FACTSHEET SWEDEN

REVOLUTIONISING THE UPTAKE OF HEALTHDATA THE SITUATION IN SWEDEN

Sweden is showing a relatively high level of confidence in their data infrastructure for NGS implementation. In Comprehensive Cancer Centers, genomic data is most often used for clinical trials and research. The NGS guidelines need to harmonize test validation, verification, clinical interpretation, and reporting of variants.

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	○	●	○

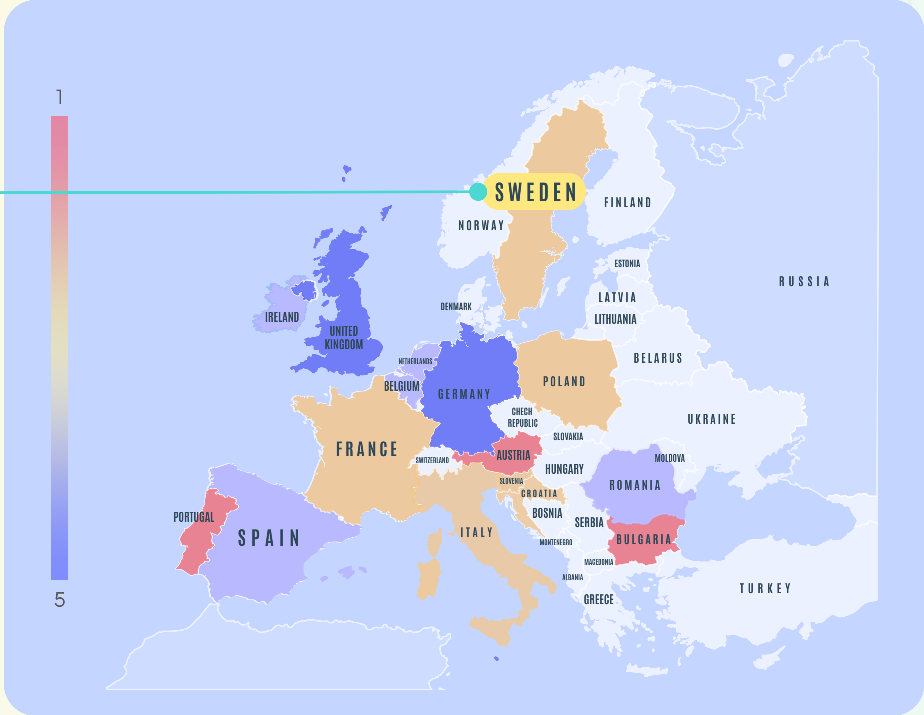
European Alliance for Personalised Medicine

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 Sweden, when it comes to the clinical data between institutions, and hospitals, they are only allowed to share data when they actively diagnose or treat one patient, but they cannot do it on a population basis. On the other hand, in the national registers, they are allowed to put the genomic data. They are moving towards genomic data sharing within the industry.



DATA INFRASTRUCTURE

Sweden is showing a relatively high level of confidence in their data infrastructure for NGS implementation. An infrastructure is currently being developed there providing national solutions for research data management and sharing.

	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
Comprehensive Cancer Centres	🟢	🔴	🔴

Linking data from sequenced genomes to clinical data (Electronic Health Records) or other types of data is mainly not done in Cancer centers. Although the public living in Sweden is open to using anonymized linked data for research purposes, some caution is advisable if the anonymized linked data joins health to non-health data.

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	🟢	🔴	🟢

Genomic data are either shared at the national level and cross border or not shared at all. 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

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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	🟢	🟢	🟢	🔴

In Comprehensive Cancer Centers, in Sweden, 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	🔴	🔴	🟢	🔴

In Comprehensive Cancer Centers, in Sweden, genomic data is most often used for clinical trials and research. The ultimate goal should be to collect NGS data together with additional test results into a molecular registry. This would improve the availability of data for clinical research, as well as facilitate evaluation and decision-making for policymakers.

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