FACTSHEET ITALY

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN ITALY

In Italy, there is active cross-border and cross-disciplinary collaboration, fostering partnerships and knowledge exchange across borders and disciplines. Italy has a relatively high level of confidence in its data infrastructure for NGS implementation. Data linking to Electronic Health Records is implemented, facilitating the integration of Next-Generation Sequencing (NGS) data and other sources for comprehensive patient care and research.

CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	○	●	○
Screening and Early diagnosis	●	○	○
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	○	●	○

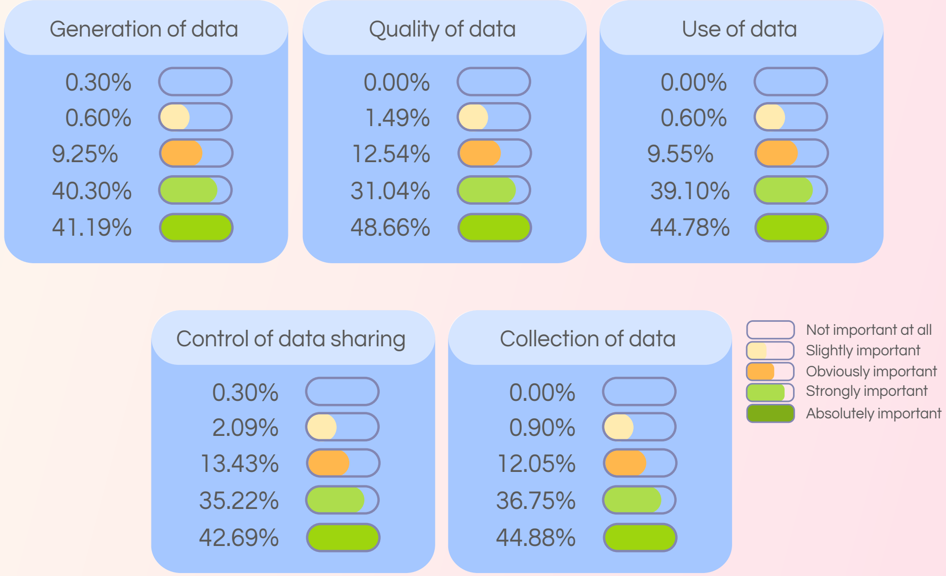
European Alliance for
Personalised Medicine

DATA SHARING AND LINKING

CORRELATION AMONG DEPENDENT AND INDEPENDANT VARIABLE

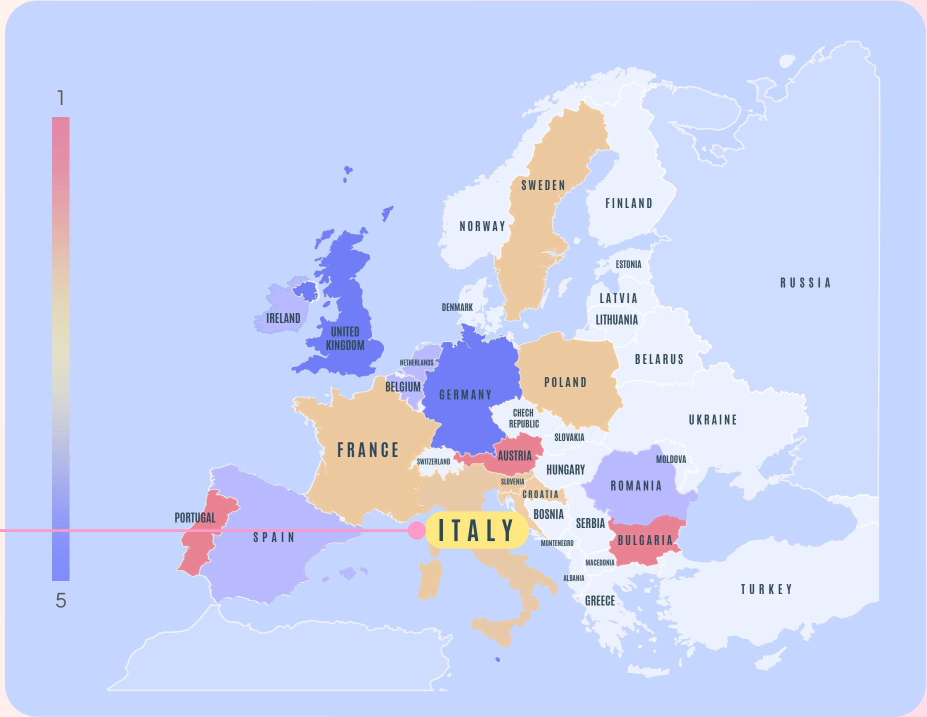
	Available	Not Available
Cross-border/cross -disciplinary collaborations	🔴	🟢
Routine sharing of data	🟢	🔴
Availability of security guidelines external/internal	🟢	🔴
Data linking to Electronic Health Record	🟢	🔴
Controlling body for data sharing	🟢	🔴

In Italy, there is active cross-border and cross-disciplinary collaboration, fostering partnerships and knowledge exchange across borders and disciplines. Routine sharing of data is practiced, enabling the exchange of information for research and innovation purposes. However, the availability of security guidelines, both external and internal, is not specified, potentially indicating a need for more established guidelines to ensure the security and privacy of shared data. The presence of a controlling body specifically for data sharing is not mentioned, suggesting a potential lack of a dedicated authority overseeing data sharing practices in Italy.



