



EU Secondary Use of Health Data: Implications for Addressing Health Inequalities in Cancer Care

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Health Data and European Policy Experience



napwha national association of
people with HIV australia

- Helped establish PWHIV organizations in Australia (national & state)



ICLEI
Local Governments
for Sustainability

- Developed dashboards on population health and wellbeing for city governments



European
Commission

- Lead author of European Commission's API Framework for Digital Governments



**HEALTH DATA
GOVERNANCE SUMMIT**
GOVERNING DATA FOR BETTER HEALTH

- World Health Organization:
Data governance research and maturity assessment

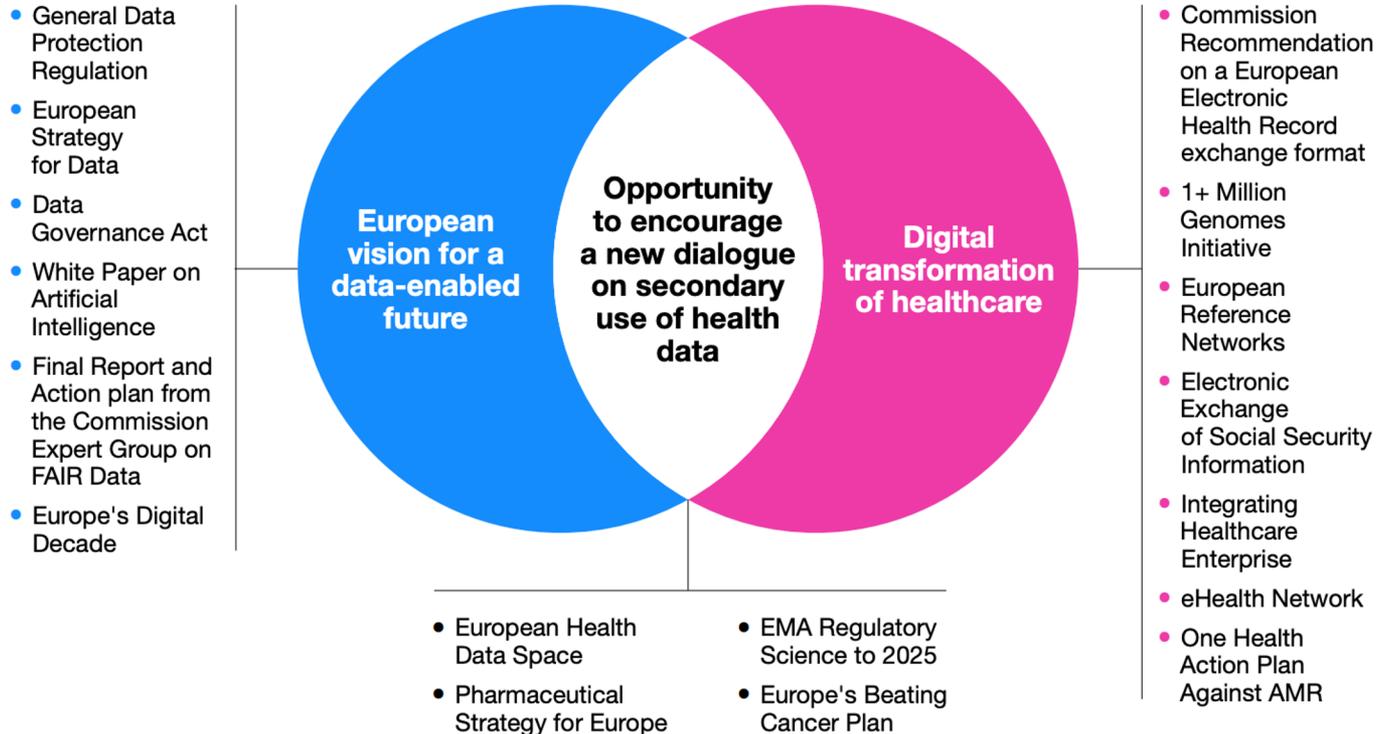
Secondary Use of Health Data

The use of **aggregated health data from population-level sources** including electronic health records, wearables technologies, health insurance claims data, health registry data (or burden of disease registries), health research data, and drug consumption data **to improve personal care planning, medicines development, safety monitoring, research and policymaking.**

**So how do we make
that a reality?**



In fact, a lot of current European-wide health policy goals will require secondary use of health data...



