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Joint Action on Health Information

D8.3 - Guidelines for accessibility and availability of health information

Work package 8. Tools and methods for health information support

T8.3.1 Guidelines on accessibility and availability of data and indicators

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Executive summary

The guidelines for accessibility and availability of health information, Deliverable 8.3 (D8.3), is prepared within Task 8.3.1 - Guidelines on accessibility and availability of data and indicators of the Joint Action on Health Information (InfAct). The report is essentially a guidance to facilitate health data and information availability and accessibility for research purposes and policy making. As part of the InfAct web-based platform for health information research in EU, this guidance document will facilitate EU member states' (MSs) in population health monitoring and health system performance monitoring and assessment activities.

To achieve the goals of T8.3.1, a structured questionnaire was developed and administered to all MSs' representatives under T8.1 - Generating knowledge on data collection methods, and availability and accessibility of health information. The results of the cross-sectional study are presented in the Report on health data collection methods and procedures (D8.1). In addition, EU research networks (RNs) were identified and assessed in terms of quality assurance, data availability and accessibility. The results of the web-based search will be presented in this report prior to recommendations on availability, quality and accessibility of health data and information.

The findings of the cross-sectional study and the assessment of EU RNs underline the gap in health data and information availability, accessibility, or reusability for research activities and policy making. In particular, only 30% of the identified projects and 8 RNs share data with other EU projects or RNs, limiting the use of health data in and across EU countries. Moreover, few RNs provide both macro and microdata on their websites while information on quality assessment procedures of collected data was not reported or was incomplete for various RNs.

The guidance document will facilitate the assessment of health inequalities across EU countries in terms of quality, availability, accessibility and comparability of health data and information.

InfAct: Guidelines for accessibility and availability of health information

I. Introduction

Research networks are the key for international collaborations that can enhance research activities by connecting researchers, private and public institutions, organizations, regional and national research networks, and countries across the globe. Indeed, RNs offer multidisciplinary expertise and promote information exchange between researchers across Europe and extra-EU countries. They are essential for health information system as providers of health information and data.

There are many types of networks and various definitions of a network. A network is generally a relationship between three or more individuals or groups characterized by shared objectives to achieve common goals [1]. For the purpose of this report, a RN is defined as a project involving at least two institutions or stakeholders in a country (national RN) or institutions/stakeholders in at least two countries (international RN).

RNs differ in lifespan, which is related to financial resources, relevance and multisectoral engagements. These factors influence the network's capacity in achieving their objectives and goals [1]. One of the main activities of RNs is the collection of data and information from verified sources into compiled databases and various type of publications available in digital (websites) or paper formats. Thus, their data and information can be considered more reliable compared to those from individual sources. Some of the advantages of RNs in the public health context are: i)   data collection and sharing information; ii) performing collaborative research across different geographical regions; iii) strengthening research capacities at regional, national and international levels by conducting research according to standardized methods and practices. Some RNs also provide training materials and courses addressing healthcare professionals.

II. Aim

The aim of this guidance document is to elaborate recommendations on accessibility and availability of health data and information based on the cross-sectional study on data collection methods, and availability and accessibility of health information and the web-based search of RNs. This document provides the main findings of the assessment of RNs

according to quality assurance, data availability and data accessibility criteria defined in T8.1.

III. Approach

The guidance document was developed according to the findings of A) the cross-sectional study conducted in Task 8.1 and B) the web-based search of RNs conducted in T8.3.1.

A.   Cross-sectional study

A questionnaire was developed to identify data collection methods, availability and accessibility of health information in projects/studies performed in Europe. Data collection was carried out from June to October 2019. The projects/studies could be part of European research networks (e.g., European Health Examination Survey-EHES, European Core Health Indicators Monitoring-ECHIM, European Collaboration for Healthcare Optimization-ECHO, European Cardiovascular Indicators Surveillance Set-EUROCISS, etc.) [2-5], but the related data or indicators are not included in databases of international organizations (e.g., WHO-Europe, OECD, Eurostat). The projects/studies eligible for the survey satisfied the following criteria:

i)   health data provided by the project/study are representative of the population at national or regional level;

ii)   health data cover topical areas of population health monitoring and/or health system performance assessment;

iii)   the project/study do not focus on rare diseases, infectious diseases and cancer;

iv)   health data are accessible as micro or macrodata (aggregated results) which are not included in databases of international organizations such as the World Health Organization-WHO, European Statistical Office-Eurostat, Organization for Economic Cooperation and Development-OECD;

v)   the project/study produced scientific outputs (e.g. research papers, reports, etc.).

