Health Information Research Infrastructure:
Policy Paper

Introduction

The right to health is considered one of the most basic human rights and plays a fundamental role in all societies. Moreover, a healthy population is a prerequisite for economic productivity and prosperity. EU countries[1] share the ambition of improving citizens health, tackling health inequalities, providing optimal prevention and universal access to safe, effective and efficient healthcare in a financially sustainable way.

Health systems are one of the most important contributors to population health. However, population ageing, technical innovations in health care, and growing citizen expectations increase financial constraints on health systems. On the other hand, increasing national health expenditures need to be able to meet growing demands. Health information, including data on health, health determinants and health systems performance in Europe allows for oriented research to increase the knowledge base and underpin policy decision-making.

To make the most of health investments, health policies and decision-making must be based on robust evidence from research on population health and health systems from high quality and timely data. International comparative research, benchmarking and exchange of best practices is indispensable for strengthening the evidence base for national and international decision-making on health and health systems.

Gap analysis

At present, there are three main challenges that hinder the availability, accessibility and use of high quality health information[2] for research and policy-making.

FRAGMENTATION

The collection and usage of data on population health and health system performance is highly fragmented in Europe and needs coordination and strengthening. Much of the evidence and knowledge remains either unused for research purposes, **dispersed, difficult to access, or incomplete** in important areas. An example is the limited data on non-communicable diseases, even though they are the main cause of death and poor quality of life and high healthcare costs in the EU[3].

Better health information governance is needed to facilitate data collection and bring together research networks in Europe, and ensure that the generated knowledge is robust and accessible.
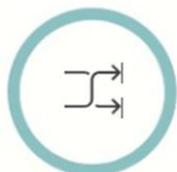
PROJECT BASED

Under the lead of Eurostat, the European Statistical System provides a solid working base for gathering and providing essential health data. However, beside this core activity by Eurostat and other international institutes and organizations, a wide range of health data collection and research activities are **funded through ad hoc projects**. This results in important and relevant

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[1] This includes EU Member States, EFTA and EEA countries.
[2] Health information is understood here as all data, evidence and knowledge that determines health and health service performance at individual or population level to facilitate research, promotion, prevention, care and support policy-making.
[3] Foreman KJ et al. Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016-40 for 195 countries and territories. Lancet. 2018 Nov 10;392(10159):2052-2090. Epub 2018 Oct 16.

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output, but causes a **lack of research continuity, lost expertise, data collection mechanisms, fading research capacity, and dissolving networks**[4].

> Mechanisms are needed to feed the knowledge and know-how generated by these networks and projects into a more permanent structure, to ensure a long-term continuity and more sustainable financing sources.

Large differences can be found in terms of **availability**, **quality,** and **comparability** of health data and information between and within countries. This makes it difficult to learn from each other. Without health information, evidence based policy is difficult to achieve. Moreover, health information tends to be poorest in areas where health itself is poorest. This does not allow to assess the full magnitude of health inequalities across the EU[5], let alone to identify appropriate, targeted action.

> Better support and coordinated action are required to reduce health information inequalities across the EU, to support countries in better use of their health data and improve the quality and comparability of data.

The way forward

The need to establish a sustainable and integrated health information infrastructure at EU level has been recognised by individual Member States, as well as, by the European Commission (EC) and the Council of the European Union[6]. A previous project called BRIDGE Health[7], has investigated possible solutions and different structures for a comprehensive, integrated and sustainable EU health information infrastructure to support research and evidence-based policy-making for EU countries.

A **European Research Infrastructure** is found to be the most feasible solution to solve the current limitations. An integrated approach offers the governance and coordination for a sustainable structure that will effectively underpin the entire research lifecycle and provide expertise, knowledge, and access to linked, reliable and precise health information.

The Joint Action on Health Information (InfAct) brings together 40 institutes and ministries from 28 countries across Europe. The aim of InfAct is establishing a **Health Information Research Infrastructure**. This work builds on the accumulated experience of several EC-funded projects. Within InfAct, partners will apply for the European Strategy Forum on Research Infrastructures (ESFRI) roadmap. ESFRI contributes to the development of a strategic roadmap by selecting vital new European Research Infrastructures for the next 10-20 years. The ESFRI application is based on expression of political support by at least three Member States, and a wide scale of inter-institutional agreements such as agreements with national public health institutes. Successfully

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[4] M. Verschuuren, et al., Public health indicators for the EU: the joint action for ECHIM (European Community Health Indicators & Monitoring), Archives of Public Health 2013, 71:1-12

[5] Health inequalities in the EU — Final report of a consortium. Consortium lead: Sir Michael Marmot.
http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf

