

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN BELGIUM

In Belgium, there is a supportive environment for data sharing, with routine sharing of data being available. The Belgian Cancer Registry provides systematic data collection for all cancer cases. The country has established mechanisms and policies to enable secure data sharing among stakeholders.

CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Screening and Early diagnosis	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data infrastructure	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information provided to patients/citizens after involving them in NGS testing	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Sharing genomic data with other institutions in the same country or cross- border	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
The purpose of genomic data in cancer centers	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>



DATA SHARING AND LINKING

CORRELATION AMONG DEPENDENT AND INDEPENDANT VARIABLE

Available

Not Available

Cross-border/cross-disciplinary collaborations



Routine sharing of data



Availability of security guidelines external/internal



Data linking to Electronic Health Record

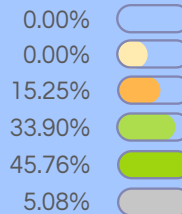


Controlling body for data sharing

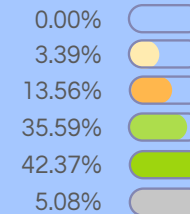


In Belgium, there is a supportive environment for data sharing, with routine sharing of data being available. The country has established mechanisms and policies to enable secure data sharing among stakeholders. Additionally, Belgium has a controlling body that oversees data sharing activities, ensuring compliance with privacy and security guidelines. However, data linking to Electronic Health Records may not be readily available or widely implemented.

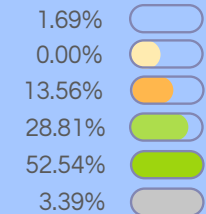
Generation of data



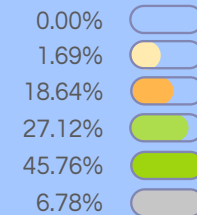
Quality of data



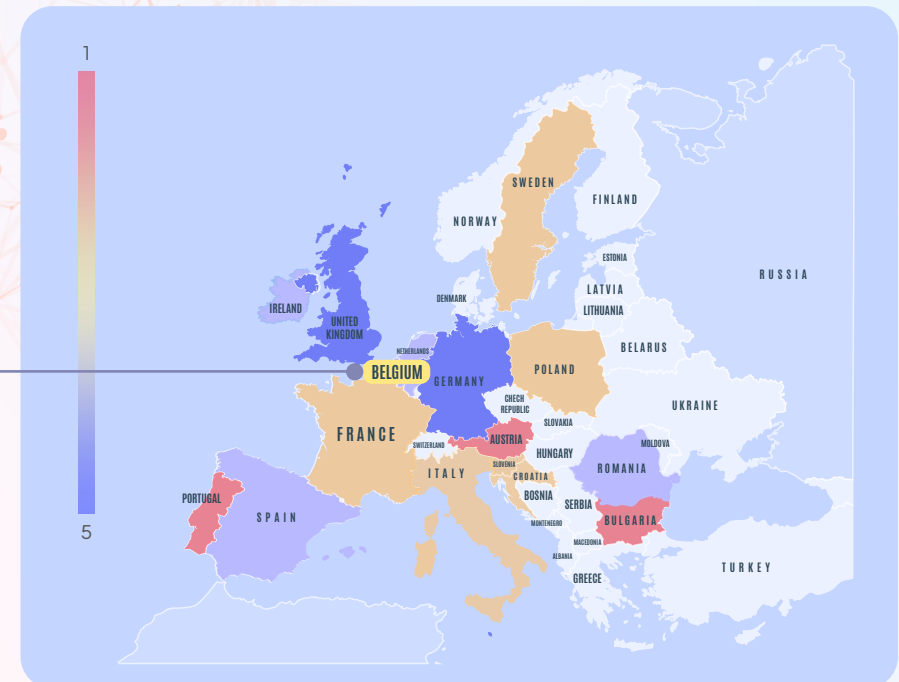
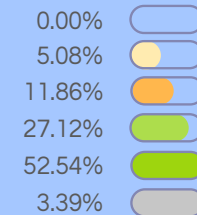
Use of data



Control of data sharing



Collection of data



DATA INFRASTRUCTURE

The Belgian Cancer Registry provides systematic data collection for all cancer cases. They have a relatively high level of confidence in their data infrastructure for NGS implementation.



Confidence Level (95.0%)