B.   Web-based search of EU RNs

The search was performed from April to June 2019 through Google search engine. Additional RNs were identified through the multi-country survey carried out in T8.1. The websites of the identified networks were then evaluated according to the WP8 survey sections:

i)   General characteristics (i.e., name/acronym of the RN; responsible authority and funder; years of activity; main objectives; principal area of research; coordinating

and participating countries; level of representativeness; types of data sources used; data sharing activities; main diseases, health topics, or risk factors considered; elaboration of indicators);

ii) Quality assurance (i.e., information on data quality assessment is provided);

iii) Data availability (i.e., availability of micro or macrodata, data formats and metadata standards);

iv) Data accessibility (i.e., criteria for exchange and sharing of statistical data and metadata are provided)

Regarding quality assurance, eight quality dimensions or criteria shown in Figure 1 were defined by Eurostat [6] (i.e., relevance, accuracy, timeliness, punctuality, comparability, coherence, accessibility and clarity) while two quality criteria were considered by ECHO (coverage and internal reliability) [4]. This set of 10 quality criteria was used for the assessment of the identified projects/studies and RNs.
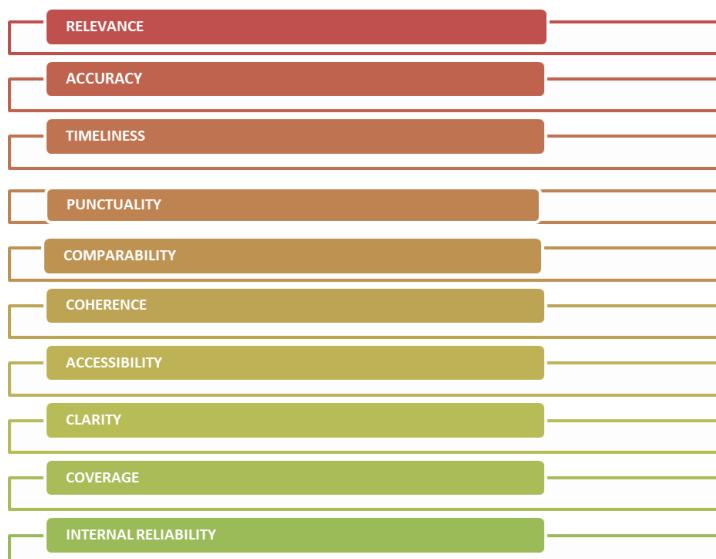
Figure 1. Quality criteria or dimensions defined by Eurostat and ECHO

A brief description of the criteria is reported below [4,6]:

- **Relevance** is the degree to which statistics meet current and potential user needs. It refers to whether all statistics that are needed are produced and the extent to which concepts (definitions, classifications etc.) reflect users' needs.

- **Accuracy** in the general statistical sense denotes the closeness of computations or estimates to the (unknown) exact or true values.

- **Timeliness of information** reflects the length of time between its availability and the event or phenomenon it describes.

