INFACT
Joint Action on Health Information

The burden of health reporting in the European Union

D5.2 'Cataloguing health information networks,
projects and indicator sets': indicator sets
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"…an indicator should be usable, in the sense it is easy to communicate; indicators that are already reported across countries, including those in the SDG monitoring framework, are appealing as they reduce reporting burden."[1]

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Executive summary

This document is part of Deliverable 5.2, prepared within task 5.2 'Cataloguing health information networks, projects and indicator sets' of the Joint Action on Health Information (hereinafter referred to as InfAct) with project number 801553 and funded by the Health Programme of the European Union.

This subtask discusses health data (indicators) that are collected by different international organisations and used for a number of international comparative health reports and comparative research efforts. International networks and projects that deal with collecting, improving and comparing health data and information play an important role as well, but are discussed in a separate report.

The purpose of the document is to provide options on how to ease the reporting burden of the European countries regarding the delivery and reporting of health indicators.

The document describes the major European health data collections and data sets, examines the operationalisation of six specific health indicators in detail in order to look at issues of comparability, to judge the availability of indicators, and discuss data quality and the reporting burden connected to each indicator. Finally, it describes the major actors, projects and programmes that have influenced the current state of health indicator collecting and reporting in Europe.

Some of the main problems are overlapping but differing indicators, irregular data collections and having to organize double data deliveries.

The system of National Nodes on health information proposed by the Joint Action InfAct can probably contribute to harmonizing and streamlining this process and ensure well-functioning and timely data and information flows.

The problem of the reporting burden has been acknowledged by the agencies that collect the data and report on them, but the final solution must come both from these technical agencies and from the national political level.

Suggestions are made to reduce the burden of reporting and to improve and harmonize the now very shattered process of defining, collecting and reporting on health indicators in Europe.

Key points

Delivering a wide range of not fully harmonized indicators to the different international agencies can be burdensome for national agencies.

Streamlining, collaboration and data sharing, together with political support at the highest level, are both needed to ease the reporting burden and improve the quality and comparability of the indicators and improve the evidence to support national and international health policymaking.

InfAct: A health information system perspective on the reporting burden for health information, data and indicators in Europe:

A critical view on the development and exchange of international comparative health information and data

I. Introduction

This report is an attempt to alleviate the problems connected with health reporting, in particular with easing the burden of health reporting. It is part of task 5.2 in the Joint Action on Health Information (InfAct[1]). This subtask discusses health data (indicators) that are collected by different international organisations and used for a number of international comparative health reports and comparative research efforts. International networks and projects that deal with collecting, improving and comparing health data and information play an important role as well, but are discussed in a separate report. The report will present both a general and a specific view on reporting problems, followed by some insights and proposed solutions, for instance in the area of coordination and communication at the national level.

The general overview will describe the current major international health data and indicator repositories and ongoing efforts to improve, harmonize and develop European health indicator sets, identifying some of the complex interactions taking place as well as pointing out options and possibilities for simplification, harmonization and reducing double efforts.

The specific view will first examine some common issues connected to international indicator reporting. It will then go on to take the form of an analysis of indicator consistency and comparability in the databases of the three big actors in the field of European health reporting: WHO Europe, EU/Eurostat and OECD.

Lastly, the report will demonstrate how communication and coordination at the national and international level may help to ease the reporting burden.
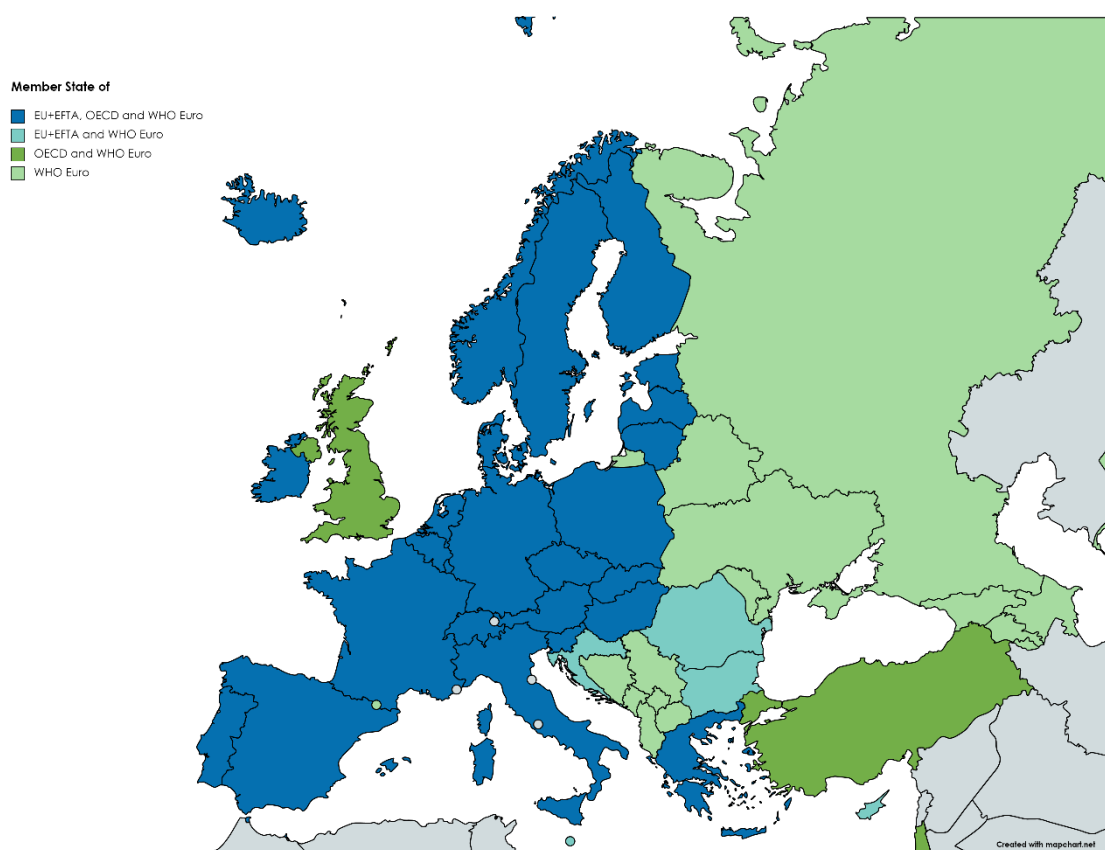
Why do we need to share international comparable health information?

European countries share their health data with a number of international organisations. These shared data collections create comparable databases that allow the comparison of their population health and health system performance with those of other countries. International comparisons add another dimension to assessing a country's population health and the underlying causes, including health care and prevention. Such comparisons provide a better view on the developing health situation in Europe and the existing inequalities and enable countries to learn from each other, regarding e.g. policies and interventions, and serve as an early warning system by identifying undesirable trends in other countries. Comparable data from their member states will also allow the international organizations to prepare comparative assessments of Regional (e.g. European) health and healthcare.

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[1] https://www.inf-act.eu/

Health data transfers from countries to international organizations have as basis either legal obligations (i.e. EU-regulations: 1338/2008 and 359/2015)) or (semi-)voluntary gentleman's agreements between the countries and international organisations (e.g. for WHO, OECD). In the case of Eurostat, the statistical office of the EU, there is a legal obligation for the 27 EU Member States and 4 EEA/EFTA states to deliver specific datasets. The data that are requested currently include a large part of, but not all, health and healthcare data. OECD collects data from its 37 members, which do not include all European countries, nor all EU/EFTA countries, but also include a number of countries outside Europe. WHO Europe collects data from all the 53 countries in what is defined as the European region.

Figure 1: the different subsets of European countries

The health data collections that result are published in large data and indicator repositories for the use of national and international policymakers, health researchers and other interested parties. The organisations also publish them regularly in comparative international health reports.

Why is organising and/or taking part in the European health information system often a burden for the reporting countries?

Given that there are several international organisations that collect different sets of national health data, often separately; this requires a serious effort by the professionals in

the various countries that deliver the data, as the datasets need to be delivered according to defined specifications. Often, moreover, national data are collected separately, by different national institutions. This means the data are not automatically present at one location, so a national effort is needed to collect the data and make them ready for the international exchange. This is an additional burden on all national health information systems.

Then, a second serious effort emerges, but for other professionals, when these health data, mostly in the form of indicators, are incorporated into concepts of comparative international health reports. These reports contain an evaluation or interpretation of the data, which then require critical scrutiny by national domain- and data-experts. The concept reports are sent to ministries and/or national experts, but often deadlines are short or inconveniently timed (e.g. the month of August). Having different kinds of international organisations and networks in place has its advantages, but may also mean that policy makers are confronted with different numbers for the same phenomenon, which is difficult to work with. Moreover, there is a huge overlap in conclusions and messages that pertain to population health and health systems in these reports.

In the meantime and in parallel there are several committees and expert groups of health information experts who are working in the background on the evaluation and harmonization of existing data sets, and developing new indicator sets and new metadata as well as on defining new health data needs and possible data sources. Finally, still other expert work is going on to develop new and better health data classifications in order to optimize the basis for working with and better comparing health data. This work requires different forms of expertise as different data types and methods of collection are involved and very different classifications are needed as well as knowledge about data interoperability at the national and international level. Together with the fact that within countries there may be multiple organisations dealing with the collection of the data, the overview of who is doing what even within single countries may be missing, which can create both omissions and double work and prevents the implementation of a national health information strategy.

As countries would ideally participate with the right national expertise in all or most of these various activities and processes, this requires sufficient national expert capacity. This may especially become a burden for smaller or poorer countries that may already have less sophisticated health information systems. The emergence of a so-called health information gap could be a non-desirable result.

The managers and governing bodies of those responsible for all these health information activities sometimes feel that at least part of this international work is a 'burden'. These activities, including the data deliveries, the assessment and evaluation of many international health reports, and constant calls for new indicator development and work related to classification and standardization. The fact that these data are also available directly via repositories can create other problems. When, for instance, apparently similar indicators that show different numbers in different data repositories, users will get irritated or confused. All this can be felt by those involved in managing the national health information system as a health reporting burden and the ambition to reduce this burden is the motive behind this report.

It is generally felt by both researchers and policy makers that it is important that international organizations collaborate, reduce double work and try to minimize the burdens of health reporting [2, 3] in order to:

- make optimal use of the respective expertise of each stakeholder,
- reduce the reporting burden of member states,
- avoid doubling or tripling of work by the international organizations and/or the publication of inconsistent information,
- efficiently support capacities necessary for population health monitoring, both at the national and international level, and
- maintain a valid and reliable data and information base, both at national and international level.

We aim to provide an overview of what is and has been going on in the area of health data exchange and indicator development in Europe and identify and discuss some of the problems that cause objective and subjective burdens of health reporting. We will put this in the context of the current interaction of countries and international organizations in the health information area. We aim to suggest improvements that may reduce the burden of health reporting.

What kind of problems may be connected to the data that are being collected?

There are key indicator sets that are explicitly meant to be collected by as many countries as possible [4, 5], but some indicators may still be unavailable [6].

When data are unavailable, estimates are often made [3], but these may not be fully comparable.

