

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN CROATIA

In Croatia, national registries collect data on public health priorities and are accessible via the national public health information system. There should be monitoring by a national agency and some kind of universal protocol for data sharing between institutions and cross-border.

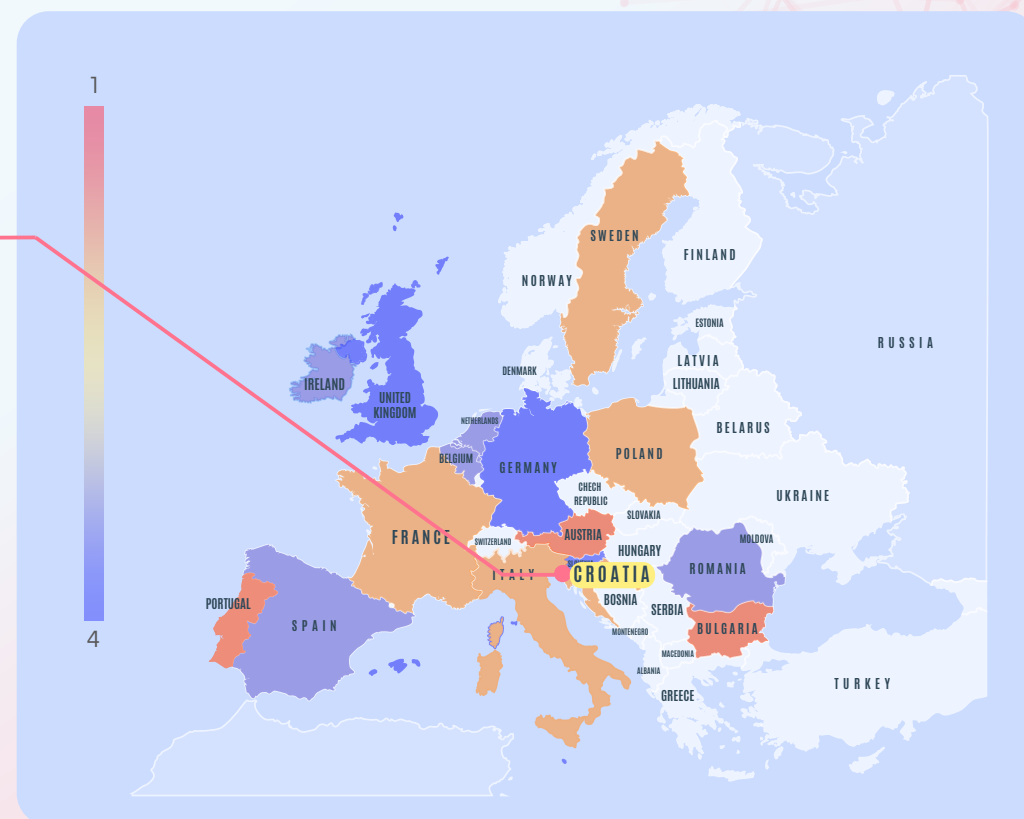
CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	☐	☒	☐
Data infrastructure	☒	☐	☐
Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data	☐	☒	☐
Information provided to patients/citizens after involving them in NGS testing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



DATA SHARING AND LINKING

CROATIA	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 Croatia, they share research data from the projects but not NGS data that arose from patient testing. They link clinical data to genomic data in the NGS testing of patients. There should be monitoring by a national agency and some kind of universal protocol for data sharing between institutions and cross-border. A pseudonymization of data is feasible.



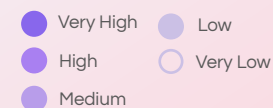
DATA INFRASTRUCTURE

In Croatia, national registries collect data on public health priorities and are accessible via the national public health information system. It is mandatory for providers to make pseudoanonymised cancer data available in the National Cancer Registry.



CONFIDENCE LEVEL (95.0%)

Belgium	●
CROATIA	●
Spain	●
Italy	●
France	●
Germany	●
United Kindgom	●
Ireland	●
Slovenia	●
Poland	●
Sweden	●



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	●	●	●
Basic Laboratories 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	●	●	●
Basic Laboratories 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	●	●	●	●
Basic Laboratories Cancer Centres	●	●	●	●

Although multiple laboratories in Croatia carry out genetic testing, there should be more coordination concerning the standards for these tests. It is very important to ensure that genetic test results are appropriately interpreted and that the patients receive correct and comprehensive information about the disease being tested. Not only there there should be better access to this service but also more regulation.

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

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	●	●	●	●
Basic Laboratories Cancer Centres	●	●	●	●

Genomic data are used both for clinical trials and for research. In Croatia, the genetic tests that are available are funded by Croatian Health Insurance Fund (CHIF). If a specific test can not be performed within Croatia, there is a possibility for medical recommendation of testing abroad.



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