- **Punctuality** refers to the time lag between the release date of data and the target date when it should have been delivered, for instance, with reference to dates announced in some official release calendar, laid down by regulations or previously agreed among partners
- **Comparability** aims at measuring the impact of differences in applied statistical concepts and measurement tools/procedures when statistics are compared between geographical areas, non-geographical domains, or over time.
- **Coherence of statistics** is their adequacy to be reliably combined in different ways and for various uses. When originating from different sources, and in particular from statistical surveys of different nature and/or frequencies, statistics may not be completely coherent in the sense that they may be based on different approaches, classifications and methodological standards.
- **Accessibility** refers to the physical conditions under which users can obtain data: where to go, are access to data free or restrictive, etc.
- **Clarity** refers to the data's information environment whether data are accompanied with appropriate documentation and metadata, illustrations such as graphs and maps, whether information on their quality is also available (including limitation in use etc.) and the extent to which additional assistance is provided.
- **Coverage** measures the extent to which the sample stored describes actual performance. Also represents a measure of the potential relevance of the data stored.
- **Internal reliability** is a measure of whether the information stored is consistent over the years. It is a necessary condition for accurate estimations.

IV. Results

A. Cross-sectional study

The results of the cross-sectional study are detailed in the Report 8.1-Generating knowledge on data collection methods, and availability and accessibility of health information. In summary, the survey collected information on 91 projects/studies from 18 EU countries. The main results of the survey showed that:
- only one-third of the projects share data with EU research networks;
- less than half of the projects follow meta-data reporting standards for data description;

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- less than one-third of the projects evaluate all quality criteria defined by Eurostat (i.e., relevance, accuracy, timeliness, punctuality, comparability, coherence, accessibility and clarity) and ECHO (coverage and internal reliability);
- microdata are never accessible in open access while macrodata are accessible in one-third of the projects.

These results demonstrate that evidence produced by research is not always available, comparable or usable for research purposes and policy making.

B.   Web-based search of EU RNs

1. General characteristics of the networks

A total of 57 RNs (Annex 1) were identified through the desk research and, to date, eight RNs are still active: Euro-Peristat, CoNARTaS, EUBIROD, EHES, ELSO, RECAP preterm, SHARE, and MultiCom. A brief description of each RN is reported in Annex 2. Information about the coordinating country is depicted in Figure 2. Most RNs were coordinated by Italy (10/55), followed by the Netherlands and Spain with 7/55 RNs each. The participating countries in the networks went from a minimum of two countries (i.e., the Family life courses, intergenerational exchanges and later life health - FAMHEALTH established in Norway and the UK) to the majority or all EU MSs (e.g., Euro-Peristat, EuroCARE, ECHI, SHARE, RARECARE, etc.). Countries from other geographical regions were also part of the RNs, such as North and South America (e.g., the USA, Canada, Argentina, Brazil), Africa (e.g., South Africa, Kenya), and Asia (e.g., China, Japan, South Korea). More than 40 RNs are funded or co-funded by the EU Commission; funds are also provided by Ministries of Health, research councils and institutes of the participating countries. Few RNs (5/57) were supported by private foundations (e.g., Bill and Melinda Foundation). Most RNs are representative at both international and national levels (22/57) or only international level (16/57), while 14/57 are representative at all three levels (international, national, and regional).
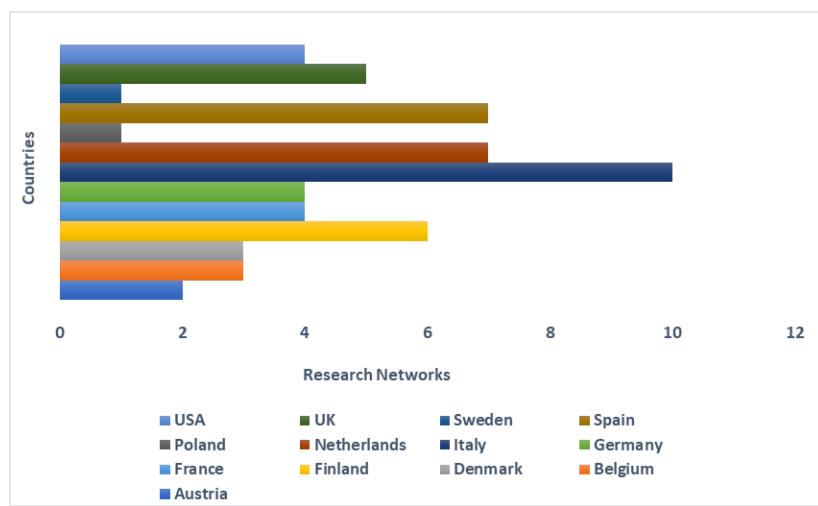
Figure 2. Coordinating countries of the research networks