Even when data are collected, both comparability and quality may still be problematic [4, 7], partly because of weak use of metadata (rich data descriptions and definitions) [8], but also because countries' health systems, including their health information systems [9], are organised in different ways.

II. Approach

The authors have used the information from both the scientific and grey literature available to them from their many years of experience in the area of international health information and indicator development in Europe, both as researchers or experts representing their country in expert groups on health information and as users of international and national health data sets. A short list of resources in the form of links to indicator lists, metadata sets, data presentation tools and relevant reports will be presented.

We chose to focus on the existing European health indicator sets and data repositories and their development as the central elements of this study, because health indicators may create ambiguities by different operationalisations and definitions and via the possible use of different data sources for the same indicators. Furthermore, they are often politically sensitive as part of international comparative health reports. Indicators, datasets and policies are intimately involved, in that indicators will be needed to prioritize or evaluate a policy, but a policy is also needed to decide which indicators to use in surveillance [10]. A very good or very bad score for a country on an indicator in an international health report may cause political havoc.

We will describe a number of processes and organizations that are central in European health data collection and indicator development and thereby play a central role, current or future, in the European burden of health reporting.

With regard to indicator sets, we will focus on international indicator sets that consist of indicators from combined fields and sources, such as the indicator set used in WHO's European Health for All database (Euro-HfA) and those by OECD and Eurostat.

We will not look into international indicator sets that consist of indicators from one specific field or area, such as disease-specific registries, many of which are not included in international databases. The latter type of indicator sets are often made primarily by and for researchers, who also deliver the data. They also contain very specialised indicators that mainly serve a strictly medical or a scientific purpose. This information is often also too detailed for the more general international comparative health reports. Still, they can be very relevant for more detailed international comparisons of specific aspects of health and care.

III. Results

In our analysis of the underlying field of data collection and reporting, we will first discuss the data and indicator repositories of WHO Europe, OECD and Eurostat, which are relevant for many European countries. Next, we will consider the ECHI(M) and subsequent BRIDGE Health and InfAct projects, which are focusing on health information harmonization and health reporting, on health indicator matters and on reducing the reporting burden in Europe. We will also consider the JAF Health indicator list, which analyses the performance of national healthcare systems but overlaps with other health indicator sets.

We know that there is also work going on at the back-office of the data exchange process, solving technical problems and problems about data quality and definitions. There is also work at the front office, i.e. the actual content of the collected health information in terms of the definitions and prioritising of the indicators that are to be collected.

Large international health datasets

WHO/OECD/Eurostat: data and indicator repositories

Three main agencies have under different mandates been collecting health data/indicators that are comparable between European countries within each agency, but not necessarily between the agencies, , over the past decades. They all started by collecting indicators for use in printed health reports, and later made their own data tools for presenting comparable data. We will not consider the reports in this context, but look at the presentation tools and indicator sets.

WHO Europe has been collecting data for use in the Health for All database, later subsumed by the European Health Information Gateway [11]. All the 53 countries belonging to what the WHO defines as the European Region are included in this health information system, which is continuously developing to offer the most comprehensive set of health information tools in Europe. In this report, the abbreviation HFA is used for the Health for All data set.
Other relevant data sets from WHO are the Health 2020 monitoring framework, here abbreviated H2020 (now to be replaced by an new monitoring framework, based on the new European Program of Work 20-25) [12], and WHO's Global non-communicable diseases monitoring framework, abbreviated NCD. SCORE (Survey, Count, Optimize, Review, Enable) for Health Data [13] represents WHO's global commitment to support Member States to improve population health, as was the Joint Monitoring Framework [14], which was also framed as a means to reduce the reporting burden. As of April 2021, only a few European countries are represented in the data portal (see Resources), but there are country reports for most European countries and plans for expansion.

OECD, the Organisation for Economic Co-operation and Development, consists of 37 countries, whereof 28 (depending on definitions) lie in Europe. The OECD.Stat system includes data for some countries outside OECD, but does not always contain data for all the member countries, depending on the indicator. The abbreviation for the OECD Health Statistics data set used in this report is OECD HS.

Eurostat has 31 national partners, namely the EU, EEA and EFTA countries. The European Statistical System, ESS, is the partnership between the Commission and the national statistics institutes and other responsible authorities. ESS also works with candidate countries, other Commission and international agencies, including OECD, the United Nations, the International Monetary Fund and the World Bank. On Eurostat's web pages, there are different reports and databanks that cover many different statistical fields, including public health and healthcare. The two main indicator sets of the European Commission are the European Core Health Indicators (ECHI) and the Joint Assessment Framework on Health (JAF-Health). The former was initiated by DG SANTE whereas the latter resides under the wing of DG EMPL.

In collaboration with the national partners, data are collected regularly, both by requesting data from the partners and by coordinating surveys, such as the European Health Interview Service, EHIS. Key data from EHIS are featured in Eurostat's database, along with data from many other areas.

Historically, not all countries have been required to report to these health information systems, but since all three of them have collected many of the same indicators, a lot of work had to be done in triplicate (at least for countries that were members of the three organisations).

From 2010, WHO, OECD and Eurostat have used the Joint Questionnaire on Non-Monetary Health Care statistics (JQNMHC) [15, 16] to obtain health data from participating countries while ensuring that the same definitions are used for all three institutions. The JQNMHC, which explicitly is meant to reduce the reporting burden in the participating countries [16], was revised and expanded in 2013, 2015, 2017 and 2019, but the reporting burden is still seen as a problem. A major reason for this is the fact that there is no integrated EU health infrastructure [2], which is one of the reasons behind the Bridge Health project and InfAct [17], which aimed to establish a sustainable and integrated EU health information system for both public health and research purposes.

Nevertheless, there can be no doubt that the JQNMHC made a significant improvement in reducing the reporting burden for the participating countries.

The Joint health accounts data collection [18], better known as SHA (System of Health Accounts) [19] is another attempt by the same three parties to reduce the reporting burden of the participating countries.

Other important health indicator sets and data collections with relevance in the European context include the Sustainable Development Goal Indicators [20], and WHO's Global Reference List of 100 Core Health Indicators, both included in the Resources section.

Below, we elaborate further on the two EC indicator sets: the ECHI and the JAF-health indicators.

ECHI/ECHIM/BRIDGE/InfAct: establishing and developing the ECHI-indicator list

Between 1998 and 2008 three ECHI (European Community Health Indicators) projects, funded by the European Union Health Programmes, constructed the ECHI indicator set [21, 22], in order to make a common health information and knowledge system to monitor

health and provide a snapshot of public health in Europe. During the process, a great number of indicators were suggested, and the ECHI longlist contained almost 500 indicators [23]. A shortlist of indicators was suggested in 2004, and when the project was over, the shortlist contained 88 indicators [reference?].

The Joint Action ECHIM (2008 – 2012) built on the work of these earlier projects, expanded the metadata for the indicators and finally ended up re-naming the ECHI indicator set. From 2013, ECHI stands for European Core Health Indicators [4], and they are available from the European Commission's public health web pages.

The BRIDGE-Health project (Bridging Information and Data Generation for Evidence-based Health Policy and Research) [24, 25] and the Joint Action on Health Information (InfAct) made practical suggestions to further refine and modernise the indicator list, but also concluded sustainable governance and systematic update procedures are needed.

These ECHI-related projects did a great deal to standardise European health indicator reporting, and the use of the shortlist undoubtedly led to great savings in labour as well as greater international comparability. Nevertheless, the reporting burden is still a problem for many European health institutions [2], and many different indicator sets are in use in different kinds of reporting.

The JAF Health indicator list

The JAF (Joint Assessment Framework) Health indicator list [26] is here included as an example of the many different kinds of health information-related work that is ongoing in the present context, and shows how much of this work is indicator focussed and indicator driven.

The JAF Health indicator list has taken up a number of ECHI-indicators but has a focus on the assessment of performance of national healthcare systems within the context of the Open Method of Coordination (OMC). The OMC is used by Member States to support the definition, implementation and evaluation of their social policies and to develop mutual cooperation. It is a tool of governance based on common objectives and indicators, the method supplements the legislative and financial instruments of social policy. It is part of the implementation of the process of coordination of social policies, particularly in the context of the renewed Lisbon Strategy.

It was developed in 2013 with the support of the Commission services (in particular DG Employment, Social Affairs and Inclusion and Eurostat, with due consultation of DG SANTE and DG ECFIN) and discussed in the Indicator Subgroup (ISG) of DG EMPL's Social Protection Committee (SPC), and the member states in the SPC agreed upon the indicator list. The JAF-list is divided into six dimensions: 1) Outcome; 2) Access; 3) Quality; 4) Non-healthcare determinants; 5) Resources; 6) Socio-economic situation. For each indicator, the country's distance to the EU average is used as a flag to signal a potential area where that health system differs from that of other countries. The most recent JAF health indicator list was agreed on by the ISG in June 2017 [26].

The JAF Health indicator list is currently under review. OECD has proposed adjustments with the overall aim of having a more concise list of indicators that better measure

inequalities in health and access to quality care, and highlights the link between health and employment. In January 2020 there were discussions in the Indicator Subgroup regarding a roadmap for the future on the basis of an external report [27].

The future work on the JAF Health indicator list was thought to require 3 main steps, which also point to needed developments for the other health indicator lists:

Step 1: Reviewing of the JAF Health dimensions and indicators on the basis of a previous OECD report [28].

Step 2: Considering avenues for further work to get more effective and granular data on access to healthcare. The ISG Indicators Subgroup has been invited to consider whether data achieved through proposed methods would add value and be useful in designing access policies. (to be finalised by the middle of 2021)

Step 3: Considering further expanding JAF on the basis of new streams of work (step 2). (to be finalised by the end of 2021).

Comparing the indicator sets

In the near future, an important task would be to examine the differences and commonalities between the different European data sets and indicator lists, and try to see where both lists and processes could be aligned or preferences discussed on the basis of data quality and policy priorities. This work must not be left to technical staff without policy support and needs to be agreed by a group of Member State experts.

Reporting issues

At the national level, the process of reporting indicators to international organizations is often complex. Seen from the national contact points and health information systems, some problems regarding international data collection have been overlapping indicators, irregular data collections and having to organize double deliveries, i.e., the same, or almost the same, indicators delivered to and collected by several international databases. Internal data collection within each country may also be an added burden, when the national contact point for an international agency must order and deliver the latest data from several different national registries and other data sources. The system of National Nodes on health information proposed by InfAct is aimed at streamlining this process and ensure well-functioning data and information flows [29].

Other issues that are parts of the reporting process:

- Having to send experts to more than one international expert group that discuss the same issues
- Having to comment on several (often annual) reports from international organizations
- Having to explain the appearance of different numbers for apparently similar indicators in different datasets
- Having to ask the owners of specific data, e.g. data registries, to deliver data to the national contact point, without the ability to pay for this extra work or the legal obligation to enforce data delivery

- Having several networks within one country that deal with the same topic but from a different organization/mandate (i.e. Burden of Disease and Health Literacy), which may be confusing for the users of the information (the WHO may draw different conclusions, or define different data needs and indicators than the EC networks, for various reasons).

From the side of the data receiving parties, data sets with gaps, either from missing years or from missing indicators, have been and still are an issue. Missing data are so common that specific methods have been devised to cope with the problem when using the data for research [30, 31].

