



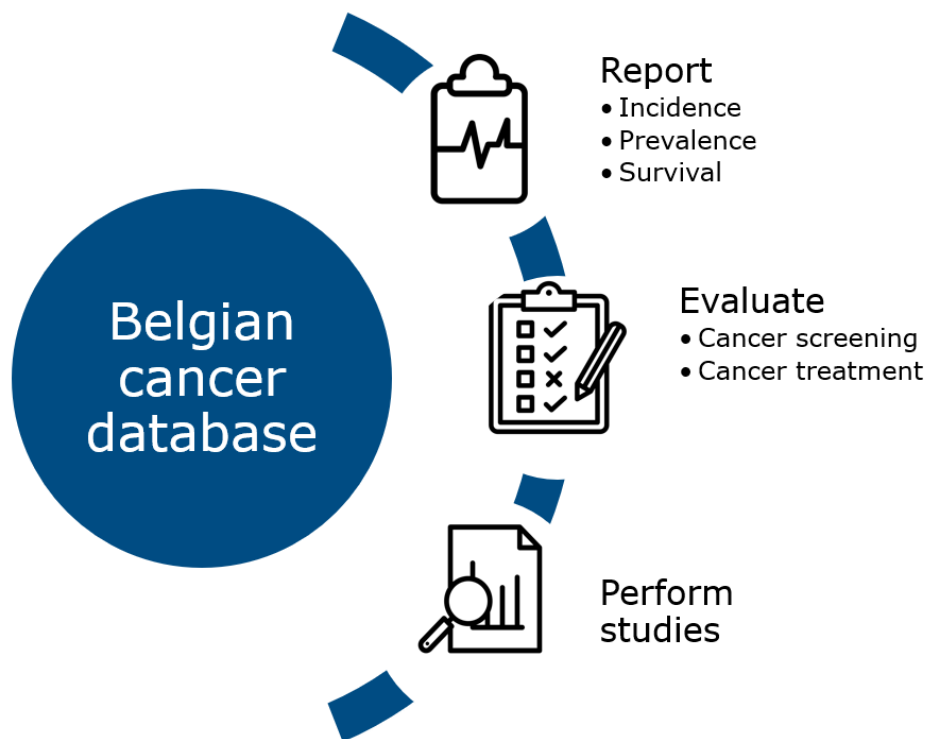
# Sensitive data sharing for research

## Challenges for a data holder

[www.kankerregister.org](http://www.kankerregister.org) | [www.registreducancer.org](http://www.registreducancer.org)



# Belgian Cancer Registry



# Legislation

- General Data Protection Regulation (GDPR)
- Coordinated Health Law of May 10, 2015: Belgian Cancer Registry (Art. 138)
- Law of December 13, 2006: Information Security Committee (Art.42)



# Data sharing at BCR – Option 1

Real-life study on the epidemiology and choice of treatment for patients with follicular non-Hodgkin lymphoma in Belgium

- Data available at BCR
- No additional data linkage needed with experimental data
- No data requested from another data holder

→ OPTION 1: Data access on our secure remote environment (VPN-Access)



# Option 1: VPN-Access

## Step 1: Research agreement

- Purpose limitation
- Overview variables: data minimalization
  - E.g.: MM/YYYY instead of MM/DD/YYYY
- Re-identification is prohibited
- No access by third parties
- Confidentiality agreement
- Publishing = only sufficiently aggregated data



# Option 1: VPN-Access

Step 2: Privacy Awareness Training

Step 3: VPN-access with two-factor authentication  
+ technical guidance

# Option 1: Challenges

- Time consuming
  - Procedure
  - Training
  - Guidance with adherence to the procedure
  - Follow-up agreement
- High costs in human resources



## Data sharing at BCR – Option 2

Study to investigate the association between early-in-life exposures to ionizing radiation and risk of cancer

- Experimental data
  - Health insurance data
  - BCR data
  
  - Data are analysed at DWH of external organization
- OPTION 2: Data transfer





# OPTION 2: Data transfer

## Step 1: Information Security Committee Approval

- Data protection info of all data holders involved
  - Contact info
  - DPO
  - Supervising physician
  - Lawfull basis data processing
  - Applicable legislation
  - Technical and organizational measures
- List data variables: proportionality and data minimalization
- Data flow: Thrusted Third Party and Small cell risk analysis
- DPIA and agreements

# OPTION 2: Data transfer

## Step 2: Data transfer agreement

- Purpose limitation
- Overview variables: data minimalization
- Re-identification is prohibited
- No access by third parties
- Confidentiality agreement
- Publishing = only sufficiently aggregated data

## Step 3: Data transfer

# OPTION 2: Challenges

- Information Security Committee
  - Time consuming
  - Approval form only in Dutch or French
  - Strict approach of the GDPR
  - After submission form many changes required
  - International studies?

# Questions?