The main authorities or responsible organizations of the RNs (Figure 3) are National Health or Research Institutes (16/56), Universities (9/56) and the EU consortium (8/56). Information about the responsible authority was not available for one RN: the International Cancer Benchmarking Partnership (ICBP).
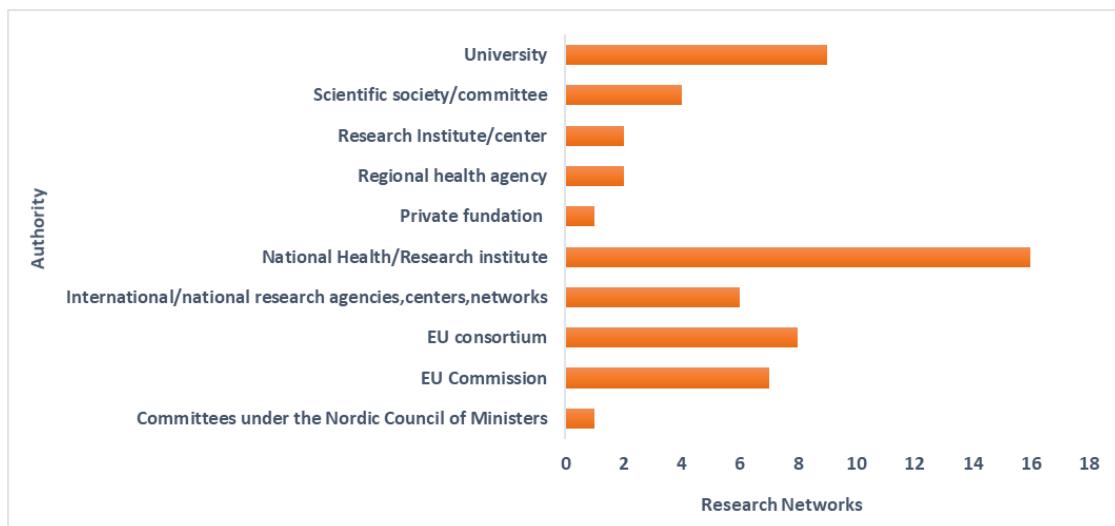

Figure 3. Authorities or responsible organizations of the research networks

The principal area of research for the majority of the networks (Figure 4) is health monitoring (32/57) and, to a lesser extent, health system performance monitoring/health system performance assessment (8/57).
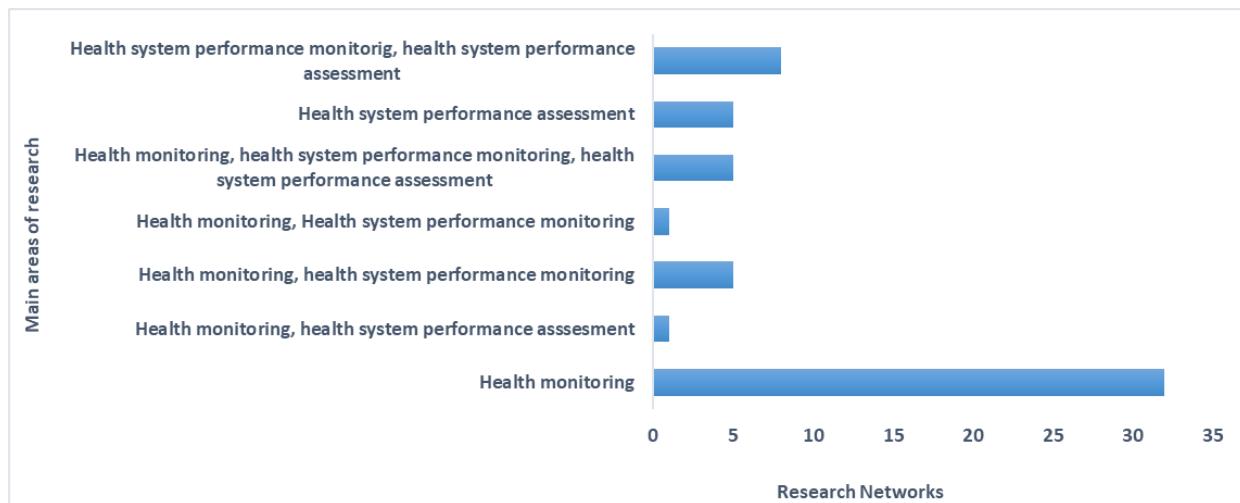
Figure 4. Main areas of activity of the research networks