● Essential

● Complementary

ACTIONS **TIMETABLE**
A MODERN APPROACH TO CANCER: NEW TECHNOLOGIES, RESEARCH AND INNOVATION AT THE SERVICE OF PATIENT-CENTRED CANCER PREVENTION AND CARE

 Knowledge Centre on Cancer: better coordination of scientific and technical related initiatives at EU level.	2021-2022
 European Cancer Imaging Initiative: innovative solutions for greater accuracy and reliability in diagnostic imaging.	2022

SAVING LIVES THROUGH SUSTAINABLE CANCER PREVENTION

 Vaccinate at least 90% of girls and a significant increase of boys against human papillomaviruses by 2030 with support from EU funds and investment in infrastructure.	2021-2030
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IMPROVING EARLY DETECTION OF CANCER

 EU Cancer Screening Scheme: including updating Recommendations on screening and new Guidelines and Quality Assurance schemes.	2022-2025
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ENSURING ACCESS TO HIGH STANDARDS IN CANCER DIAGNOSIS AND TREATMENT

 EU Network linking recognised National Comprehensive Cancer Centres in all Member States by 2025.	2021-2025
 Cancer Diagnostic and Treatment for All initiative: access to innovative cancer diagnosis and treatments.	2021-2025
 European Initiative to Understand Cancer (UNCAN.eu): planned under the foreseen Mission on Cancer, to help identify individuals at high risk from common cancers.	2021-2025

IMPROVING THE QUALITY OF LIFE FOR CANCER PATIENTS AND SURVIVORS

 Better life for cancer patients initiative: Cancer Survivor Smart-Card and European Cancer Patient Digital Centre.	2021-2023
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REDUCING CANCER INEQUALITIES ACROSS THE EU

 Cancer Inequalities Registry: reducing inequalities between Member States and regions.	2021-2022
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PUTTING CHILDHOOD CANCER UNDER THE SPOTLIGHT

 Helping Children with Cancer Initiative, including EU Network of Youth Cancer Survivors.	2021-2023
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Building infrastructure to support data sharing