For both parties, the international agencies and the data sources in the different countries, international comparability has been and still is the desired outcome, but not always obtainable, especially since thin metadata have made it difficult to know exactly what the data stand for [32]. If different definitions are used in different datasets, inconsistency leads to confusion.

Lippeveld et al. (2000) define the requirements for health information systems (HIS): "In summary, health information systems integrate data collection, processing, reporting, and use of the information necessary for improving health service effectiveness and efficiency through better management at all levels of health services"[33]. The present report sees reporting as the most important part of an international health information system, but with the understanding that a national HIS has to serve more functions than just reporting indicators. Quality assessment, clinical trial support, local or regional management support, patient safety monitoring and several other forms of health data use are also important at the national level.

Health indicator consistency across major databases

Table 1: Availability of indicators in major European datasets

Indicator name	HfA WHO	ECHI	JAF	OECD HS	WHO H2020	WHO NCD
Smoking	Y	Y	Y	Y	Y	Y
Self-reported health	Y	Y	Y	Y	N	N
Cancer screening	N	Y	Y	Y	N	N
Alcohol consumption	Y	Y	Y	Y	Y	Y
Life expectancy	Y	Y	Y	Y	Y	N
Vaccination coverage	Y	Y	Y	Y	Y	Y

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WP 5.2 of InfAct has selected six indicators/indicator areas to analyse to look at possible issues of comparability, both between countries and between indicator sets, judge the availability of indicators, their quality and reporting burden. The six selected indicators are: alcohol consumption, life expectancy, vaccination coverage, smoking, self-perceived health and cancer screening. Originally, the aim was to collaborate with the European Health Information Initiative (WHO Euro) on this, but the activities of the EHII were subsequently put on hold, and the future of the EHII is by no means certain, though there are plans to bring the network back in action. Still, previous work on indicator comparisons from different indicator sets as done under the EHII flag contributes to assessing the comparability and relevant differences between international indicator sets [34, 35].

Smoking

Comparability

On the whole, the different European indicator sets on tobacco smoking are quite comparable, in that the definition commonly used is the same, Daily smoking, age 15 or older as measured by a health interview survey. There are, however, differences in the different data sets, particularly regarding the age group 15-18 years. This group may be included in the survey, or can be covered by special youth surveys. This is illustrated by Figure 2, below.

Figure 2: operationalisation of smoking in different European datasets

Level	Status	Dataset	Code	Indicator name	Indicator operationalisation
Indicator		ECHI	44	Regular smokers	Proportion of people aged 15+ reporting to smoke cigarettes daily.
Indicator	WiP	ECHI	45	To be established - Pregnant	To be established - Pregnant women smoking
Indicator		EU JAF	L-1	Regular smoking	Regular daily smoking (total population 15+, 15- 24, men, women, income quintile gap q1-q5)
Indicator		OECD		Tobacco consumption	Grammes per capita (15+)
Indicator		HFA	3010	Tobacco smoking	% of regular daily smokers in the population, age 15+
Indicator		WHO H2020	1.1.b.	Tobacco use	Age-standardized prevalence of current (includes both daily and nondaily or occasional) tobacco use among people aged 18 years and over
Indicator		WHO NCD	9.	Tobacco use	Prevalence of current tobacco use among adolescents
Operationalisation		ECHI	44	Regular smokers	Proportion of people aged 15+ reporting to smoke cigarettes daily.
Operationalisation		ECHI	44	Regular smokers	Proportion of men aged 15+ reporting to smoke cigarettes daily.
Operationalisation		ECHI	44	Regular smokers	Proportion of women aged 15+ reporting to smoke cigarettes daily.
Operationalisation		ECHI	44	Regular smokers	Proportion of people reporting to smoke cigarettes daily, for age group 15-24
Operationalisation		ECHI	44	Regular smokers	Proportion of people reporting to smoke cigarettes daily, for age group 25-64
Operationalisation		ECHI	44	Regular smokers	Proportion of people reporting to smoke cigarettes daily, for age group 65+
Operationalisation		ECHI	44	Regular smokers	Proportion of people aged 15+, whose highest completed level of education is ISCED class 0, 1 or 2, reporting to smoke cigarettes daily.
Operationalisation		ECHI	44	Regular smokers	Proportion of people aged 15+, whose highest completed level of education is ISCED class 3 or 4, reporting to smoke cigarettes daily.
Operationalisation		ECHI	44	Regular smokers	Proportion of people aged 15+, whose highest completed level of education is ISCED class 5 or 6, reporting to smoke cigarettes daily.
Operational	WiP	ECHI	45	To be established - Pregnant	To be established - Pregnant women smoking
Operationalisation		EU JAF	L-1	Regular smoking	Regular daily smoking (total population 15+, 15- 24, men, women, income quintile gap q1-q5)
Operationalisation		OECD		Tobacco consumption	Grammes per capita (15+)
Operationalisation		OECD		Tobacco consumption	Cigarettes per smoker per day
Operationalisation		OECD		Tobacco consumption	% of population aged 15+ who are daily smokers
Operationalisation		OECD		Tobacco consumption	% of females aged 15+ who are daily smokers
Operationalisation		OECD		Tobacco consumption	% of males aged 15+ who are daily smokers
Operationalisation		OECD		Tobacco consumption	% of population aged 15-24 years old who are daily smokers
Operationalisation		OECD		Tobacco consumption	% of females aged 15-24 years old who are daily smokers
Operationalisation		OECD		Tobacco consumption	% of males aged 15-24 years old who are daily smokers
Operationalisation		HFA	3010	Tobacco smoking	% of regular daily smokers in the population, age 15+
Operationalisation		HFA	3011	Tobacco smoking	% of regular daily smokers in the population, age 15+, male
Operationalisation		HFA	3012	Tobacco smoking	% of regular daily smokers in the population, age 15+, female
Operationalisation		HFA	3013	Tobacco smoking	Age-standardized prevalence of current tobacco smoking among people aged 15 years and over, WHO estimates (%)
Operationalisation		HFA	3014	Tobacco smoking	Age-standardized prevalence of current tobacco smoking among people aged 15 years and over, WHO estimates (%), males
Operationalisation		HFA	3015	Tobacco smoking	Age-standardized prevalence of current tobacco smoking among people aged 15 years and over, WHO estimates (%), females
Operationalisation		HFA	3016	Tobacco smoking	Number cigarettes consumed per person per year
Operationalisation		HFA	3017	Tobacco smoking	Total number of cigarettes consumed (in million pieces), per year
Operationalisation		WHO H2020	1.1.b.	Tobacco use	Age-standardized prevalence of current (includes both daily and nondaily or occasional) tobacco use among people aged 18 years and over
Operational	Additional	WHO H2020	1.1.b.	Tobacco use	Prevalence of weekly tobacco smoking among adolescents
Operationalisation		WHO NCD	9.	Tobacco use	Prevalence of current tobacco use among adolescents
Operationalisation		WHO NCD	10.	Tobacco use	Age-standardized prevalence of current tobacco use among persons aged 18+ years

Some countries also collect data for tobacco sales, but these indicators are inconsistent and do not cover smuggling and other forms of illicit tobacco distribution [36] or buying and selling across national borders. It also lacks insight in the number of people smoking in certain age groups, which is relevant information on health risks in the future.

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Availability

In addition to Daily smoking, there are also data collections for Occasional smoking, Current smoking (Daily smoking + Occasional smoking), Ever smoked, Annual tobacco consumption (in grammes or in number of cigarettes), Average number of cigarettes per day, reported by smokers or calculated for the whole population, but these datasets contain data from fewer countries. Most countries report different indicators on Daily smoking for men and women, and there are also data sets for specific age groups and for different educational or income groups, indicating social inequalities in smoking. Specifically for monitoring adolescents' smoking behaviour, there are questions about smoking in WHO's recurrent Health Behaviour in School-Aged Children survey (HBSC) [37], which presently is performed in 48 countries and presents data on children between 11 and 15 years of age; as well as in the European School Survey Project on Alcohol and Other Drugs (ESPAD, www.espad.org), aiming to collect comparable data on substance use among 15-16 year old students in as many European countries as possible, i.e. 35 countries in 2019 (and 100.000 students).

The Daily smoking indicator for the total population is available in HFA, H2020, NCD, ECHI, JAF and OECD HS.

Quality

Since most of the smoking indicators are based on self-reported behaviours, the data are burdened by the common problems regarding self-reports. A systematic review shows that under-reporting of the amount people smoke is common, but with varying levels of under-reporting depending on the population surveyed [38]. There is also the problem of systematic non-response [39]. Smoking indicators based on sales volume may be faulty, however, since tobacco smuggling is a big problem in Europe [40].

EU Member States often have both national health interview surveys and participate in the international ones (EHIS and SILC), which often requires harmonisation of sets of questions and items. The actual number of interviewees that participate in EHIS and SILC is quite small in many countries, however, which puts limits to the statistical significance of several more detailed items. In addition, EHIS is only conducted once every 6 years, which limits its usability to an extreme degree. In addition, some countries have been given permission not to report on specific indicators since there are no nationally validated translations of the questions used or the data are not collected for other reasons.

Self-reported health

Comparability

There are several indicators that describe personal evaluations of people's own health. In this context, we have not included the indicators for self-reported disabilities, (long-standing) chronic conditions and specific illnesses, though they are definitely connected to the indicator selected.

A review of 27 studies demonstrates that self-reported health is a strong predictor of mortality, and therefore, a reliable indicator for health in general [41].This indicator is known under many names; Self-reported health, Self-rated health, Self-perceived health, Self-Assessed health, but these seem to be the same indicator and they are comparable across studies [41, 42]. The main difference

seems to be in the range of possible replies, but most of these 27 surveys list five categories, from Very good, good, fair, bad to very bad. Labeling of the categories outside EU is often different.

Availability

"How is your health?", independently of how it is phrased, is a very common question in health surveys, and the indicator is therefore widely available. It is one of the questions directed towards 11-15-year-olds in the HBSC survey [37]. Eurostat's EU-SILC survey [43] includes this question, and data are published for self-perceived health according to sex, age, labour status, income, education, degree of urbanisation, country of birth and citizenship.

This indicator is available in HFA, ECHI, JAF and OECD HS.

Quality

One might argue that different populations might have different understandings of this indicator, but nevertheless, the indicator seems fairly robust and comparable [44].

Reporting burden

The price of health interview surveys does not seem to have hindered most European countries in collecting this indicator, which is among the most commonly collected indicators in Europe. Still, there is considerable resistance to the frequency and extent of the European health interview surveys, such as EHIS and EU SILC, which also collect this and other health data. The current frequency of data collection in EHIS is 6 years, which seems inadequate for proper trend assessment.

Cancer screening

Comparability

European citizens are currently being screened for several types of cancer, including cancer of the lung, prostate, colon, breast and cervix; the last three are currently officially organised within the EU [45]. There are different population based screening programmes, covered by individuals themselves and different insurance schemes, which means that comparability is dependent on both national guidelines, finances and the availability of equipment and experts to perform the screening. [46] We have chosen to look at cervical cancer screening, since there is an indicator for this in the ECHI short list [4] as well as in the EHIS survey and OECD's database. Since different countries have different recommended intervals between screenings, it can be difficult to compare, but the ECHI definition ("reporting a pap smear test in the past 3 years") will only partially cover adherence to the different national recommendations the authors have been able to identify, with recommended intervals from 2 to 5 years.