BELGIUM



Croatia



Spain



Italy



France



Germany



United Kindgom



Ireland



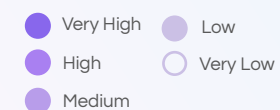
Slovenia



Poland



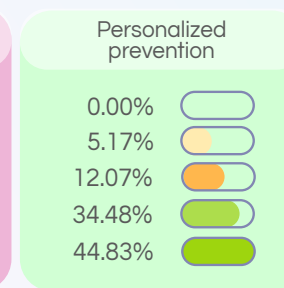
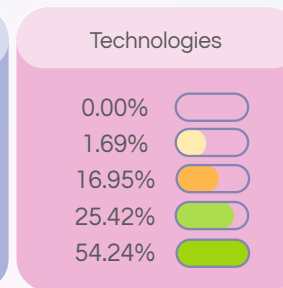
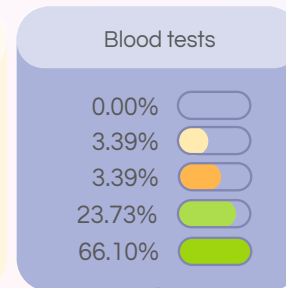
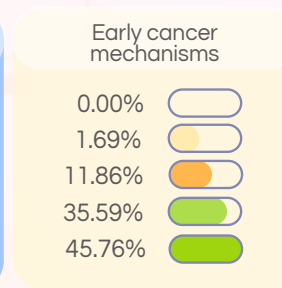
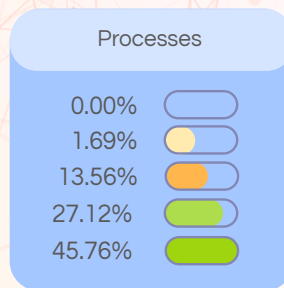
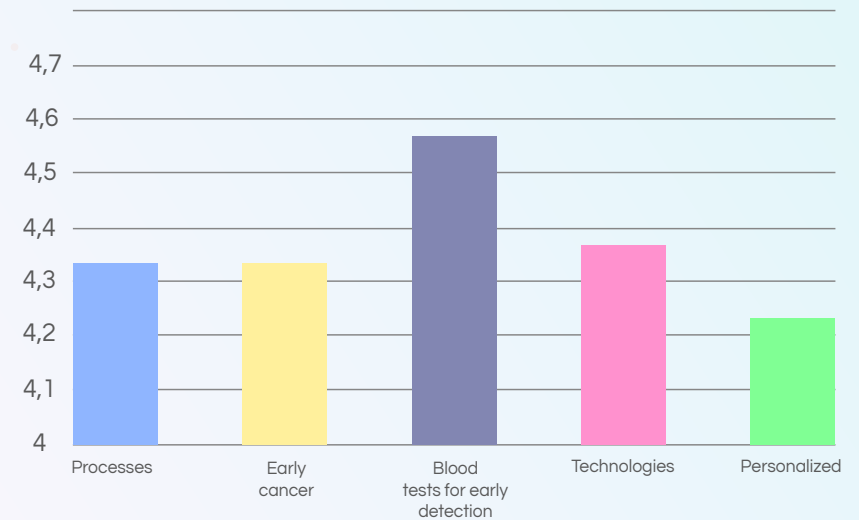
Sweden



SCREENING AND EARLY DIAGNOSIS

Analysis of measures for cancer treatment across countries and regions demonstrated both similarities and differences in the perceived importance and prioritization of these measures, with data from Belgium indicating a low perception of importance.

SCREENING AND EARLY DIAGNOSIS



Legend for importance levels:

- Not important at all
- Slightly important
- Obviously important
- Strongly important
- Absolutely important

Processes occurring before tumor development: The development of cancer is a multistep process in which normal cells gradually become malignant through progressive accumulation of molecular alterations.

Early cancer mechanisms: Cancer is a disease caused when cells divide uncontrollably and cooperate with other cells in their local environment which fosters tumor progression.

Blood tests for Early Detection: Specific blood tests are designed to identify tumor (bio)markers that may be found in the blood when some cancers are present before showing symptoms or being detected through conventional imaging approaches.

Technologies for Early Diagnosis: Numerous cancer-associated deaths occur from cancers for which we do not screen. To overcome this, new scalable and cost-effective technologies are developed to allow for the detection and diagnosis of cancers at an earlier stage when these are more responsive to treatments.

Personalized prevention and early screening: Everybody does not have the same risk of developing a cancer. Careful analysis of individual risk factors to adapt prevention and systematic screening to the risk level would increase the rate of early diagnosis

LINKING DATA FROM SEQUENCED GENOMES TO CLINICAL DATA (ELECTRONIC HEALTHRECORDS) OR OTHER TYPES OF DATA

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	Done regularly	Done on request
Comprehensive Cancer Centres	●	●
Clinical Cancer Centres	●	●

Linking data from sequenced genomes to clinical data (Electronic Health Records) or other types of data is mainly done on a regular basis both in Comprehensive Cancer Centers and Clinical Cancer Centers. Linking the EHR to genomic data enables the repurposing of vast phenotype data for genomic discovery, and EHR-based discovery can inform clinical practice.

SHARING GENOMIC DATA WITH OTHER INSTITUTIONS IN THE SAME COUNTRY OR CROSS-BORDER

SHARING GENOMIC DATA WITH OTHER INSTITUTIONS IN THE SAME COUNTRY OR CROSS-BORDER

	Not sharing	Sharing at the national level	Sharing at the national level and cross border
Comprehensive Cancer Centres	●	●	●
Clinical Cancer Centres	●	●	●

Sharing genomic data is in most Cancer Centers done at the national level, but also some Cancer Centers do not share data. To improve human health, sharing genomic research data is essential for translating research results into knowledge, products, and procedures.

INFORMATION PROVIDED TO PATIENTS/CITIZENS AFTER INVOLVING THEM IN NGS TESTING

INFORMATION PROVIDED TO PATIENTS/CITIZENS AFTER INVOLVING THEM IN NGS TESTING				
	Report on any positive biomarkers and relevant treatments	A summarized NGS testing report	Risks and benefits of the test	No information is provided
Comprehensive Cancer Centres	●	●	●	●
Clinical Cancer Centres	●	●	●	●

Comprehensive Cancer Centers are often offering complete information to patients/citizens after involving them in NGS testing. Health literacy, as called out in Europe's Beating Cancer Plan, should play a more important role not only in prevention but also in the context of precision medicine and respective NGS testing.

THE PURPOSE OF GENOMIC DATA IN CANCER CENTER

THE PURPOSE OF GENOMIC DATA IN CANCER CENTER				
	For research	For clinical trials	For research and clinical trials	For other purposes
Comprehensive Cancer Centres	●	●	●	●
Clinical Cancer Centres	●	●	●	●

Genomic data is often used for both research and clinical trial purposes. There should be initiatives like the 1+ million Genomes Initiative, which more has the aim of collecting large amounts of genomic data for research, prevention, and personalized medicine purposes.



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