of Radiation Oncology Centres
- Aim: **examine the conditions under which to include SBRT in the medical nomenclature**
- Methods:
 - **prospective registration** of clinical and technical data through online registration tool on BCR website



Guidance of reimbursement

- Example guidance reimbursement of Stereotactic Body RadioTherapy (SBRT) in Belgium

- Results:

- 20/25 radiotherapy centres participated
 - [10/2013 – 12/2019]
 - 6,296 SBRT registrations

Final report Innovative Radiotherapy – part
Stereotactic Body Radiation Therapy (SBRT)

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- Since 1 January 2020, four new “prestations” (billing codes) have been introduced for stereotactic radiation in the nomenclature of medical prestations for radiotherapy in Belgium (Articles 18 § 1 and 19).

Cancer treatment variables : 3 categories

Surgery – Radiotherapy – Systemic treatment

After the coffee break... 