Availability

The cervical Pap smear test is the oldest cancer screening test and has been proven to have great effect [47]. It is therefore commonly used in all parts of the world, but the percentage of women screened varies; there are social inequalities in the risk of cervical cancer [48].

The percentage of women (most often aged 20-69, but in some countries other age groups) who received such a test in the last two or three years is a commonly available indicator.

Reporting countries may use administrative data or data from population surveys.
This indicator is available in NCD, ECHI, JAF and OECD HS.

Quality
The quality of this indicator varies, as not all health systems have the capacity to report on the number of women screened, especially outside population based, national schemes, and it is not included in the major European health surveys. There are, moreover, important differences in the various screening programs that would make it difficult to construct a comparable indicator.

Reporting burden
It can be a major challenge to report on this indicator in some European countries, particularly in countries where different insurance companies are the data owners (personal communication). Where data are available from representative surveys, the situation is not so complicated.

Alcohol consumption

Comparability
Two main types of indicators for alcohol consumption are in use.

One type is *Alcohol per capita*, or APC, which is defined as recorded amount of alcohol consumed per adult (15+ years) over a calendar year, in litres of pure alcohol. In some sources, such as WHO's HfA, this indicator may be subdivided by type of beverage the alcohol was consumed in; beer, wine or spirits. This indicator only takes into account the consumption which is recorded from production, import, export, and sales; data are often collected via the taxation system.

The other type of indicator is *self-reported alcohol consumption*, which may be collected for adolescents (e.g. in HBSC and ESPAD) or adults (e.g. in EHIS), and over time frames ranging from daily to past 12 months. There are questions about alcohol use in general and about problematic/hazardous alcohol use, representing different purposes of the indicators. Regarding the latter, the screening tools AUDIT and AUDIT-C are commonly used [49, 50].

Availability
The APC indicator or indicators are commonly available.
Many of the questions in AUDIT/AUDIT-C regarding self-reported alcohol use are included in internationally used questionnaires, such as EHIS [51]. Even when all three AUDIT-C questions are used (How often do you have a drink containing alcohol?/How many standard drinks containing alcohol do you have on a typical day?/How often do you have six or more drinks on one occasion?), the AUDIT-C score, which identifies hazardous drinking at different scores in men and women, is not necessarily calculated. The different indicator sets use different definitions, eg cut-offs and time surveyed [34, 35].
This indicator is available in HFA, H2020, NCD, ECHI, JAF and OECD HS.

Quality
APC indicators only measure officially sold alcohol, and do not include home-made alcohol products, smuggling or legal tax-free sales. Whether total amount of alcohol sold divided by all citizens aged 15 and older is an appropriate measure, when legal purchasing age in

Europe generally is older than 15 [52], may be discussed. Nor does APC measure problematic drinking.

Like all other indicators based on self-reporting, the alcohol indicators are subject to bias and under-reporting of socially undesired behaviours, and there is concern about validity [53]. It is also likely that people with very high alcohol consumption do not take part in surveys [54].

According to literature, having both kinds of indicators available is optimal [55].

Reporting burden
The APC indicators are often available as a by-product of the alcohol taxation system, and hence, cannot represent a great burden on the countries. Health interview surveys are costly, but in general, questions on self-reported alcohol use do not seem to be a great obstacle for European countries.

Life expectancy

Comparability
There are several similar indicators that describe this dimension, the most common ones are *Life expectancy at birth* and *Life expectancy at 65*, though other age limits are also used. On the whole, these indicators are very clear and comparable, since the only outcomes measured are death and age at death, often reported by national Cause of Death registries.

Healthy life expectancy (Health-Adjusted Life Years, Disease-Adjusted Life Years, Healthy life years etc) is a set of indicators related to this indicator, but much more problematic, since the definition of health varies [56].

Availability
This indicator is available in HFA, H2020, ECHI, JAF and OECD HS.

Quality
In countries that record deaths, which include all European countries [56], the quality of this indicator is acceptable. It becomes more problematic when specific causes of death are involved.

Reporting burden
As long as cause of death registration takes place, this indicator should be readily available.

Vaccination coverage

Comparability
Different countries have different recommendations, both for childhood vaccinations and adult vaccinations, such as annual influenza vaccinations, often recommended in the age group 65+. Regarding the childhood vaccinations, specialized knowledge is required to compare between countries, since the specific vaccines, the number of vaccines required for a child to be considered fully immunised, as well as the ages at which the vaccines are recommended, differ from country to country. To examine comparability, use of operationalisation such as the definition from the European Health Information Gateway; "Percentage of infants reaching their second birthday fully vaccinated against measles" is required.

Availability
Vaccination coverage is generally considered to be quite high in Europe, and most countries deliver data. See Quality, below.
This indicator is available in HFA, H2020, NCD, ECHI, JAF and OECD HS.

Quality
The quality of the indicators for vaccination coverage differ widely from country to country. It is known that there are countries that deliver data based on surveys or on delivery of vaccines to practitioners. It may be argued that only countries with person-identifiable vaccination registries can deliver good data.

Reporting burden
Delivering data of high quality may represent a high burden to countries which do not have a national vaccination registry.

Coordination and communication at the national level – some solutions to the problem of reporting burden

Going back to the national contact points for data collection and dissemination, reporting national health indicators to international organisations can be described as three distinct actions:

- Collecting the data – from surveys, registries or administrative systems, either directly or through other collecting agencies and actors
- Processing the data – quality control, calculating averages, standardising or selecting suitable data according to age groups or sex or other sub-groups
- Delivering the data to the organisation that is requesting the data, in the desired format and according to the set metadata

All these three work processes must be performed in order to produce international indicators out of raw data.

For the national experts who report or deliver data, there is often the need to collaborate across sectors and between institutions as data collection is often not done by one national organization. At the national level there are several solutions to these problems:

- Having as few sub-systems as possible makes it possible to collect data and indicators for the same geographical areas, population and age groups etc
- Collaboration may decrease the reporting burden lower in the system, so the reporters will not have to report the same data repeatedly to different national and international agencies
- Striving for one-stop-shopping for health indicators to ensure that the country reports the same data to different international agencies

If possible, agencies that are asked to deliver an indicator to an international organisation should first attempt to identify whether another agency (possibly the national expert in the field) is already delivering this indicator. Open communication within the national and international health data reporting communities is vital to identify common issues.

It may help if there are regular meetings among national organizations that deal with international health data delivery and some form of coordination and discussion of emerging problems and challenges in data quality and delivery. This would need to be developed and institutionalized in Europe at a level that supersedes the level of the international organisations such as WHO Euro, Eurostat and OECD. It would require bringing together both data specialists and content (medical and epidemiological) specialists, depending on the data types involved. Organising this at a higher level may prevent double work by committees set up by single international organisations.

The InfAct project [17] has generated the concept of *National Nodes for health information* as national organizations that could perform these and other tasks [29, 57].

The process of national coordination and looking at international comparability of national data has the advantage of providing an external view of the quality of national health data and, for instance, the need to work according to international classifications and definitions in national data collections or to start collecting data anew or differently. It can also point at possible new indicators or alternative data collections as present in other countries.

Explicit ways of reducing the reporting burden have taken the form of developing key indicator lists (see the Resources section), common reporting tools and synchronized reporting times and/or methods. New reporting methods, such as online direct reporting, with fail-safes, systems that can take data from existing (national) reporting systems or systems made for another purpose, PDA/mobile phone-based reporting, expert systems that extract data from text/photographs, multi-purpose reporting and other methods may all simplify reporting, but they have so far found limited use.

The most important explicit tool seen in the European context so far has been the Joint Questionnaire developed by OECD, WHO Europe and Eurostat [16]: the integration of previous separate questionnaires from the three agencies into one joint questionnaire was designed to reduce the data collection burden on national authorities as well as improve the consistency of data across international databases.

The collaboration between EC, OECD and the WHO Observatory on health systems on the State of Health in the EU cycle, ie. Country reports and Health at a glance Europe are also positive in this context, since this work engenders collaboration and information exchange. Implicitly, this may reduce reporting burden and increase reporting consistency via a long-term process of indicator alignment.

Having a common reporting agenda among the international organisations may prevent the publication of more than one comprehensive and comparative report in one year or addressing the same issues, i.e. cancer or chronic diseases or lifestyle factors by various organisations simultaneously in a short period of time.

Contributions from international projects, committees and expert groups have served *implicitly* to reduce the reporting burden.

The implicit ways of reducing the reporting burden are visible to the participants, in the actual exchange process, but not necessarily to people outside the inner circle. Nevertheless, we will argue that online indicator banks, specific expert centres, inventories of indicators or survey questions and relevant projects have been important. The EU Expert Group on Health Information (EGHI), WHO's Collaborating Centres, the Institute for Health Metrics and Evaluation (IHME) and their Global Burden of Disease Study [58, 59], and in particular the European Health Interview & Health Examination Surveys Database and the now defunct Health Metrics Network have all served to decrease the reporting burden.

Some solutions that can be suggested:

- A joint WHO/Euro, European Commission and OECD publication calendar for health reports, including updating and harmonisation of indicators
- Joint WHO/Euro, European Commission and OECD capacity building activities, both internally and directed towards the members and increasing technical knowledge about health indicator collection, meta data exchange and reporting issues.
- A central repository/exchange mechanism for health data related methods and good practices, with open access to all interested parties
- A joint WHO/Euro, European Commission and OECD research & development agenda for health information, developed together with national and international stakeholders in the field of health information research, such as the national public health institutes. Part of this work may build on the initiating work by EU supported health information projects and joint actions.
- A joint WHO/Euro, European Commission and OECD health indicators core set.

This need for collaboration has several times been recognized by the organizations themselves, at a technical level, and confirmed by the EC, OECD and WHO when IANPHI and the Expert Group on Health Information (EGHI) have urged them to more closely work together (personal communication). However, agreement and collaboration on a political level are required to ensure good health reporting in Europe.

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IV. Implications and limitations

In this paper we introduced the reader to the more obvious and general parts of the health information exchange processes going on in Europe. We must stress, however, that the health information landscape is much broader. There are many other relevant organisations, data sets, data collecting projects, larger and smaller health information networks and collaborations, that are all part of the European health information landscape. A publication by participants in the BRIDGE Health project [60] is also a good source of information regarding issues of indicator comparability, availability and quality and the complexity of the European health information landscape.

The implications of our observations are that there is an urgent need for improving national and international health information systems, using an open process where the many actors in the field, both large and small, have a chance to be heard.

The observations made in the report may be regarded as a snapshot of ongoing issues in the present day, and cannot be seen as necessarily valid in ten years' time.

V. Conclusions and recommendations

There is both the need and possibility to reduce the burden of health reporting in Europe. This report provides many suggestions, but the authors understand some proposals are more feasible, or desirable, in the specific national and international context.

A general proposal that we believe to be universally applicable, is that international organisations need to collaborate more, avoid double reporting, harmonize their indicator sets and spend more resources training their national contact points and otherwise invest in capacity building.

