

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN SLOVENIA

In Slovenia, there is a lack of cross-border/cross-disciplinary collaborations, indicating limited partnerships and cooperation across different sectors and borders. Routine sharing of data is also not prevalent, suggesting potential challenges in data exchange and collaboration. Slovenian Cancer Registry provides surveillance data along the whole continuum of cancer care.

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	☐	☒	☐

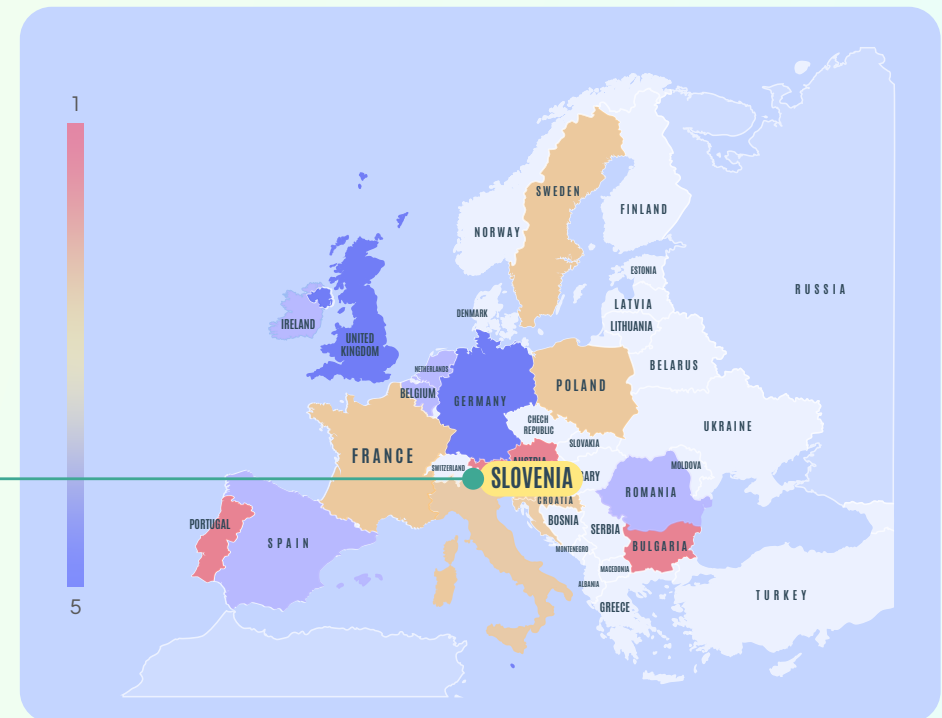


DATA SHARING AND LINKING

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 Slovenia, there is a lack of cross-border/cross-disciplinary collaborations, indicating limited partnerships and cooperation across different sectors and borders. Routine sharing of data is also not prevalent, suggesting potential challenges in data exchange and collaboration. However, there is an availability of security guidelines, both external and internal, indicating efforts to ensure data security and protection. Data linking to Electronic Health Records and the presence of a controlling body for data sharing suggest efforts toward efficient data management and coordination within Slovenia.



DATA INFRASTRUCTURE

Slovenia is showing a relatively high level of confidence in their data infrastructure for NGS implementation. Slovenian Cancer Registry provides surveillance data along the whole continuum of cancer care. Data links with other national health care and administrative databases are facilitated by unique resident identification numbers.



Confidence Level (95.0%)

Belgium



Croatia



Spain



Italy



France



Germany



United Kindgom



Ireland



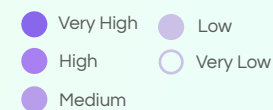
SLOVENIA



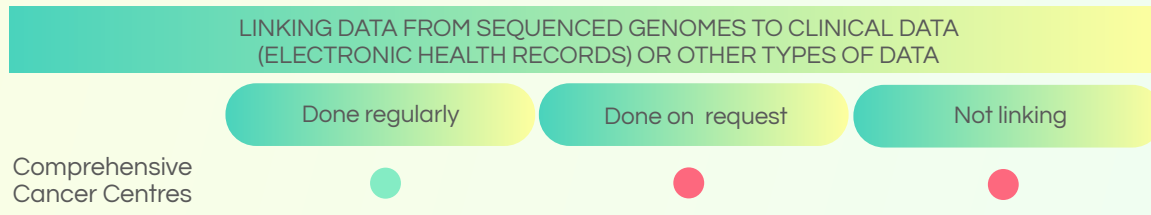
Poland



Sweden

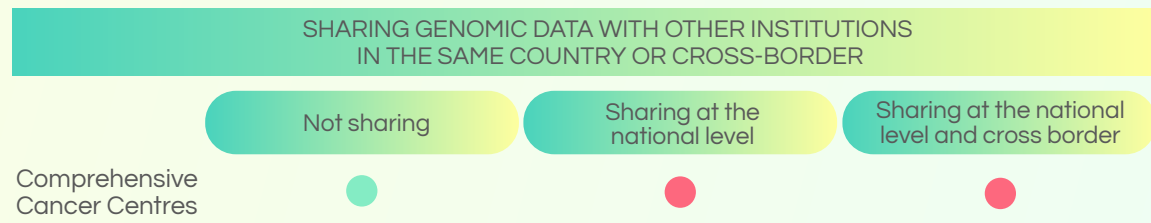


LINKING DATA FROM SEQUENCED GENOMES TO CLINICAL DATA (ELECTRONIC HEALTHRECORDS) OR OTHER TYPES OF DATA



In Comprehensive Cancer Centers, linking data from sequenced genomes to clinical data (Electronic Health Records) or other types of data is most often done regularly. 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



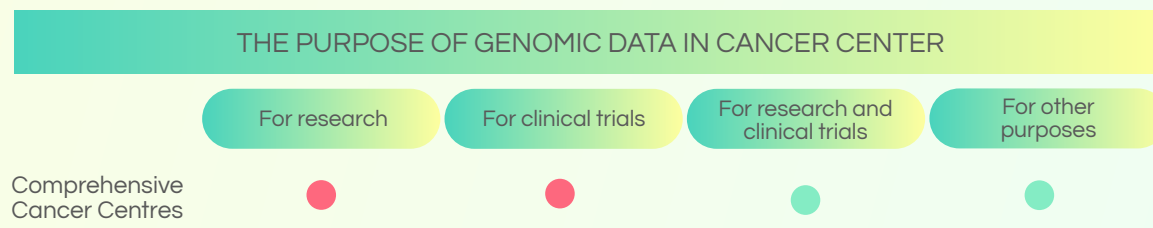
Sharing genomic data with other institutions in the same country or cross-border is most often not in place in Slovenia. The Central Registry of Patient Data (CRPD) is a core platform of the Slovenian eHealth system, enabling sharing of electronic health records on a national level.

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



Comprehensive Cancer Centers are often offering complete information to patients/citizens after involving them in NGS testing. It is essential to address the role of the healthcare professionals, access to information, incidental findings, and comprehensiveness of NGS testing by patients and relevance for family members.

THE PURPOSE OF GENOMIC DATA IN CANCER CENTER



Genomic data are used for both clinical trials and research purposes. Besides generating useful clinical information, NGS testing can also reveal a large number of data that may be considered disproportionate, although useful for research purposes. NGS testing can produce results that are not directly linked to the current cancer treatment, so this also needs to be taken into account.



DENIS HORGAN



Email:
denishorgan@euapm.eu



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