Various types of data sources are used by the RNs, such as administrative data (e.g., hospital discharge records, mortality data, pharmaceutical prescriptions), population-based surveys/interviews, longitudinal or cohort studies, population-based disease registries (e.g., diabetic registries, breast units registries, registers of road and workplace accidents), medical records (e.g., electronic health data), and so on. The majority of RNs used a combination of different data sources.

The diseases or health topics under consideration varied greatly according to the objectives and areas of activities of the RNs, they included for instance unhealthy lifestyles, non-communicable diseases (e.g., cardiovascular diseases, diabetes, cancer, mental disorders, perinatal and maternal health, etc.), non-fatal injuries, age-related diseases, environmental hazards and urban health, health system performance, healthcare utilization, health inequalities, health promotion and interventions, and more.

Risk factors, high-risk conditions or health behaviors under consideration (Annex 3) were also related to the main areas of research of the RNs, such as behavioral, environmental, socio-economic, and disease-specific risk factors. Main indicators elaborated from the collected health data included (Annex 3) prevalence, incidence, outcome and performance measures, attack rates, injury disability indicators, and more.

Most RNs (40/49) do not share data with other projects or RNs. Data sharing is in place for eight RNs (Table 1) and in progress for the MSDA network.

Table 1. Research networks sharing data with other projects or networks

RESEARCH NETWORK	DATA SHARED WITH PROJECTS/NETWORKS
MONICA	MORGAM, euCanShare, ENGAGE, CHANCES, BiomarCARE, AFFECT-EU
DKA-type 1 diabetes	Joint International Project DKA at onset of pediatric type-1 diabetes
IDB	EUROSAFE
B.I.R.O.	EUropean Best Information through Regional Outcomes in Diabetes (EUBIROD)
EUNICE	EUROCARE and EUROCHIP
SHARE	English longitudinal study on aging (ELSA), U.S Health and Retirement Study (HRS)
EHDEN	EHDEN is part of the IMI Big Data for Better Outcome Program (BD4BO)
BRIDGE	ECHIM; EHES; COPHES/DEMOCOPHES/ENRIECO; Euro-Peristat, Riche, Chicos; EuroHOPE; EHLEIS

2. Quality assurance procedures

In this section, we investigated if information on quality assessment of the collected data is performed and reported on the websites of the RNs. Most RNs (41/57) reported the information. Some examples of RN that provided information on quality assessment procedures are depicted below (Table 2).

Table 2. Examples of research networks providing information on quality assessment of collected data

EUROCISS	Relevance= European wide research network, already finished project; Accuracy= data collected from different databanks, aims at validating criteria and definitions; Timeliness= already finished project; Punctuality= ok; Comparability= uses several indicators, aimed at using validated and comparable data; Coherence= good; Accessibility= good; Clarity= ok; Coverage= most European countries.
EUROSAFE	Relevance= good; Accuracy= good, validated data collected; Timeliness=data collected annually; Punctuality= good; Comparability= good, uses EU databanks; Coherence= data combined from various datasets for complete HI; Accessibility= reports, tables and figures easily accessible, IDB database link provided; Clarity= good; Coverage= most EU countries
EHES	Relevance= good, produced guidelines are still relevant and accessible; Accuracy= definitions and classifications of the measurement methods made; Timeliness= project already ended,; Punctuality= validated methods for measurements; Comparability= aimed at enhancing comparability of HI by producing guidelines for protocols and measurement methods within EU; Coherence= validated methods; Accessibility= guidelines still accessible, project already ended; Clarity= good; Coverage= aimed at all EU members conducting health surveys
GBD	Relevance= good; Accuracy= uses several data collection methods; Timeliness= annually collected; Punctuality= good; Comparability= challenges in comparing data due to different collection methods; Coherence= surveys used, different data methods; Accessibility= good; Clarity= good; Coverage= very good, nearly all countries participating

Information on quality assessment procedures was not reported or was incomplete for 15 RNs; some examples are depicted in Table 3.