High comparability of data, harmonisation of data collections, policy relevance and purpose of selected indicators, filling essential information gaps and improving timely and coordinated indicator use among the international organisations would be the primary aims and goals. Capacity building, technical support and exchanging good practices of health reporting will contribute to better use of health information for policy making and to reducing the current health information gap between European countries.

The system of national nodes on health information that has been proposed by InfAct seems a worthwhile suggested approach to assist in improving the highly needed European Health Information System.

The existing Joint Questionnaires, such as the Joint Questionnaire on Non-Monetary Health Care statistics and the joint System of Health Accounts questionnaires are commendable, and should be expanded. Regular evaluation, quality control, updating and allowing for improvements of international health indicator sets is recommendable to optimize their policy relevance and impact.

Work on refining the different public health indicator sets in Europe will require highly skilled technical specialists, but also political support at a high level, in the understanding that policy and indicators cannot exist independent of each other.

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13. **SCORE** [h[ttps://www.who.int/data/data-collection-tools/score](https://www.who.int/data/data-collection-tools/score)]
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VII.   Resources

When a specific resource cannot be found under the expected sub-heading, such as a list of SDG indicators under the sub-heading *Indicator lists*, the reader should look under other sub-headings – the link to the SDG portal is under *Data presentation tools*.

All accessed December 4, 2020.

1.   Indicator lists

European Core Health Indicators (ECHI)
https://ec.europa.eu/health/indicators_data/echi_en
https://ec.europa.eu/health/sites/health/files/indicators/docs/echi_shortlist_by_policy_area_en.pdf

GPW 13 WHO Impact Framework Programmatic targets and indicators: Mapping SDGs to GPW13
https://www.who.int/docs/default-source/documents/gpw/gpw13-wif-targets-and-indicators-en.pdf?sfvrsn=81cf3546_20

Sustainable Development Goal Indicators:
https://unstats.un.org/sdgs/indicators/Global%20Indicator%20Framework%20after%202019%20refinement_Eng.pdf; https://unstats.un.org/sdgs/indicators/indicators-list/

Universal Health Coverage Indicators
https://www.who.int/data/gho/data/major-themes/universal-health-coverage-major

WHO Global Reference List of 100 Core Health Indicators (plus health-related SDGs) (2018)
https://www.who.int/healthinfo/indicators/2018/en/

WHO Targets and Indicators for Health 2020 (2014)
https://www.euro.who.int/__data/assets/pdf_file/0009/251775/Health-2020-Targets-and-indicators-version2-ENG.pdf

JAF (Joint Assessment Framework) Health indicator list
https://ec.europa.eu/social/main.jsp?advSearchKey=SPCannualreport&mode=advancedSubmit&catId=1307&doc_submit=&policyArea=0&policyAreaSub=0&country=0&year=0 (p52-)

OECD: A selection of key health indicators
https://www.oecd.org/els/health-systems/health-data.htm

2.   Metadata

OECD Health Statistics 2019 – Definitions, sources and methods
https://www.oecd.org/els/health-systems/Table-of-Content-Metadata-OECD-Health-Statistics-2019.pdf

UN SDG metadata
https://unstats.un.org/sdgs/metadata/

WHO Indicator Metadata Registry List
https://www.who.int/data/gho/indicator-metadata-registry

3. Data presentation tools

ECHI data tool
https://ec.europa.eu/health/indicators_data/indicators_en

E-Handbook on SDG Indicators
https://unstats.un.org/wiki/display/SDGeHandbook/Home

European Health Information Gateway
https://gateway.euro.who.int/en/

European Health Information Gateway: European Health for All database
https://gateway.euro.who.int/en/datasets/european-health-for-all-database/

OECD Health Statistics 2020
http://www.oecd.org/els/health-systems/health-data.htm

UN SDG Database
https://unstats.un.org/sdgs/indicators/database

UN SDG Toolkit
http://sdgtoolkit.org/what-is-it/indicators-and-goals

WHO Statistical Information System (WHOSIS)

4. Other resources

EuroHealthNet
https://eurohealthnet.eu/

European Health Interview & Health Examination Surveys Database
https://hishes.wiv-isp.be/

Eurostat
https://ec.europa.eu/eurostat

Health at a Glance: Europe
https://ec.europa.eu/health/state/glance_en
https://ec.europa.eu/health/state/country_profiles_en

Health Metrics Network: Framework and Standards for Country Health Information Systems (2012)
https://www.who.int/healthinfo/country_monitoring_evaluation/who-hmn-framework-standards-chi.pdf

Guidelines for National Nodes
https://www.inf-act.eu/sites/inf-act.eu/files/2020-01/MS23_Guidlines%20NN%20in%20InfAct.docx.pdf

SCORE for Health Data Technical Package addresses
https://www.who.int/data/data-collection-tools/score/dashboard#/

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Creating a catalogue of EU health information projects and networks

D5.2 'Cataloguing health information networks, projects and indicator sets': projects and networks. May 31st 2021

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Executive summary

This document is Deliverable 5.2, prepared within Task 5.2 of the Joint Action on Health Information (InfAct, Information for Action!) with project number 801553 and co-funded by the Health Programme of the European Union. Task 5.2 is split into two parts, this report covering 'projects and networks', another report covering 'indicator sets'.

The overall goal of task 5.2, and described in this report, is to create a catalogue in the area of population health and healthcare of (1) expert networks that collect comparable public health data in Europe, as well as (2) previous and ongoing health indicator / health information generating projects with EU coverage, and to make this easily accessible and manageable. An additional aim of task 5.2 is to deliver a draft paper, to be published separately from this report, and addressing two aspects 1) analysis of the presence of EU Member States in a selection of networks in order to provide a view on health information inequalities within the EU and 2) overview of the scientific publications from the identified networks that contain international comparisons and indicator development. regular EU data collection system

The catalogue is based on a search in PubMed, Embase, Scopus, Google, Cordis and the CHAFEA project database, using in- and exclusion criteria. The focus is on a) population health oriented topics and b) health system/health services oriented topics, i.e. serving population health monitoring and health system performance assessment. Out of the scope of this report are infectious diseases (specifically); individual rare diseases; prevalence and outcomes of treatments, interventions and diagnostics, and solely qualitative information collections.

The information is being incorporated into the Health Information Portal: www.healthinformationportal.eu. This portal has been developed in InfAct. It will be further developed in the context of DIPoH, the distributed infrastructure on Population Health.

This work provides the opportunity to build on past work, avoid duplications, look beyond the closing date of a project, keep project information, outcomes and networks alive, and connect experts and expertise in the area of public health and health care. The information base will serve researchers, policy makers, (inter)national organisations and others.

Key points

- The European Health Information Portal is a valuable means to connect European Union (EU) wide knowledge and expertise in the area of health information, and make it easily accessible and reusable.
- A sustainable infrastructure is needed for the consolidation and reusability of EU health information efforts and expertise.

Glossary

- <u>DIPoH</u>: Distributed Infrastructure for Population Health (DIPoH applied for the 2021 ESFRI road map). This infrastructure plans to support high-level health research by facilitating the identification, the access, the assessment and reuse of data; combine a central coordination office, national nodes across EU countries and pan-European research networks on specific population health topics; and deliver services by providing a one-stop shop for population health data, developing innovative methods, building health information capacity and developing knowledge translation research. DIPoH already has a practical roll-out: PHIRI, the Population Health Information Research Infrastructure for COVID-19 (2020-2023; https://www.phiri.eu/).
- <u>European Health Information Portal</u>: the one-stop shop facilitating access to population health and health care data, information and expertise in the European Union, available at www.healthinformationportal.eu.
- <u>Health information</u>: All organised and contextualised data about the health status of populations, the factors that determine health status, the performance of healthcare, and prevention, that is fit-for-use and contributes to decision-making.
- <u>Health information inequality</u>: an unequal capacity to monitor and evaluate population health and health system performance using routinely collected data; health information inequalities hamper an effective EU Health Information System.
- <u>Indicator</u>: a measurement that reflects a given state or condition
- <u>InfAct</u>: Joint Action for Health Information, Information for Action! (2018-2021; https://www.inf-act.eu/). InfAct builds towards a sustainable and solid infrastructure on EU health information and strengthens its core elements based on capacity building, health information tools and political support. InfAct builds on BRIDGE Health: BRidging Information and Data Generation for Evidence-based Health policy and research (2015-2018; https://www.bridge-health.eu/).
- <u>Network</u>: a group of interconnected people; here: collecting comparable health data in Europe
- <u>Project</u>: a creative activity limited by time and resources; here: previous and ongoing health indicator / health information generating projects with EU coverage

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I.   Introduction

A. Background

The European health data and information landscape is scattered. Many national and international agencies, institutes, programs, projects and committees play a role in harmonizing, collecting and disseminating existing and new health data and information for health research and health policy support. The European Commission (EC) supports the conception and conduct of many health information related projects serving population health monitoring and health system performance assessment. For example, the Health Monitoring Programme[1] (HMP) adopted in 1997 intended to pave the way for permanent EU health monitoring. This resulted in many international comparative projects and networks. Many of these ended and are no longer followed-up. This obviously is inherent to any project-based funding system, but also points at the difficulty of maintaining networks to coordinate, communicate among the participants and harmonize the definition and collection of the data after the funding stops, even when results remain relevant. An important problem in this regard is the lack of an infrastructure to embed all this information in and prevent the loss of earlier gathered knowledge, expertise and data.

The Joint Action on Health Information (InfAct[2]) attempts to connect European Union (EU) wide knowledge and expertise in the area of health information, and make this easily accessible and reusable. An important way to do this is through the European Health Information Portal[3] (HIP). This portal was developed in InfAct and is further developed in the PHIRI[4] project. It functions as a one-stop shop facilitating access to population health and health care data, information and expertise in Europe. It includes or will include catalogues of meta-data, libraries and repositories for tools, methods, standards and guidelines, discussion fora, health information related news, information on important networks and efforts by international organisations, research output and other knowledge products. It communicates and advocates the scientific work of projects and programmes developed under the flag of DIPoH. It offers the services and tools necessary for researchers to access and link different data sources and to use Pan-European data in a GDPR compliant, federated way.

In this context, we sought to create a sustainable information base of past and current work performed in the field of international health information that has dealt with collecting comparable health-related data and/or defining comparable health indicators.

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[1] In 1997, Decision No 1400/97/EC called for a program of Community action on health monitoring, which aimed for the establishment of a Community health monitoring system
[2] https://www.inf-act.eu/
[3] http://www.healthinformationportal.eu/
[4] Population Health Information Research Infrastructure, https://www.phiri.eu/

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B. Aim of task 5.2

The task aim is to create a health information catalogue of health information projects and networks in order to facilitate:

- accessing a collective memory of relevant projects and outputs to avoid loss of relevant knowledge and expertise.
- finding international expert networks that are collecting comparable health data and information which is relevant for a) comparing and benchmarking public health issues or b) for comparative health (system) analyses and not available in the regular EU data collection system.