[6] Council of the European Union. Council conclusions on the "Reflection process on modern, responsive and sustainable health systems". Brussels, 10 December 2013. [cited 2016 Jun 16]. Available at: http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/140004.pdf

[7] BRIDGE Health. Bridge Health: Concept Paper Technical Report BRIDGE Health N° WP1_2016_03 Available at: http://www.bridge-health.eu/sites/default/files/Technical%20Report%20WP1_2016_03_Concept%20Paper_final_V2_0.pdf
Bogaert P, et al. Towards a sustainable EU health information system infrastructure: A consensus driven approach. Health Policy (2018), https://doi.org/10.1016/j.healthpol.2018.10.009

applying for the ESFRI roadmap provides the Health Information Research Infrastructure with a stamp of **scientific excellence, Pan-European relevance, and socio-economic impact**. This approach paves the way for a European Research Infrastructure Consortium ([ERIC](#)) on health information.

Health Information Research Infrastructure

The Health Information Research Infrastructure will facilitate health information research by bringing together existing Pan-European research networks, supporting the development of new ones and gathering country specific experts in health information on a single web-based platform. The Research Infrastructure will operate through an integrated system of distributed nodes. These will sustainably work together under one governance structure and ultimately improve the health of European citizens. A comprehensive overview of the assets, activities and impact of the Health Information Research Infrastructure can be found in annex I.

The ideas of sustainability, connecting, supporting decision-making and improving health in Europe is taken up in the mission and vision of the future Research Infrastructure (Figure 1).
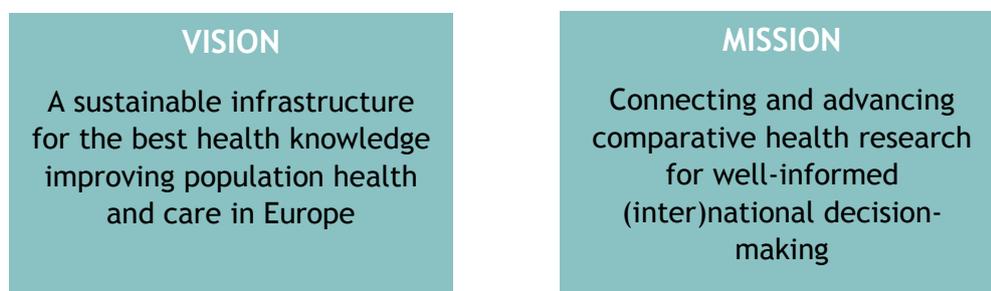

VISION	MISSION
A sustainable infrastructure for the best health knowledge improving population health and care in Europe	Connecting and advancing comparative health research for well-informed (inter)national decision-making

Figure 1: Vision and mission Health Information Research Infrastructure

The services
The Research Infrastructure will focus on the following four services:

1 One-stop-shop for EU health information research
Find the data, expert, network, guidelines or tool you are looking for

2 Innovative research in health information
Be the first to know and use the latest developments and methodologies

3 Capacity building in health information
Get expert support and training on collection, analysis, reporting, interpretation and translation

4 Decision making based on evidence based research
Know your (health) policies are based on proper evidence

Figure 2: The services of Health Information Research Infrastructure

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1.   One-stop-shop for EU health information research

The Research Infrastructure is a one-stop-shop for population health and health systems research enabling health information driven research. It pools data, research experts, research networks, guidelines and tools on a single web-based platform. It facilitates and supports the development and hosting of virtual and FAIR[8] (Findable, Accessible, Interoperable, and Reusable) data repository platforms for research. It provides central coordination for EU countries to share data and exploit economies of scale by facilitating the extension of existing data repositories and its reuse. The platform provides a forum to foster multilateral research cooperation to form and expand research networks.

2.   Innovative research in health information

The Research Infrastructure supports methodological cutting-edge and innovative research developments. This includes the development of new and more efficient methods and tools for data collection, quality assessment, (re)use, analysis, interpretation, reporting, disseminating, knowledge uptake and archiving. More specifically, the development of new research methodology with respect to the analysis of big data and data linkage, use of new emerging data sources, and priority setting and horizon scanning to inform policy-making.

3.   Capacity building in health information

The Research Infrastructure provides methodological and technical expert support for the development of comparable, standardised and accessible data and indicators for health status and determinants, health services and health systems. It enhances best practice exchange between countries and support mutual learning by focused capacity building in health information driven research through dedicated training programmes and mobility programs. Newly developed methodologies will be taught to enhance the expertise of the health information research workforce across Europe and thus tackle health inequalities.