Table 3. Examples of research networks not providing or providing insufficient information on quality assessment of collected data

GA2LEN	**Relevance= finished project; Accuracy= ?; Timeliness= already finished project; Punctuality= ?; Comparability= ?; Coherence= ?; Accessibility= publications available on the website; Clarity= good; Coverage= good**
JA EHLEIS	Relevance=good, several statistics and indicators elaborated; Accuracy=good, specific database created (HLY indicators); Timeliness= ?; Punctuality= ?; Coherence= ?; Accessibility= database is on the webpage, but doesn´t open; Clarity= not possible to assess
ENRIECO	Relevance=ok; Accuracy=information not available; Timeliness=project ended; Punctuality= no information; Comparability= no information; Coherence= no information; Accessibility= no access to microdata, reports/articles available; Clarity= good for reports/articles; Coverage=not all EU countries participating
EuroCARE	Relevance=good, classifications by diagnoses; Accuracy= not updated anymore, not accurate anymore; Timeliness=not updated anymore; Punctuality= ?; Comparability= good; Coherence= good; Accessibility= macrodata available on the website, not clear if more detailed data are available upon request; Clarity= old website not updated anymore; Coverage= most EU countries

The quality evaluation criteria were not applicable to the Commonwealth Fund Multinational Comparisons of Health Systems Data (MultiCom) that uses data collected and processed by OECD.

3. Availability of health data

Out of 49 RNs providing health data on their websites, 39 RNs provided only macrodata as reports and/or scientific articles. Micro- and macrodata are provided by eight RNs (i.e., EMIF, ELSO, EUROCAT, ICBP, MONICA, MSDA, RECAP preterm, and RARECARE). Microdata is the main data format offered by two networks, DKA - type 1 diabetes and SHARE, while eight RNs do not provide any data (i.e., EUPHORIC, CHICOS, ENRIECO, B.I.R.O., CoNARTaS, EHDEN, EUNICE, and HAEMACARE) due to lack of access to the website or to a specific database. Further data analysis, aggregation or stratification, is possible for 16/47 RNs providing macrodata. Metadata reporting standards for health data description are mentioned by 9/49 RNs and detailed in Table 6.

Table 6. Metadata reporting standards used in EU research networks

RESEARCH NETWORK	METADATA REPORTING STANDARDS
INTEGRIS	ECHI metadata standard (Eurostat); ICD10
HAEMACARE	ICD-0 morphology codes
IDB	ICD-10, MDS (XML schema implementation)
OHDSI	OMOP Common Data Model
MSDA	Not specified
EUBIROD	Ad hoc data standards
EUROCISS	ICD codes
Euro-Peristat	ICD-10 codes, ISCO 2008, ISCED-UNESCO codes
ECHIM/ECHI	SDMX metadata structure

4. Data accessibility

Health data provided by 40 RNs are publicly accessible as macrodata through guidelines, reports and scientific articles; microdata are not available in open access. A request for micro- and/or macrodata access is required by 14 networks, of which three apply a financial charge (i.e., EPIC CVD, DKA - type 1 diabetes, and ELSO). Data access is usually granted by scientific, ethics or steering committees, or management teams. Data of 34/49 RNs are reusable and remote access is provided by four RNs.

V. Conclusions and recommendations

This guidance document aims to facilitate the dissemination and access to standardise and comparable high-quality health information and data in MSs. The recommendations provided in this document stem out from the findings of the cross-sectional study on data collection methods, and availability and accessibility of health information and the assessment of EU RNs in terms of quality assurance, data availability and accessibility.