This will enable European experts, policy makers, journalists, researchers who are new to the field and other stakeholders to identify key networks that specialize in specific health data and information in Europe and so arrive quickly at relevant data, information and expertise; and provide a starting point for future use in research and policy making, possibly strengthen the international networks and invest in capacity building for data collection and participation of experts from not yet participating countries in these international networks and so reduce health information inequalities. In summary, this catalogue can function as a knowledge repository to look back on and build from.

C. How to read this report

The aim of this report is to describe the task deliverables and how they were achieved. The next chapter (II) describes the four steps taken to prepare the catalogue. This is followed by a brief account of the results (Chapter III), implications and limitations (Chapter IV) and the report ends with conclusions and recommendations (Chapter V).
In the Annexes, we describe the details of the search (1), the metadata template that was used to build the catalogue (2), the conceptual framework that was used to assist the search function (3), an overview of the projects and networks in the catalogue (4), and brief background information about the paper (5).

II. Approach: identification of networks and projects

We distinguish four steps in the process of developing the catalogue:
1. Specifying the scope
2. Creating and performing the search, identifying the sources, developing search terms, and preparing inclusion/exclusion criteria
3. Characterising and extracting the information, using a metadatabase structure
4. Uploading and maintaining the information

These steps are further described below.

A.   Step 1: defining the scope

The scope covers population health oriented topics (a) and health system/health services oriented topics (b). Out of scope are infectious diseases; individual rare diseases; and occurrence and effects of individual treatments, interventions and diagnostics.

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B. Step 2: developing and performing the search

The search is summarised below. For a detailed description, please see Annex 1a-d.

1. Sources

Networks and projects were searched via

- PubMed
- Embase
- Scopus
- Google
- [CHAFEA health programmes database](#)[5]
- [Cordis](#)[6]
- ECHI documentation

These sources were followed up by hand search.

2. Search strings and limits

One search was performed for both topics in our scope and prepared strings for the following terms:

A: network, data collection

B: project, data collection

C: public health, monitoring, health system, health care, performance

We searched the above mentioned journal databases, Google and EU project databases, from 2010 onwards. An exception to the date limit was made for the "Health Information" calls 2004 -2007 in the CHAFEA project database and the projects mentioned in the ECHI documentation sheets[7]. We limited the search to EU MS and associated countries' networks and projects, in the English language.

PubMed, Embase, Scopus and google were searched by an information specialist in March through May 2019. The results were collected in an Endnote file. In total, there were 1575 publications in the first screening round, and a subsequent 336 of these were screened more in-depth.

We searched the Cordis database and the CHAFEA health programmes database in July 2019 and updated the search on April 15th, 2020. The results (n=765) were collected in an excel file for more in-depth screening.

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[5] Accessed via https://webgate.ec.europa.eu/chafea_pdb/health/projects. Note: the CHAFEA mandate and activities have been reassigned and the Health Programme (EU4Health) is now under HADEA, the Health and Digital Executive Agency (https://hadea.ec.europa.eu/index_nl); at this point in time, the database is not accessible and it is currently unknown whether it will become accessible again via the above link.

[6] https://cordis.europa.eu/projects/en

[7] Verschuuren M, Achterberg P, Gijsen R, Harbers M, Vijge E, Wilk Evd, Kramers P: ECHI Indicator development and documentation - Joint Action for ECHIM Final Report Part II. Bilthoven; 2012.

3.   Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed. These are summarised in Table 1.

Table 1: In and exclusion criteria for public health and care networks and projects

	Inclusion	Exclusion
Scope	Public health Health care performance Health systems performance	Infectious diseases (specifically) Individual rare diseases
Activities	Data/information-collecting	Non-data/information collecting, NGO type networks, commercial networks, networks on legal, ethical and governance issues, or networks in scientific areas where health is a side topic
Data collection (where applicable)	Individual level	Aggregate level
Data collection (where applicable)	Longitudinal, periodic collection	One time
Outcomes	Health related outcome and performance measures	Occurrence and effects of individual treatments, interventions and diagnostics
Geographic coverage	EU and associated countries	other
Geographic coverage	≥ 5 countries	<5 countries

The criteria were applied by 3 reviewers. They reached consensus on which projects to include and which to discard. It was also agreed that there is a subjective component to this.

C. Step 3: Building the metadatabase

A database structure was set up in excel, describing the projects and networks metadata, providing also conceptual models to organise the information. Interesting examples used for preparing the database were the Dutch Health and care database[8]; Health Data Navigator[9]; FAIR Healthdata[10].

The file was shared with the Health Information Portal working group, consisting of representatives of InfAct WP 5, 7, 8 and 10. It was used to co-create a database template for the Research Networks (RN; the full template is available from the RN manual provided on the Health Information Portal under Research Networks, see Fig 1). For internal consistency, the final template for the catalogue (shown in Annex 2) was then derived from this template.

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[8] www.zorggegevens.nl
[9] http://hdn.euhs-i.eu/international-home
[10] https://fair.healthdata.be/global-search

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In order to facilitate and standardise searching the Health Information Portal, both free key words and a conceptual framework were used. The conceptual framework (Annex 3) was adapted from a mapping exercise performed within WHO European Health Information Initiative (finding overlap between indicators from WHO, EC and OECD sources.

D. Step 4: Building and maintaining the catalogue

The projects and networks were added to the European Health Information Portal. It is currently being completed. Important here is to have a sustainable mechanism in place to update the catalogue. The health information community could be involved in this. A form could be added to the Health Information Portal in which a suggestion for an update can be made. A mechanism would be needed to check the suggestion.
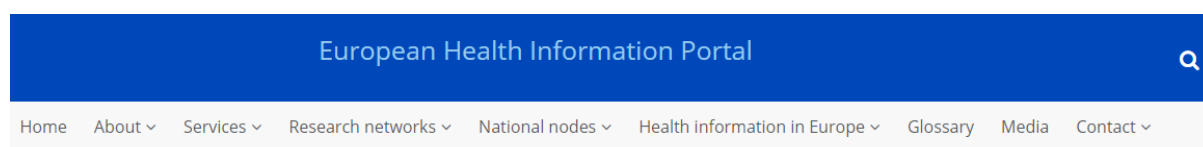

European Health Information Portal	Q
Home About ⌄ Services ⌄ Research networks ⌄ National nodes ⌄ Health information in Europe ⌄ Glossary Media Contact ⌄	

Figure 1: The sections in the European Health Information Portal

III. Results in brief

The catalogue of networks and projects is accessible via 'Health Information in Europe' and 'Services', as well as via the general search button (see Figure 1). This first version contains ~80 projects and networks (See Annex 4). However, it is part of a dynamic process and the number is expected to grow.

IV. Implications and limitations

We will almost certainly have missed some projects and networks, for example because the search terms did not reach them, because they appeared after our search was performed, or because we misjudged in applying the inclusion criteria. Also, we could not always find all the information needed in the entry. We will ask the InfAct/PHIRI/DIPoH partners to see if 1. any of the existing entries need updating and 2. if any projects and networks need to be added (or deleted).

V. Conclusions and recommendations

Many EU projects and networks have worked on comparable data and indicators in the area of public health and health systems performance. There is, however, no sustainable infrastructure for these efforts to be consolidated in. We recommend that a sustainable European Research Infrastructure Consortium is established and that an information base of previous efforts finds a place in this.

In addition, it is not easy to find a good conceptual framework for the classification of health information projects and networks. We recommend this is further elaborated upon.

Furthermore, we recommend to further develop ways to exchange best practices and discuss common problems among health information networks, via the Health Information Portal.

Annex 1a: overview of search methodology

A. Strings
Strings were prepared for the following terms:
A: network, data collection
B: project, data collection
C: public health, monitoring, health system, health care, performance
The search was combined for both objectives

B. Limits
The following limits were applied:
Period: 2010 onwards
Language: ENG
Countries: EU and associated countries

C. Sources
1. Pubmed, Embase, Scopus and Google
PubMed, Embase and Scopus were searched by an information specialist and an InfAct task 5.2 representative.
Search terms: Annex 1b.

Google was searched by by an information specialist and an InfAct task 5.2 representative.
Search terms: Annex 1c.

Period: March-May 2019.

The information specialist performed a first screening. The resulting references (n=1575), including title and link to web page, were collected in an Endnote file.

Within the Endnote file, another selection was made (n=336; i.e. n=285 for the literature databases and n=51 for Google) by an InfAct task 5.2 representative for more in-depth screening.

2. EU databases
CHAFEA health programmes database[11] and Cordis[12] were searched by an InfAct task 5.2 representative.

Search terms: Annex 1d.
Period: July 2019, update in April 2020

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[11] https://webgate.ec.europa.eu/chafea_pdb/health/projects
[12] https://cordis.europa.eu/projects/en

Annex 1b: Search terms peer-reviewed literature

PubMed search strategy:

1. "health information"[ti] OR "health knowledge"[ti] OR "health data"[ti] OR "health registries"[ti] OR "health monitoring"[ti] OR "health indicator"[ti] OR "health indicators"[ti] OR echi[ti] OR "health policy"[ti] OR "public health"[ti] OR "population health"[ti] OR "national health"[ti] OR "health care"[ti] OR healthcare[ti] OR "health system"[ti] OR "health systems"[ti] OR "health services "[ti] OR "health surveillance"[ti] OR "health monitoring"[ti] OR "health reporting"[ti] OR "population health assessment"[tiab] OR "health system assessment"[tiab] OR "health system performance"[tiab] OR "health services performance"[tiab] [229.608]

2. "health information"[ot] OR "health knowledge"[ot] OR "health data"[ot] OR "health registries"[ot] OR "health monitoring"[ot] OR "health indicators"[ot] OR echi[ot] OR "health policy"[ot] OR "public health"[ot] OR "population health"[ot] OR "national health"[ot] OR "health care"[ot] OR healthcare[ot] OR "health system"[ot] OR "health systems"[ot] OR "health services performance"[ot] OR "health surveillance"[ot] OR "health monitoring"[ot] OR "health reporting"[ot] [84.755]

3. "public health informatics"[mh] OR "public health surveillance"[mh] OR "health information management"[mh] OR "public health"[mh] OR "population health"[mh] OR "population surveillance/methods"[mh] OR "health status indicators"[mj] OR "health surveys/methods"[mh] OR "delivery of health care"[mh:noexp] OR "health care surveys"[mh:noexp] OR "quality indicators, health care"[mh] [7.323.855]

4. #1 OR #2 OR #3 [7.458.901]

5. "health information base"[ti] OR "health information system"[ti] OR "health information systems"[ti] OR "health information tool"[ti] OR "health information tools"[ti] OR "health information base"[ot] OR "health information system"[ot] OR "health information systems"[ot] OR "health information tool"[ot] OR "health information tools"[ot] [1.035]

6."health information system"[ti] OR "health care information system"[ti] OR "healthcare information system"[ti] OR "health information systems"[ti] OR "health care information systems"[ti] OR "healthcare information systems"[ti] OR "information tool"[ti] OR "information tools"[ti] OR "data infrastructure"[ti] OR "indicator system"[ti] OR "indicator systems"[ti] OR "health monitoring system"[ti] OR "health monitoring systems"[ti] OR "health information system"[ot] OR "health care information system"[ot] OR "healthcare information system"[ot] OR "health information systems"[ot] OR "health care information systems"[ot] OR "healthcare information systems"[ot] OR "information tool"[ot] OR "information tools"[ot] OR "data infrastructure"[ot] OR "indicator system"[ot] OR "indicator systems"[ot] OR "health monitoring system"[ot] OR "health monitoring systems"[ot][1.600]

