FACTSHEET IRELAND

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN IRELAND

Ireland has a high level of confidence in their data infrastructure for NGS implementation. An integrated information system that spans the entire health service is lacking there. Data are shared on the national level, and a certain amount of data is shared cross-border.

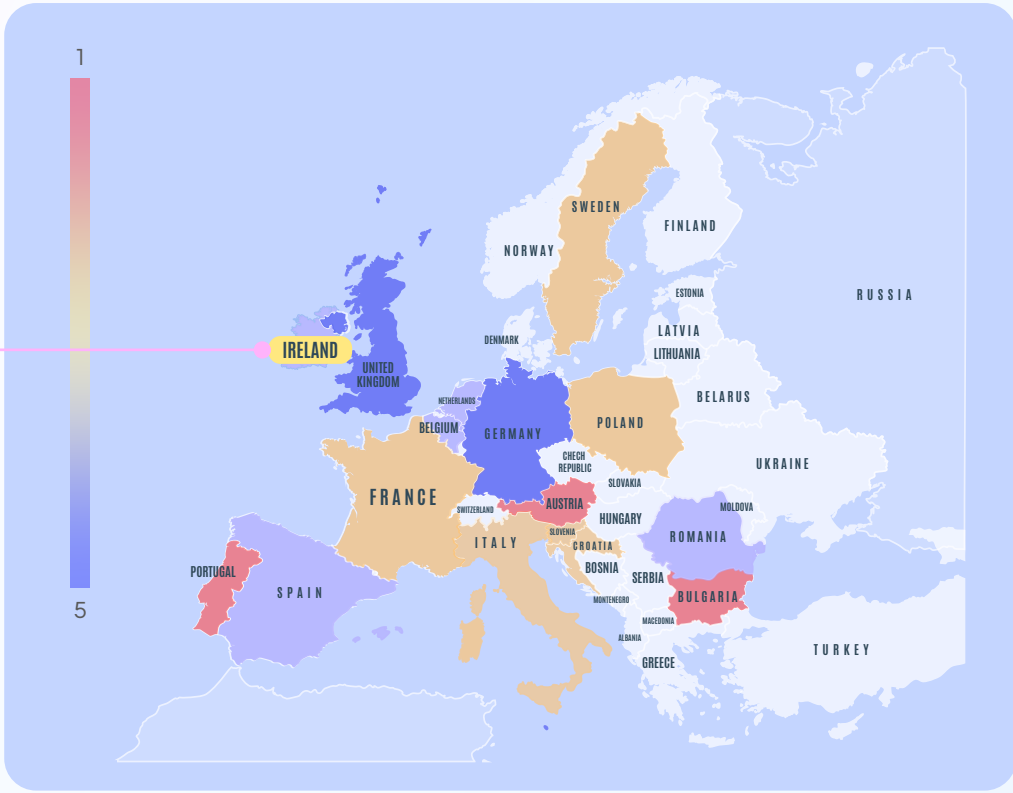
CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	●	○	○
Data infrastructure	○	●	○
Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data	○	○	●
Information provided to patients/citizens after involving them in NGS testing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

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 Ireland, there is no umbrella body that regulates data sharing across the labs. Electronic health records are not standard. They have taken GDPR to the highest level, and pseudonymization is not always feasible.



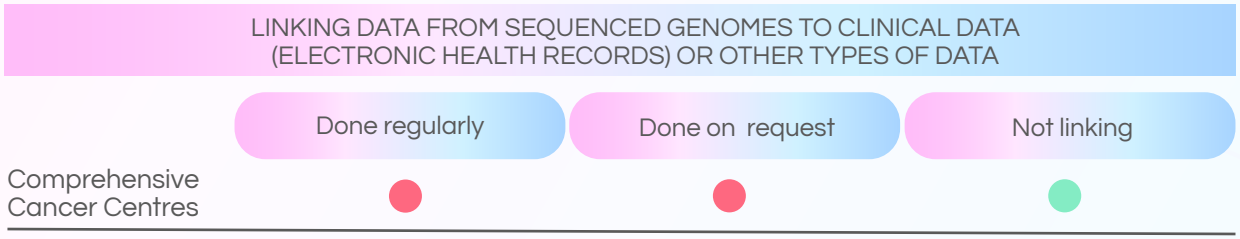
DATA INFRASTRUCTURE

Ireland has a high level of confidence in their data infrastructure for NGS implementation. An integrated information system that spans the entire health service is lacking there. To further strengthen the data infrastructure in Ireland, existing genetic and genomic data capacity and capability needs to be reviewed.

