FACTSHEET GERMANY

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN GERMANY

In Germany, cross-border and cross-disciplinary collaborations are actively pursued, fostering partnerships and knowledge exchange across borders and different fields of expertise. Germany's governance body, BfARM, currently provides access to data related to insurance and service providers, and to cost and administrative data for which no permission of citizens is needed.

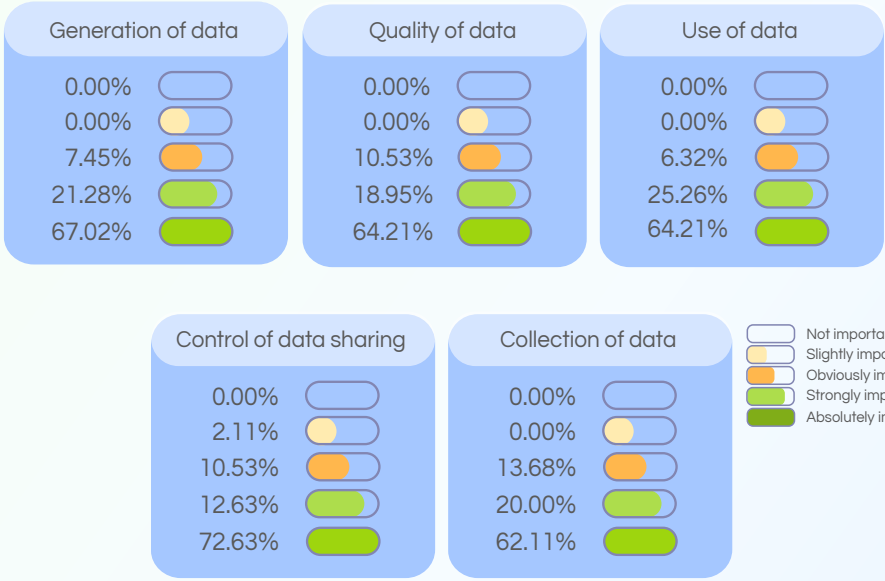
CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	●	○	○
Data infrastructure	●	○	○
Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data	○	●	○
Information provided to patients/citizens after involving them in NGS testing	○	●	○
Sharing genomic data with other institutions in the same country or cross- border	○	●	○
The purpose of genomic data in cancer centers	○	●	○

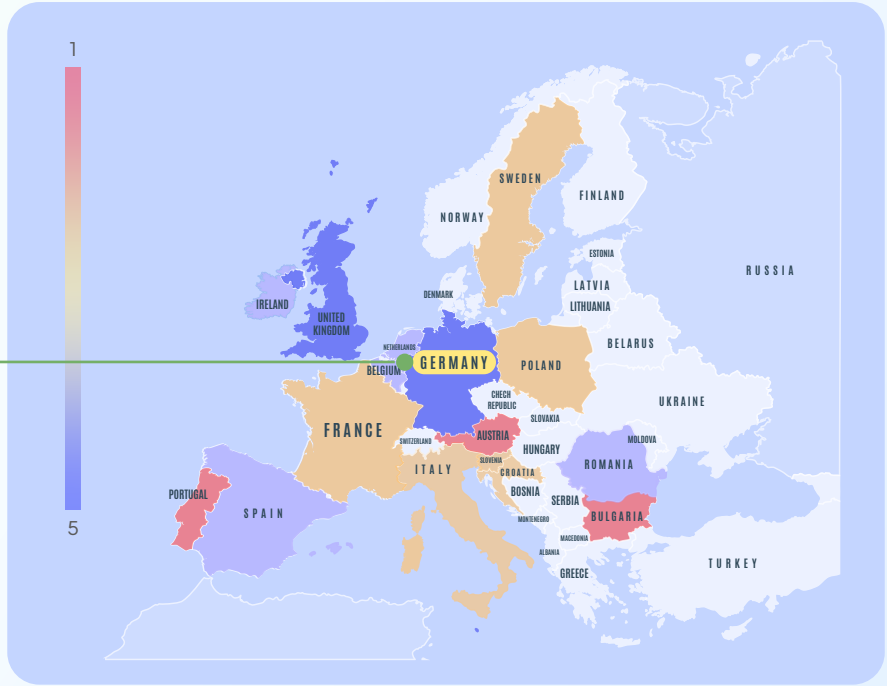
European Alliance for Personalised Medicine

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 Germany, cross-border and cross-disciplinary collaborations are actively pursued, fostering partnerships and knowledge exchange across borders and different fields of expertise. Germany emphasizes the availability of security guidelines, both external and internal, indicating a strong focus on ensuring the secure handling and protection of shared data. Data linking to Electronic Health Records is established, enabling the integration of data from various sources for comprehensive patient care. A controlling body specifically for data sharing is present, signifying the presence of an authority overseeing data sharing practices in Germany.