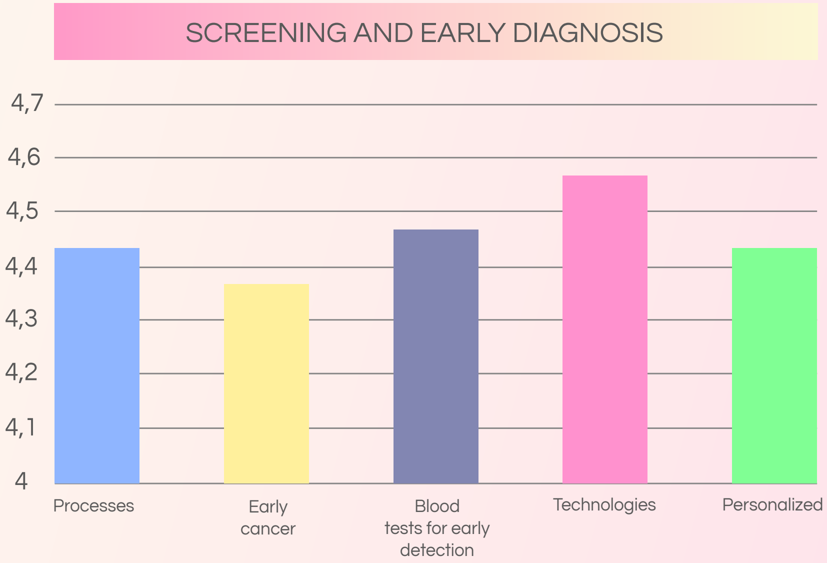
Generation of data	Quality of data	Use of data	Control of data sharing	Collection of data
0.30%	0.00%	0.00%	0.30%	0.00%
0.60%	1.49%	0.60%	2.09%	0.90%
9.25%	12.54%	9.55%	13.43%	12.05%
40.30%	31.04%	39.10%	35.22%	36.75%
41.19%	48.66%	44.78%	42.69%	44.88%

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



SCREENING AND EARLY DIAGNOSIS

In Italy, breast cancer screening is recommended every 2 years for women aged 50–69 years. Organized cervical and breast cancer screening programs have been promoted in Italy since the 90s and are provided at a regional level and implemented by local health units. Discrepancies exist, with Southern regions of Italy still showing lower invitation and attendance rates.



	Processes	Early cancer mechanisms	Blood tests	Technologies	Personalized prevention
Not important at all	0.00%	0.00%	0.30%	0.00%	0.30%
Slightly important	0.60%	0.00%	2.08%	0.59%	0.90%
Obviously important	6.27%	8.04%	5.06%	4.75%	7.76%
Strongly important	40.30%	41.37%	34.23%	30.27%	34.93%
Absolutely important	48.06%	44.94%	56.85%	62.61%	53.43%

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

DATA INFRASTRUCTURE

Italy has a relatively high level of confidence in its data infrastructure for NGS implementation. In Italy, regional cancer registries collect and transfer data to the national registry, and EPICOST Project collects data on cancer costs by region, cancer type, and disease stage to support decision making on investment in cancer care.

Confidence Level (95.0%)	
BELGIUM	◑
Croatia	●
Spain	◑
ITALY	●
France	●
Germany	◑
United Kindgom	◑
Ireland	◑
Slovenia	●
Poland	●
Sweden	●

● Very High
◕ High
◑ Medium
◔ Low
○ Very Low

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

	LINKING DATA FROM SEQUENCED GENOMES TO CLINICAL DATA (ELECTRONIC HEALTH RECORDS) OR OTHER TYPES OF DATA		
	Done regularly	Done on request	Not linking
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 either on the regular basis or on request. Data linking to Electronic Health Records is implemented, facilitating the integration of Next-Generation Sequencing (NGS) data and other sources for comprehensive patient care and research.

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 done with other institutions both at the national level and cross-border. Although there is a generally positive attitude towards data sharing in Italy, a better understanding of the lack of trust in non-profit researchers and the government is necessary to inform future genomics public communication projects and to increase awareness of NGS and advanced technologies

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

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	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	🟢	🟢	🟢	🔴

In both, Comprehensive Cancer Centers and Clinical Cancer Centers, most often full report is provided to patients/citizens after involving them in NGS testing. The NGS guidelines need to harmonize test validation, verification, clinical interpretation, and reporting of variants.

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 are used both for research and clinical purposes. Italy has pioneered the development of Public Health Genomics (PHG) policies that aim to translate the results of genomic research into health practice.

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