The evaluation of RNs confirmed the use of various sources for data collection that was observed for the projects/studies described in the Report "Generating knowledge on data collection methods, and availability and accessibility of health information". Frequently used data sources are administrative data sources (e.g., hospital discharge records, mortality data, pharmaceutical prescriptions), followed by population-based surveys/interviews, longitudinal or cohort studies, population-based disease registries (e.g., diabetic registries, breast units registries, registers of road and workplace accidents), and

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medical records (e.g., electronic health data). In most RNs, a combination of various reliable sources are used to compile databases covering different health topics and geographical regions.

The use of different reliable population health data sources in public health research activities can provide accurate findings which can be used for the development and implementation of evidence-based interventions and policy.

The availability and accessibility of macrodata through articles and reports are also confirmed, while microdata are available from the majority of the projects/studies and from less than 10 RNs. Further data analysis, aggregation or stratification was possible for only 16/47 RNs and 14/44 projects/studies providing macrodata. A request for data access is required mostly for microdata and granted by scientific, ethics or steering committees of the projects/studies or RNs. This finding highlights the compliance of the projects/studies and RNs to the General Data Protection Regulation (GDPR) on data protection and privacy in the EU and the European Economic Area (EEA). The GDPR also addresses the transfer of data outside the EU and EEA [7]. The GDPR [8] states the following:

- *"In order to facilitate scientific research, personal data can be processed for scientific research purposes, subject to appropriate conditions and safeguards set out in Union or Member State law. Scientific research purposes should also include studies conducted in the public interest in the area of public health […]".*
- *"[…] Personal data should be processed in a manner that ensures appropriate security and confidentiality of the personal data, including preventing unauthorised access […]"*
- *"Where personal data are processed for statistical purposes, this Regulation should apply to that processing. Union or Member State law should, within the limits of this Regulation, determine statistical content, control of access, specifications for the processing of personal data for statistical purposes […]. The statistical purpose implies that the result of processing for statistical purposes is not personal data, but aggregate data […]".*

"The principles of data protection should be applied to any information concerning an identified or identifiable natural person". Compliance to the EU-GDPR is essential for the protection of personal data and to ensure the free movement of personal data within the EU [8].

Most websites of the project/studies and RNs are not accessible after the completion of their research activities. In some cases, the websites are still accessible but do not report data or information useful for research purposes. The lifespan of projects/studies and RNs can certainly influence data availability and accessibility, thus in the long-term, the sustainability of research activities. The lifespan also depends on available funding resources, relevance of the research activities, and the capacity of building partnerships to achieve common goals. It should be noted that few RNs and projects/studies require a financial charge for data access.

More efforts and funding should be directed to the development of effective and sustainable projects and RNs. This will maximize the allocation of resources in MSs and prevent the fragmentation of research activities and outputs. It will also optimize the reusability of collected health data and information.

The cross-sectional study and the evaluation of RNs highlighted the heterogeneity in data collection methods and quality assessment procedures and underline the lack of available, accessible, comparable or reusable health data and information for research purposes and policy making in and across EU countries. Indeed, data reusability is reported and possible in only 30% of the projects/studies for both micro- and macrodata, and for about 70% of the RNs. One-sixth of the projects evaluate all 10 quality dimensions defined by Eurostat/ECHO and almost half of the identified RNs do not provide information on quality assessment procedures of the collected health data or the information is incomplete. Less than half of the projects and only nine RNs follow metadata reporting standards for data description. However, protocols and guidelines reporting standardized procedures in data collection, analysis and reporting are available and already applied in some projects/studies and RNs. These are, for example, guidelines for laboratory analysis provided by the Clinical and Laboratory Standards Institute (CLSI) and standardized methods for biobanking are indicated by the European research infrastructure for biobanking (BBMRI-ERIC). Regarding statistical analysis and data quality control, there are guidelines and recommendations provided by international organizations (e.g., WHO, International Agency for Research on Cancer-IARC) and EU research networks (e.g., EHES, MONItoring of trends and determinants in CArdiovascular disease-MONICA, European Prospective Investigation into Cancer and Nutrition-EPIC). For data reporting standards, recommendations are provided by international organizations (e.g., WHO, European Center for Disease Prevention and Control-ECDC), EU research networks (EHES, Health Behaviour in School-aged Children-HBSC, Infrastructure for Spatial Information in Europe-INSPIRE) and the International