7. ("data collection"[ti] OR "data reporting"[ti] OR "data source"[ti] OR "data sources"[ti]) AND (tool[ti] OR tools[ti] OR base[ti] OR system[ti] OR systems[ti] OR project[ti] OR projects[ti] OR "data infrastructure"[ti]) OR ("data collection"[ot] OR "data reporting"[ot] OR "data source"[ot] OR "data sources"[ot]) AND (tool[ot] OR tools[ot] OR base[ot] OR system[ot] OR systems[ot] OR project[ot] OR projects[ot] OR "data infrastructure"[ot]) [314]

8. "expert network"[tiab] OR "expert networks"[tiab] OR "data collecting network"[tiab] OR "data collecting networks"[tiab] OR "expert network"[ot] OR "expert networks"[ot] OR "data collecting network"[ot] OR "data collecting networks"[ot] [71]

9. ("health information systems"[mh] OR "health information exchange"[mh] OR (("data collection/standards"[mh:noexp] OR "registries/standards"[mh:noexp] OR "health surveys/standards"[mh:noexp] OR "population surveillance/methods"[mh] OR "population surveillance/standards"[mh] OR "public health surveillance/methods"[mh]) AND ("international cooperation"[mh] OR "international classification of diseases"[mh] OR "interinstitutional relations"[mh]))) AND (eu[ti] OR europe[ti] OR european[ti] OR eu[ot] OR europe[ot] OR european[ot] OR "europe"[mj:noexp] OR "european union"[mj:noexp]) [175]

10. #4 AND (#5 OR #6 OR #7 OR #8 OR #9) [1.925]

11. project[tiab] OR projects[tiab] OR project's[tiab] OR organizations[ti] OR project[ot] OR projects[ot] OR project's[ot] OR organizations[ot] [197.721]

12. "joint action"[tiab] OR (("international cooperation"[mh] OR "interinstitutional relations"[mh]) AND (eu[ti] OR europe[ti] OR european[ti] OR eu[ot] OR europe[ot] OR european[ot] OR "europe"[mj:noexp] OR "european union"[mj:noexp]) AND (health[ti] OR healthcare[ti] OR care[ti])) [3.064]

13. #4 AND #11 AND #12 [204]

14. (network*[ti] OR project*[ti] OR indicator*[ti]) AND (health*[ti] OR healthcare[ti] OR care[ti] OR incidence[ti]) AND (eu[ti] OR europ*[ti]) [521]

15. europe[tiab] OR european[tiab] OR eu[tiab] OR efta[tiab] OR "europe"[mh] OR "european union"[mh] OR europe[ot] OR european[ot] OR eu[ot] OR efta[ot] [1.514.889]

16. (#10 OR #13 OR #14) AND #15 [1.089]

17. #16 NOT ("africa"[mh] OR "asia"[mh] OR "americas"[mh] OR "australasia"[mh] OR "oceania"[mh]) [1.044]

18. #17 NOT (infectious[ti] OR communicable[ti] OR rare[ti] OR "communicable diseases"[mh] OR "rare diseases"[mh]) [1.008]

19. #18 AND 2010:2019[dp] AND english[la] [446]

Embase search strategy:

1. 'health information':ti OR 'health knowledge':ti OR 'health data':ti OR 'health registries':ti OR 'health monitoring':ti OR 'health indicator*':ti OR echi:ti OR 'health policy':ti OR 'public health':ti OR 'population health':ti OR 'national health':ti OR 'health care':ti OR healthcare:ti OR 'health system*':ti OR 'health services':ti OR 'health surveillance':ti OR 'health monitoring':ti OR 'health reporting':ti OR 'population health assessment':ti,ab OR 'health system assessment':ti,ab OR 'health system performance':ti,ab OR 'health services performance':ti,ab [258.441]

2. 'medical informatics'/de OR 'medical information system'/de OR 'public health'/de OR 'population health'/de OR 'health status indicator'/mj OR 'health survey'/mj OR 'health care delivery '/de OR 'health care'/de OR 'health care surveys'/de OR 'quality indicators'/de [496.163]

3. #1 OR #2 [661.309]

4. 'health information base':ti OR 'health information system*':ti OR 'health information tool*':ti [872]

5. 'health information system*':ti OR 'healthcare information system*':ti OR 'information tool*':ti OR 'data infrastructure':ti OR 'indicator system*':ti OR 'health monitoring system*':ti [1.417]

6. ('data collection':ti OR 'data reporting':ti OR 'data source*':ti) AND (tool:ti OR tools:ti OR base:ti OR system:ti OR systems:ti OR project:ti OR projects:ti OR 'data infrastructure':ti) [622]

7. 'expert network*':ti,ab OR 'data collecting network*':ti,ab [107]

8. ('medical information system'/de OR (('data collection method'/de OR 'register'/de OR 'health survey'/de) AND ('international cooperation'/de OR 'international classification of diseases'/de))) AND (eu:ti OR europe:ti OR european:ti OR 'europe'/de OR 'european union'/de) [591]

9. #3 AND (#4 OR #5 OR #6 OR #7 OR #8) [1.774]

10. project:ti,ab OR projects:ti,ab OR 'project?s':ti,ab OR organizations:ti [258.754]

11. 'joint action':ti,ab OR ('international cooperation'/de AND (eu:ti OR europe:ti OR european:ti OR 'europe'/de OR 'european union'/de) AND (health:ti OR healthcare:ti OR care:ti)) [2.177]

12. #3 AND #10 AND #11 [72]

13. (network*:ti OR project*:ti OR indicator*:ti) AND (health*:ti OR healthcare:ti OR care:ti OR incidence:ti) AND (eu:ti OR europ*:ti) [703]

14. europe:ti,ab OR european:ti,ab OR eu:ti,ab OR efta:ti,ab OR 'europe'/de OR 'european union'/de [530.677]

15. (#9 OR #12 OR #13) AND #14 [1.239]

16. #15 NOT ('africa'/exp/de OR 'asia'/exp/de OR 'western hemisphere'/exp/de OR 'australia and new zealand'/exp/de) [1.088]

17. #16 NOT (infectious:ti OR communicable:ti OR rare:ti OR 'communicable disease'/exp/de OR 'rare disease'/de) [1.061]

18. #17 AND [2010-2019]/py AND english:la [517]

1. TITLE((health-information) OR (health-knowledge) OR (health-data) OR (health-registries) OR (health-monitoring) OR (health-indicator*) OR echi OR (health-policy) OR (public-health) OR (population-health) OR (national-health) OR (health-care) OR healthcare OR (health-system*) OR (health-services) OR (health-surveillance) OR (health-monitoring) OR (health-reporting)) OR TITLE-ABS((population-health-assessment) OR (health-system-assessment) OR (health-system-performance) OR (health-services-performance)) [324.256]

2. KEY((public-health-informatics) OR (public-health-surveillance) OR (medical-informatics) OR (medical-information-system*) OR (health-information-management) OR (public-health) OR (population-health) OR (population-surveillance) OR (health-status-indicator*) OR (health-survey*) OR (health-care-delivery) OR (delivery-of-health-care) OR (health-care) OR (health-care-survey*) OR (quality-indicators)) [1.776.772]

3. #1 OR #2 [1.891.693]

4. TITLE((health-information-base) OR (health-information-system*) OR (health-information-tool*)) [1.339]

5. TITLE((health-information-system*) OR (healthcare-information-system*) OR (information-tool*) OR (data-infrastructure) OR (indicato-system*) OR (health-monitoring-system*)) [4.083]

6. TITLE((data-collection) OR (data-reporting) OR (data-source*)) AND TITLE(tool* OR base OR system* OR project* OR (data-infrastructure)) [1.974]

7. TITLE-ABS((expert-network*) OR (data-collecting-network*)) [462]

8. KEY((medical-information-system*) OR (health-information-system*) OR (data-collecting-network*)) OR (KEY((data-collection-method*) OR regist* OR (health-survey*) OR (polulation-surveillance-methods) OR (public-health-surveillance-methods)) AND KEY((international-cooperation) OR (international-classification) OR (interinstitutional-relations)) AND TITLE(eu OR europ*)) [23.744]

9. #3 AND (#4 OR #5 OR #6 OR #7 OR #8) [25.772]

10. TITLE-ABS(project*) OR TITLE(organizations) [1.797.455]

11. TITLE-ABS(joint-action) OR (TITLE-ABS-KEY(international-cooperation) AND (TITLE(eu OR europe*) OR KEY(eu OR europe*)) AND TITLE(health OR healthcare OR care)) [6.129]

12. #3 AND #10 AND #11 [192]

13. TITLE(network* OR project* OR indicator*) AND TITLE(health* OR healthcare OR care OR incidence) AND TITLE(eu OR europe*) [702]

14. TITLE-ABS-KEY(eu OR europe* OR efta) [1.428.787]

15. (#9 OR #12 OR #13) AND #14 [2.049]

16. KEY(africa* OR asia* OR (western-hemisphere) OR australia OR (new-zealand) OR america*) [1.223.535]

17. TITLE(infectious OR infections OR communicable OR rare) OR TITLE(infectious OR infections OR communicable OR rare) [695.118]

18. #15 AND NOT (#16 OR #17) [1.879]

19. LANGUAGE(english) and PUBYEAR AFT 2009 [24.505.252]

20. #18 AND #19 [887]

21. TITLE(network* OR system* OR project* OR program* OR source* OR infrastructure* OR collaboration OR comparison* OR indicator* OR performance OR europ* OR initiated) [6.965.450]

22. #20 AND #21 [612]

Annex 1c: Search terms google

Google search strategy

intitle:"health information" network (eu OR europe OR european)
intitle:"health information" network (transnational OR "cross national" OR cooperation OR countries OR international)

intitle:"health information" project (eu OR europe OR european)
intitle:"health information" project (transnational OR "cross national" OR cooperation OR countries OR international)

intitle:network "health information" (eu OR europe OR european)
intitle:network "health information" (transnational OR "cross national" OR cooperation OR countries OR international)

intitle:"health indicator" network (eu OR europe OR european)
intitle:"health indicator" network (transnational OR OR "cross national" cooperation OR countries OR international)

intitle:project "health indicator" (EU OR europe OR european)
intitle:project "health indicator" (transnational OR OR "cross national" cooperation OR countries OR international)

Variations to this theme were also included.

