FACTSHEET UNITED KINGDOM

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN UK

In the UK, there are multiple umbrella bodies regulating data-sharing and interoperability across laboratory hubs, and depending upon what type of data it is they have to apply for approval. The United Kingdom (UK) has a relatively high level of confidence in its data infrastructure for NGS implementation.

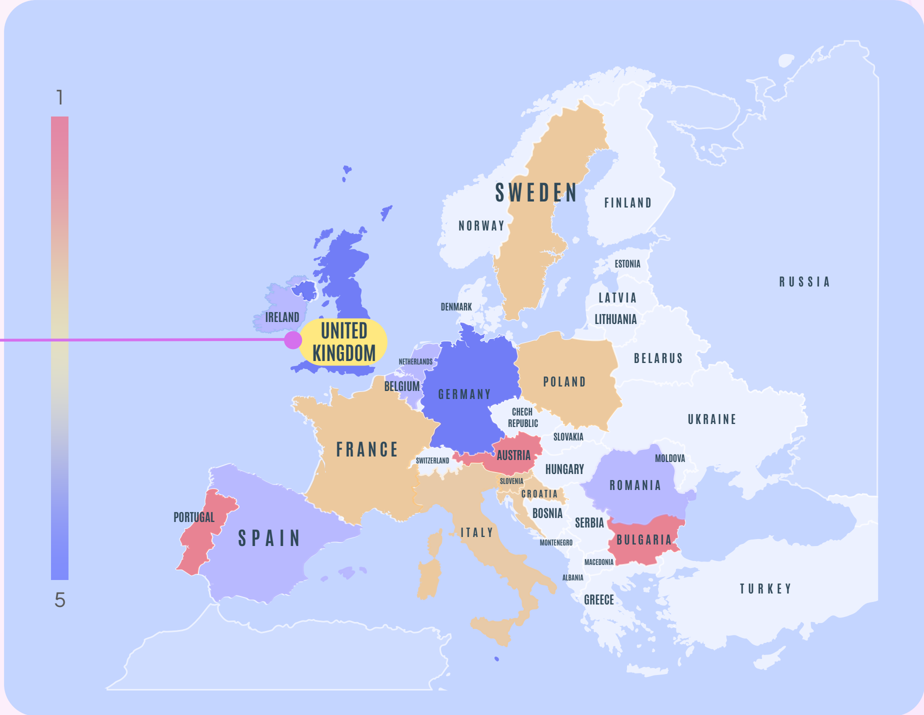
CORE PILLARS	Well Implemented	Implemented	Not Implemented
Data sharing and linking	●	○	○
Data infrastructure	○	●	○
Linking data from sequenced genomes to clinical data (Electronic HealthRecords) or other types of data	○	●	○
Information provided to patients/citizens after involving them in NGS testing	○	●	○
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

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 the UK, there are multiple umbrella bodies regulating data-sharing and interoperability across laboratory hubs, and depending upon what type of data it is they have to apply for approval. Data is mainly collected and it's mainly clinical data that they're running on. They are trying to collect clinical data based on the genetic test they've done. Also, they are trying to look at how different treatments make a difference.



DATA INFRASTRUCTURE

United Kingdom (UK) has a relatively high level of confidence in their data infrastructure for NGS implementation. There should be more collaborations among research institutions, hospitals, and other healthcare stakeholders to facilitate efficient sharing and integration of NGS data.

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

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	Done regularly	Done on request	Not linking
Clinical Cancer Centres	🟢	🔴	🔴

Linking data from sequenced genomes to clinical data (Electronic Health Records) or other types of data is in Cancer Centers mainly done on a regular basis. There should be more linking of health data and other forms of public sector data in the UK for public interest 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
Clinical Cancer Centres	🔴	🔴	🟢

Sharing of genomic data is mainly done both at the national level and cross-border in the Clinical Cancer Center in the UK. There was already evidence that the framework of laws allowing public authorities to share data for research was too complicated. A single generic power to share data for research purposes would prevent this kind of impasse for research.

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
Clinical Cancer Centres	🟢	🟢	🟢	🔴

Clinical 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

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	For research	For clinical trials	For research and clinical trials	For other purposes
Clinical Cancer Centres	🔴	🔴	🟢	🔴

Genomic data are used for both clinical trials and research purposes. Large-scale generating of genomic data could prove a powerful tool for improving population health through a better understanding of genomic contributions to health and disease.

DENIS HORGAN

Email:
denishorgan@euapm.eu

Brussels Address:
Avenue de l'Armee Legerlaan
10 1040 Brussels, Belgium