DATA INFRASTRUCTURE

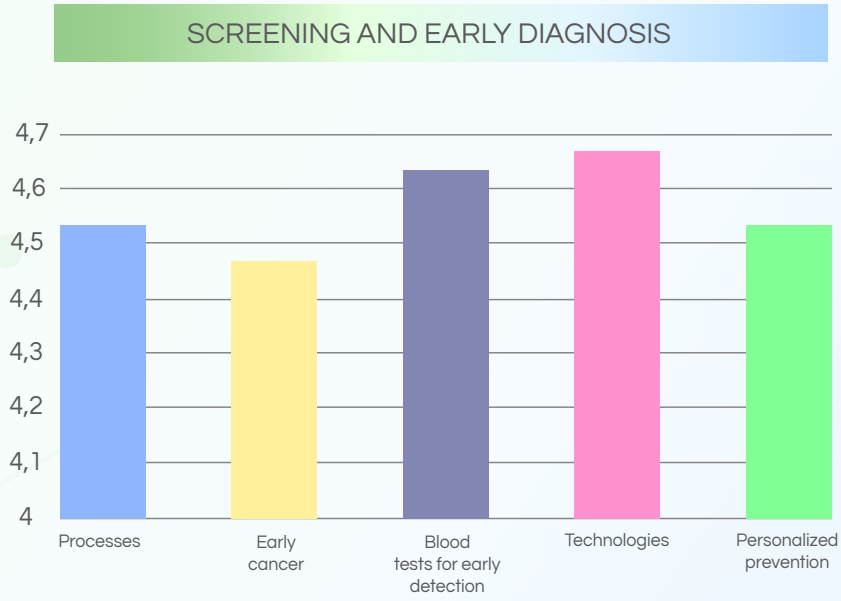
Germany's governance body, BfARM, currently provides access to data related to insurance and service providers, and to cost and administrative data for which no permission of citizens is needed. Epidemiological and survival data, in Germany, about a number of rare cancers is provided in publications based on data provided by the Centre for Cancer Registry Data.

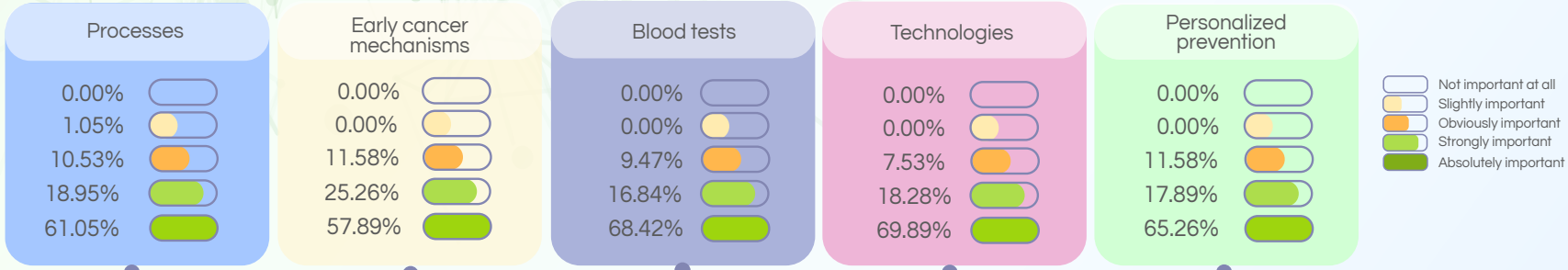
CONFIDENCE LEVEL (95.0%)	
Belgium	Low
Croatia	Very High
Spain	Low
Italy	Very High
France	Very High
GERMANY	Low
United Kindgom	Low
Ireland	Low
Slovenia	Very High
Poland	Very High
Sweden	Very High

Very High
High
Medium
Low
Very Low

SCREENING AND EARLY DIAGNOSIS

In Germany, various early detection screenings for certain cancers were introduced for all people with statutory health insurance. The offered preventive and early detection measures have been developed further based on current scientific knowledge.





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.

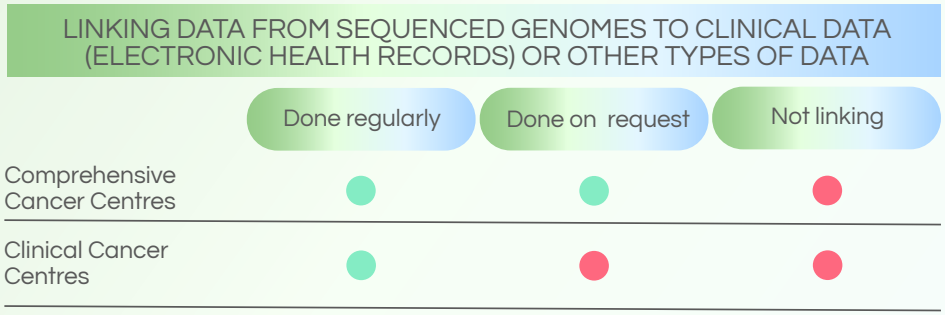
Early cancer mechanisms: Cancer is a disease caused when cells divide uncontrollably and cooperate with other cells in their local environment which fosters tumor progression.

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.