Annex 1d: Search terms EU project databases

CHAFEA health programmes database:

July 2019, updated April 2020

- Advanced search 1:
  - o Countries: EU and EFTA countries
  - o Project year: ≥2010
  - o Portfolio: "Data collection, Health indicators, Health reports, Indicators and data"

[n=8]

- Advanced search 2:
  - o Countries: EU and EFTA countries
  - o Project year: ≥2010
  - o Key words: health information, check box for "environmental factor", "lifestyle", "methods", "non-communicable diseases", "socioeconomic factors" -> annex

[n=216]

[search 1+2: n=217 unique results]

- All projects in 'health' and include project call "Health Information (Hi 2003)" and include project call "Health Information (Hi 2004)" and include project call "Health Information (Hi 2005)" and include project call "Health Information (Hi 2006)" and include project call "Health Information (Hi 2007)"

[n=137]

Cordis:

July 2019, updated April 2020

- Search 1:
  - o Search: "health information" AND (population OR public)
  - o Collection: Projects, Project Deliverables, Project Publications
  - o Domain of Application: Health
  - o Programme: FP7 FP6 H2020
  - o Language: English
  - o Start date (From): 2010-01-01

(/result/relations/categories/collection/code='publication','deliverable' OR contenttype='project') AND (programme/code='H2020' OR programme/code='FP7' OR programme/code='FP6') AND applicationDomain/code='health' AND ('health information' AND ('population' OR 'public'))

[n=48]

- Search 2:
  - o Search: (compar* OR benchmark*) AND (health AND (population OR public))
  - o Collection: Projects, Project Deliverables, Project Publications
  - o Domain of Application: Health
  - o Programme: FP7 FP6 H2020
  - o Language: English
  - o Start date (From): 2010-01-01

(/result/relations/categories/collection/code='publication','deliverable' OR contenttype='project') AND (programme/code='H2020' OR programme/code='FP7' OR programme/code='FP6') AND applicationDomain/code='health' AND (('compar*' OR 'benchmark*') AND ('health' AND ('population' OR 'public')))

[n=392]

[search 1+2: n=411 unique results]

Annex 2: The metadata template

The metadata template[13]

Q	Item	Type of data
1	Contact	Text (email address)
	Is the network/project active?	Yes/no
	Start date	Date
	End date	Date
	Internal contact	*URL address*
	Name of network/project	e-mail address
	Acronym	Text
	Network/project website and link text	URL address
	Network/project link to EU database	URL address
	Topics	Dropdown list
	Free keywords	Text
	Aim of the network/project	Text
3	Coordination	
	Leading institute	Text
	Principal investigator	*Text*
4	Partners	
	Participating institutions (will provide participating country)	Text
	Experts and contributors	Text
	Related projects, network nodes	Text
7	Outputs	
	Type of output	Dropdown list
	Description	Text
	Link	URL address
	Topic	Dropdown list
	Keywords	Text

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[13] aligned with the European Health Information Portal template for Research Networks (the version for the projects and networks catalogue is shorter and contains a few additional variables, in green)

INFACT
Joint Action on Health Information

Annex 3: The conceptual framework

Level 1	Level 2	Level 3	Level 4
Determinants of health	Individual characteristics and behaviours	Behaviours	Alcohol consumption
			Food consumption
			Physical activity
			Reproductive and maternal
			Tobacco use
			Use of psychoactive substances
		Individual characteristics	Birth weight
			Blood pressure
			Cholesterol
			Overweight/obesity
	Physical and social environment	Physical environment	Housing and sanitation
			Pollution
		Social environment	Social network
			Work-related
	Socioeconomic and demographic factors	Demographic factors	Demographic factors
		Socioeconomic factors	Education
			Employment/occupation
			Income/poverty
Health status	Morbidity/disability	Accidents & injuries	Home/leisure
			Self-injury
			Traffic
			Work
		Communicable diseases	Airborne and/or vaccine-preventable diseases
			Covid-19
			Food and water borne
			Sexually transmissible and/or blood borne
			Zoonotic
		Disability	Disability
		Non-communicable diseases	Cancer
			Cardiovascular diseases
			Dental diseases
			Diabetes
			Mental diseases
			Reproductive, maternal and newborn health
			Respiratory diseases
		Self-reported health status	Self-perceived health/morbidity
	Mortality	Age- and cause-specific mortality	All causes
			Cancer
			External causes

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			Infectious diseases
			Non-communicable diseases (excluding cancer)
		Life expectancies	Health expectancy
			Life expectancy
			Reduction of life expectancy (PYLL)
		Maternal, perinatal and newborn mortality	Infant mortality
			Maternal mortality
	Wellbeing	NA (Wellbeing)	Wellbeing
Health systems	Health resources and activities	Care utilisation	Consultations
			Diagnostic exams
			Hospital utilisation
			Long-term care
			Reproductive, maternal and newborn health
			Surgical procedures
		Health employment and education	Education
			Health workforce migration
			Nurses and/or midwives
			Physicians
			Remuneration
			Workforce other
		Pharmaceutical sales & consumption	Generic market
			Pharmaceutical consumption
			Pharmaceutical sales
		Physical and technical resources	Hospitals and beds
			Medical technology
			Other care units/beds
	Health system performance	Access	(Un)met needs or their causes
			Health care coverage
		Costs/expenditure	Assets
			Financing scheme
			Function
			Provider
			Provision factors
			Revenues
		Quality	Autopsy
			Cancer screening
			Cancer survival rates
			Care
			Patient experience
			Patient safety
			Premature/avoidable mortality
			Reproductive, maternal and newborn health
			Vaccination coverage

Annex 4: The catalogue

The below table presents the projects and networks that were added to the European Health Information Portal based on the search described in this report. Some projects and networks that were not selected here, may still be added later to fulfil other purposes.

Overview of selected projects

Adopting Hospital Based Health Technology Assessment	**AdHopHTA**
Alzheimer Cooperative Valuation in Europe	**ALCOVE**
Improving Knowledge and Communication for Decision Making on Air Pollution and Health in Europe	**APHEKOM**
BBMRI - Large Prospective Cohorts	**BBMRI-LPC**
BRidging Information and Data Generation for Evidence-based Health Policy and Research	**BRIDGE Health**
Childbirth Cultures, Concerns, and Consequences: Creating a dynamic EU framework for optimal maternity care	**CCCC**
Consortium on Health and Ageing	**CHANCES**
Developing a Child Cohort Research Strategy for Europe	**CHICOS**
Child health indicators of life and development Project	**CHILD**
Implementing good practices for chronic diseases	**CHRODIS PLUS Joint Action**
Consortium to Perform Human Biomonitoring on a European Scale	**COPHES**
Children of Prisoners, Interventions & Mitigations to Strengthen Mental Health	**COPING**
COURAGE in Europe - COllaborative Research on AGEing in Europe	**COURAGE IN EUROPE**
The DECIPHER Project (Distributed European Community Individual Patient Healthcare Electronic Record)	**DECIPHER**
Demonstration of a study to Coordinate and Perform Human Biomonitoring on a European Scale	**DEMOCOPHES**
Interventions to Promote Healthy Eating Habits: Evaluation and Recommendations	**EATWELL**
European Burden of Disease Network	**EBoDN**
European Core Health Indicators	**ECHI (I, II, III and JA ECHIM)**
European Collaboration for Healthcare Optimization	**ECHO**
European consortium in healthcare outcomes and cost-benefit research	**ECHOUTCOME**
European Community Respiratory Health Survey III	**ECRHS III**
EPODE European Network	**EEN**

European Health Data and Evidence Network	EHDEN
European Health Expectancy Monitoring Unit	EHEMU
European Health Examination Survey	EHES
European Health and Life Expectancy Information System	EHLEIS
European Medical Information Framework	EMIF
Establishment Of Environmental Health Information System Supporting Policy Making	ENHIS2
European Network for a Healthy Workplace	ENHWP
Environmental Health Risks in European Birth Cohorts	ENRIECO
European Study of Adult Well-Being	ESAW
The European Study on the Epidemiology of Mental Disorders	ESEMeD
EUropean Best Information through Regional Outcomes in Diabetes	EUBIROD
EUropean Core Indicators in Diabetes Mellitus	EUCID
Human Biomonitoring in Europe	EUHBM
European Health Interview and Health Examinations Surveys database	EUHSID/HIS HES Database
European Musculoskeletal Conditions Surveillance and Information Network	EUMUSC.net
European Network for Health Technology Assessment	EUnetHTA
European Union Network for Patient Safety	EUNetPaS
European Network for Indicators on Cancer 2006-2009	EUNICE
European Health Promotion Indicator Development Project	EUPHID
European Registration of Cancer Care	EURECCA
EUROpean Cancer Registry-based study	EuroCARE
Registry of Congenital Anomalies	EUROCAT
European Cancer Health Indicator Project	EUROCHIP-III
European Cardiovascular Indicators Surveillance Set	EUROCISS
European Collaboration on Dementia	EuroCoDe
European drug emergencies network	Euro-DEN
Diagnosis-Related Groups in Europe - Towards Efficiency and Quality	EuroDRG
Shaping EUROpean policies to promote HEALTH equitY	EURO-HEALTHY
European Health Care Outcomes, Performance and Efficiency	EuroHOPE
uropean monitoring of excess mortality for public health action	EURO-MOMO

the European research network for out-of-hours primary health care	EurOOHnet
Better Statistics for Better Health for Mothers and their Newborns in Europe	Euro-Peristat
EuroREACH A Handbook to Access Health Care Data for Cross-country Comparisons of Efficiency and Quality	EUROREACH
European Association for Injury Prevention and Safety Promotion	EUROSAFE
Tackling Health Inequalities in Europe	EUROTHINE
European Urban Health Indicators Part Two: Using indicators to inform policy	EURO-URHIS 2
European human biomonitoring framework	HBM4EU
Hospital Data Project 2	HDP2
The European Health Literacy Survey	HLS-EU
The European Injury Data Base	IDB
International Network of Obstetric Survey System	INOSS
The joint action on healthy life years	JA EHLEIS
Joint Action on Health Equity	JAHEE
Joint Action on Monitoring Injuries in Europe	JAMIE
Joint Action to support the eHealth Network	JAseHN
Promoting mental well-being and healthy ageing in cities	MINDMAP
Models of Child Health Appraised	MOCHA
Multinational MONItoring of Trends and Determinants in CArdiovascular Disease	MONICA
MOnica Risk, Genetics, Archiving and Monograph Project	MORGAM
European Union Multidisciplinary Research Network on Health and Disability in Europe	MURINET
Observational Health Data Sciences and Informatics	OHDSI
ProgrammE in Costing, resource use measurement and outcome valuation for Use in multi-sectoral National and International health economic evaluAtions	PECUNIA
Health Professional Mobility in the European Union Study	PROMeTHEUS
Research on Children and Adults Born Preterm	RECAP-preterm
European information network on drugs and drug addiction	REITOX
A platform and inventory for child health research in Europe	RICHE
ROAdmap for MEntal health Research in Europe	ROAMER
Survey of Health, Ageing and Retirement in Europe	SHARE

Annex 5: Outline paper

Keywords
Health information, international comparison, health policy, population health monitoring, networks, projects, infrastructure, European Union, InfAct.

Title: EU health information efforts: the harvest of policy supporting networks

The importance of attaining a solid base of comparative health data and indicators for the European Union (EU) and its Member States (MS) was addressed by the European Commission (EC) in 1997 by its initiative for a Health Monitoring Programme (HMP).
This article aims to provide a (non-exhaustive) overview of EU subsidized projects and networks that impact(ed) the European Health Information arena. It looks into their achievements in terms of datasets and publications.
In addition, the article aims to investigate if differences exist in the participation rate of MS in these projects and networks, as health information inequalities among MS may be an important obstacle to reduce EU-wide health inequalities.

The article will be submitted to 'Archives of Public Health'.