4.   Decision-making based on evidence based research

The evidence and knowledge produced by research are not always readily usable and may need further analyses, syntheses and translations to inform policy-making. The Research Infrastructure supports researchers and institutions in charge of health and health related research to optimise their output to better inform policymakers and citizens.

The users

The Research Infrastructure will serve a wide scale of different users, of which the primary users are researchers in public health and population sciences as well as epidemiologists, statisticians, pharmacist, health professionals, data scientists, ethicists, sociologists etc. The secondary users are policy and decision-makers in national and international organisations both governmental and non-governmental organisations or civil societies, as the outcome of the infrastructure will benefit their work. Other users include:

- The healthcare sector.
- Data providers and developers in various health information domains.
- Students and educational organisations of population health and health services.

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- The media and the general population.
- Other European level infrastructures.
- Industry and private sector.

National added value

The Research Infrastructure facilitates the availability of EU health information and integrates national data into an international context for better knowledge and stronger evidence to build on. The pooled knowledge provides a better view of the national situation and trends in both population health and health system performance. In addition, the availability of expertise and training strengthens national research capacities and offers more options to share and find best practices in other countries. This provides the opportunity for better national investments based on evidence-based knowledge. Finally, it contributes to developing stronger national health information systems and strengthen the evidence base that supports well-informed decision-making at all levels.

Added value in European health information landscape

The Health Information Research Infrastructure is the missing piece of the puzzle in the current European landscape of health information. The services provided by the Research Infrastructure are not meant to duplicate current activities by international organisations such as WHO, OECD, and EC, but to fill the gap. The Research Infrastructure brings together EU networks of experts that perform comparative research in the field of population health and/or health system performance. It provides long term continuity, pooled research opportunities, and a stable structure to accommodate these networks. It ensures return of investment provided by MSs towards health information activities. Most importantly, the Research Infrastructure is EU focused and works for the benefit of the MSs in a bottom up manner, whilst liaising with international organisations.

Next steps

The ESFRI application is now in the process of development by a core writing group within InfAct and is expected to be submitted by the summer of 2020. Additional political and scientific support for the development of the ESFRI roadmap application is sought. Your expression of interest in supporting our cause is highly appreciated.

Definitions

Health information is defined as:

"All data, evidence and knowledge on health and health service performance at individual or population level to facilitate research, promotion, prevention, care and support policy-making"

Health information system is defined as:

"An integrated effort to collect, process, analyse, report, communicate and use health information and knowledge to influence policy and decision-making, programme action, individual and public health outcomes, and research"

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INPUTS/ASSETS	OUTPUTS/ACTIVITIES	OUTCOMES/IMPACT
What we invest and have available	*What we do and who we reach*	*What is our short-term impact?*
Building blocks for a strong organization Governance, experience, commitment **Our special assets** Experts, good practices, networks **Experience with project and network development** Senior investigators and project developers **Output and experience from previous research** Good practices, tools, methods, evidence **National nodes for health information** Direct access to national resources	**Provide services to our research networks** Build and expand platform functionalities Support data management and exchange Support cross-national capacity building Support data quality maintenance Support project development and fundraising **Provide services to policymakers and stakeholders** Build a policy portal for health information Assess national health information systems	**A comprehensive set of research networks** **More comparable data for research** **More equal national research capacities** **More effective use of existing data** **More efficient use of research funds** **Improved knowledge transfer** **A common research agenda** **Better data and indicators for health policies**
Our ambitions and values	*How we work on impact and future strength*	*What is our long-term impact?*
Be a reliable and desirable research partner **We believe in European research collaboration** **Work with stakeholders in the field of health and health care and citizen oriented research** **Aim for equity, sustainability, quality, efficiency** **Aim for FAIR data** **Better health and care is our core business** **We work for the public good**	**Liaise, communicate, teach and advocate** Liaise with stakeholders and decision-makers Liaise & coordinate with other ERIC's Collect & distribute information and news Organize our advocacy and communication Organize conferences, meetings and fora **Develop and implement knowledge brokering** For health professionals and policymakers Reach out to NGO's, citizens and private parties **Enlarge our conglomerate of distributed research networks** Identify and support new partner networks **Expand our research focus and potential impact** Support knowledge transfer research Foster foresight studies Support cost-effectiveness research Support horizon scanning and priority setting	**A stronger, sustainable EU health research infrastructure** **Full grasp of population health, determinants of health and their trends** **Understanding health system dynamics** **Mature national health information systems** **The leads in comparative EU population health research** **Better EU health and well-being** **Efficient European healthcare systems** **Health is wealth: stronger economies**

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