Using data for design of health promotion



Using data to track vaccination rates



Using data to improve diagnosis and screening



Data sharing infrastructure



Data for personalised healthcare



Data for directing towards health inequalities



Data for digital service delivery

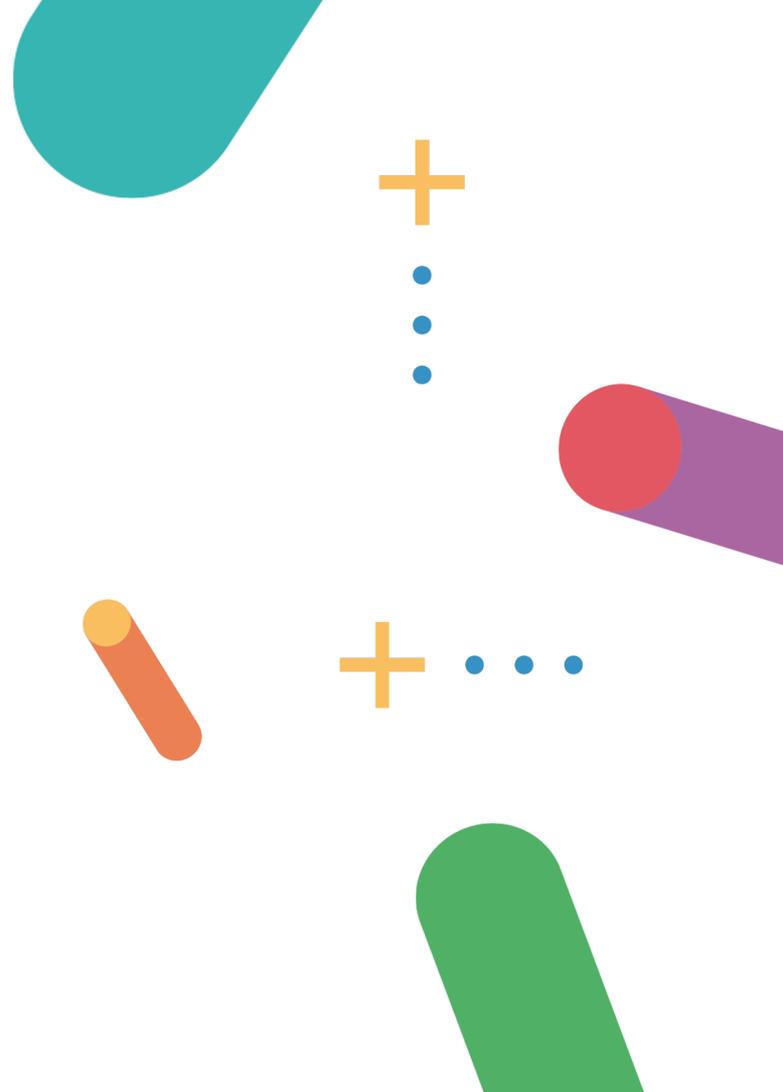


Data for addressing health inequalities



Using data for improved health outcomes

A trustworthy ecosystem



Trust is enabled...

- At a **country level** through legal frameworks and accountability
- At a **stakeholder/organisational level** through data governance processes
- At a **community level** through participation and continual engagement

Using health data to address inequalities



...Requires multi-stakeholder collaboration



Patients, people, carers,
people interested in their
own health and wellbeing,
patient organisations



Information
regulators



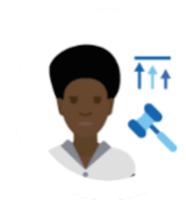
Health system
administrators, government
and private health insurance
payers



Healthcare
professionals



Competition
regulators



Health ministers, health
system leaders, diagnostic
and preventative care
professionals



Healthcare
regulators



Policy and
lawmakers



Pharmaceutical and diagnostic
industry, healthcare device
inventors, and other stakeholders
designing healthcare
interventions, including health
tech startups

...Requires enabling multiple benefits



Use cases	Optimise health systems	Improve the patient journey	Encourage patient–public participation	Expand innovation
Key benefits enabled	<ul style="list-style-type: none"> Assist with strategically directing services to those with greatest health burden <p>https://www.nature.com/articles/s41598-021-82047-0</p> <p>https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-021-11024-z</p>	<ul style="list-style-type: none"> Enables early, personalised and advanced diagnostics Personalised care pathways and clinical decision support systems ...Based on sub-population characteristics <p>https://journals.lww.com/eurjcancreprev/Abstract/2021/03000/Inequalities_in_adherence_to_cervical_cancer.8.aspx</p>	<ul style="list-style-type: none"> Encourages participation from rare disease networks and cancer patient advocacy groups <p>https://www.jmir.org/2020/3/e12689</p>	<ul style="list-style-type: none"> Enables new research Expands innovative medicine and technology development Facilitates predictive modeling <p>https://cancer.jmir.org/2021/2/e24828/</p>

Key themes emerging from our research

An open and trustworthy health data ecosystem can help Europe respond to the multiple urgent challenges facing society and the economy today

Secondary use of health data is essential to enable broader health policy goals

Trust in data sharing amongst patients and the European population is the cornerstone of enabling secondary use of health data

Clarity and harmonisation on interpretations of the General Data Protection Regulation (GDPR) is needed

Current data governance and data management infrastructure needs to be defined

Work is needed at the country level to document existing data governance processes including:

- Share anonymisation and aggregation techniques so that data is protected while being made available for interpretation and sharing
- Codes of conduct for entities making use of health data for secondary purposes
- Agreed definitions of health data models and preferred open data standards
- Data sharing agreements between entities
- Processes to submit to ethics bodies
- Health technology assessment processes.

Investment is needed at a country level to ensure interoperability of electronic health records systems