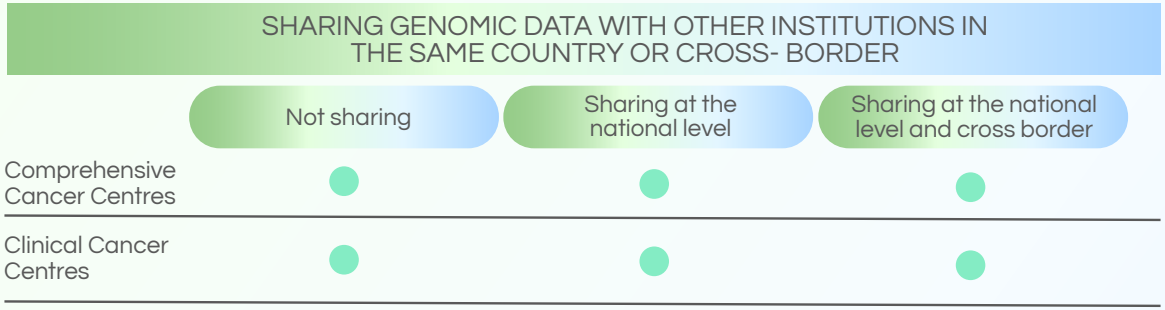
Personalized prevention and early screening: Everybody does not have the same risk of developing a cancer. Careful analysis of individual risk factors to adapt prevention and systematic screening to the risk level would increase the rate of early diagnosis

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



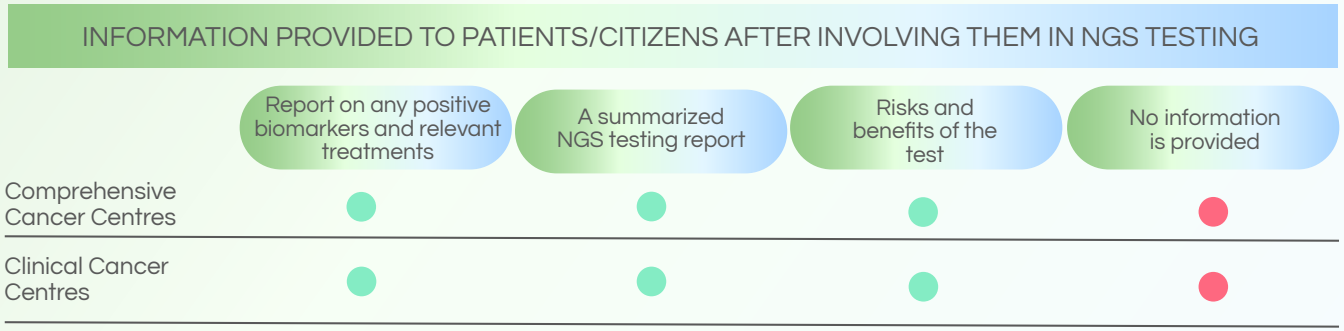
In Germany, both in Comprehensive Cancer Centers and Clinical Cancer Centers, linking data from sequenced genomes to clinical data (Electronic Health Records) or other types of data is done either regularly or on request. Data linking to Electronic Health Records is established, enabling the integration of data from various sources for comprehensive patient care.

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



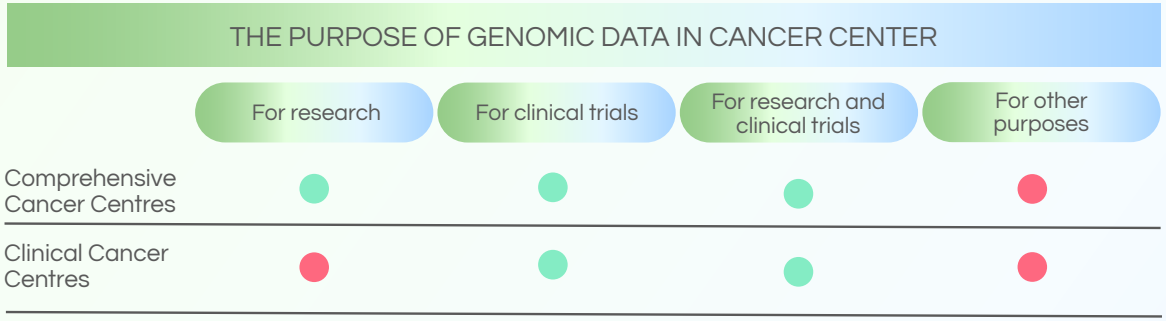
Sharing genomic data with other institutions is done nationally and/or cross-border. However, routine sharing of data is not a common practice in all the cancer centers suggesting potential limitations in the regular exchange of data among healthcare professionals and researchers.

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



In Germany, Comprehensive Cancer Centers and Clinical Cancer Centers are often offering complete information to patients/citizens after involving them in NGS testing. Efficient use of NGS can deliver patient benefits by identifying treatments (known as molecularly guided treatment options (MGTOs) that closely match genomic driver alterations.

THE PURPOSE OF GENOMIC DATA IN CANCER CENTER



Genomic data are mainly used for both research and clinical trial purposes. They aim to enable more secure and regulated cross-border access to at least one million completely sequenced genomes and additional health data.

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