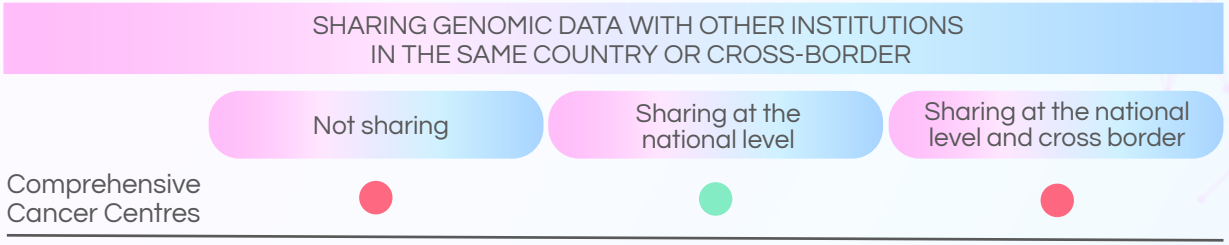
CONFIDENCE LEVEL (95.0%)	
Belgium	Low
Croatia	High
Spain	Low
Italy	High
France	High
Germany	Low
United Kindgom	Low
IRELAND	Low
Slovenia	High
Poland	High
Sweden	High

Very High
High
Medium
Low
Very Low

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

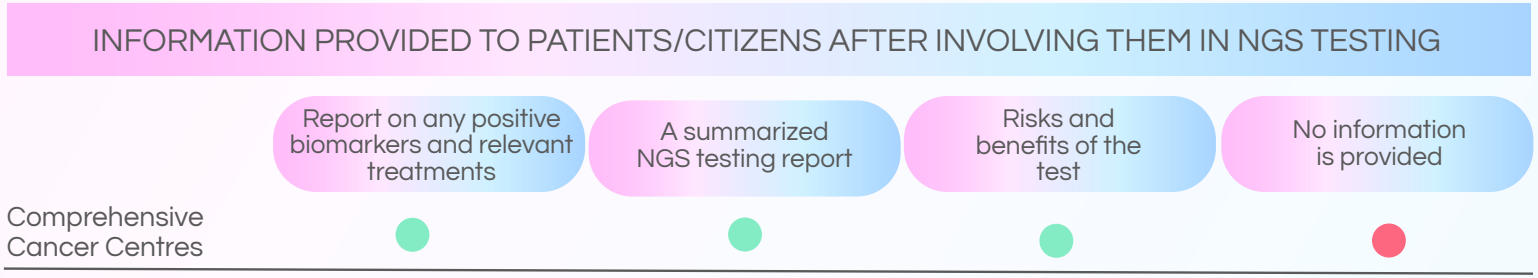


Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data is mainly not in place. Electronic health records are not standard. Linking the EHR to genomic data enables the repurposing of vast phenotype data for genomic discovery, and EHR-based discovery can inform clinical practice.



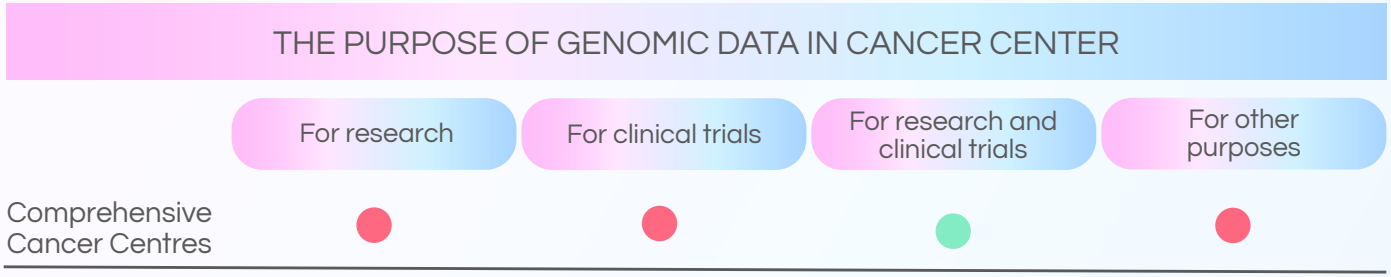
They do share some genomic data because they are referring patients to each other. Data are shared on the national level, and a certain amount of data is shared cross-border. To improve human health, sharing genomic research data is essential for translating research results into knowledge, products, and procedures.

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



Patients/citizens are provided with a summarized NGS testing report after NGS testing, while limitations of the test, risks and benefits of the test, and performance of the test are provided to them before the 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 CENTERS



Genomic data are used both for research and clinical purposes. The Irish Genomic Data Infrastructure (GDI) hub will establish best practice to manage the Irish genetic data, protecting the security of the personal data contributed by individuals.

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