Committee of Medical Journal Editors (ICMJE) for the conduct, reporting, editing, and publication of research studies in medical journals. Standardization procedures ensure that three criteria are met: i) the aims of data collection are made explicit and all necessary and pertinent information are collected; ii) data are collected using the same method; iii) the same definitions are used. Standardization is also essential for comparing population groups, geographic areas, or trends over long periods of time [9].

Adherence to guidelines and protocols on standardized procedures in data collection, analysis and reporting is essential to ensure the comparability of research outputs. Likewise, adherence to FAIR Data Principles [10] is also fundamental in order to make data FINDABLE (data and supplementary materials have sufficiently rich metadata and a unique and persistent identifier); ACCESSIBLE (metadata and data are understandable to humans and machines, and data is deposited in a trusted repository); INTEROPERABLE (metadata use a formal, accessible, shared, and broadly applicable language for knowledge representation); and REUSABLE (data and collections have a clear usage license and provide accurate information on provenance).

Although quality criteria or dimensions are available for quality assessment of collected health data, these criteria are seldom applied in RNs and projects/studies. Data quality assessment should be performed through mixed methods, such as qualitative and quantitative assessment methods, to assess data from multiple data sources [11,12].

Quality assessment of health data and information is essential to obtain accurate, reliable and valid data that can be used for effective population health monitoring/public health surveillance and health system performance assessment.

Finally, only one-third of the identified projects and one-sixth of RNs share data with other EU projects or research networks. Data sharing among research networks, institutions and healthcare organizations is fundamental for access to relevant health data. Lack of data sharing in MSs is a barrier to comprehension of epidemiological events and finding of potential solutions. This issue is more evident in times of emergency, such as the COVID-19 pandemic.

Research networks could play a major role in tackling health data and information inequalities by enhancing quality, availability, accessibility of health data and data sharing across European networks.

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ANNEX 1. European research networks identified through the web-based search

RESEARCH NETWORK	ACRONYM	YEARS OF ACTIVITY
Best Information through Regional Outcomes: a Shared European Diabetes Information System for Policy and Practice	B.I.R.O.	2005-2008
Better Statistics for Better Health for Mothers and their Newborns in Europe	Euro-Peristat	1999 to date
BRidging Information and Data Generation for Evidence-based Health policy and research	BRIDGE	2015-2017
Cancer Control using Population-based Registries and Biobanks	CCPRB	2004-2009
Cancer Registry Based project on Haematologic Malignancies	HAEMACARE	2005-2008
Committee of Nordic Assisted Reproductive Technology and Safety	CoNARTaS	2008 to date
Comparative Effectiveness Research on Psychiatric Hospitalisation by Record Linkage of Large Administrative Data Sets	CEPHOS-LINK	2014-2017
Comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of mental health care	COFI	2014-2018
Deepening our understanding of quality improvement in Europe	DUQuE	2009-2014
Developing a Child Cohort Research Strategy for Europe	CHICOS	2010-2013
Diagnosis-Related Groups in Europe - Towards Efficiency and Quality	EuroDRG	2009-2011
Environmental Health Risks in European Birth Cohorts	ENRIECO	2009-2011
EU Public Health Outcome Research and Indicators Collection	EUPHORIC	2004-2008
European Association for Injury Prevention and Safety Promotion	EUROSAFE	2007-nr
EUropean Best Information through Regional Outcomes in Diabetes	EUBIROD	2005 onwards: EUROBIROD project (2008-2012), EUROBIROD Network ongoing
EUROpean Cancer Registry-based study	EuroCARE	1978 to 2007
European Cardiovascular Indicators Surveillance Set	EUROCISS	2000-2007
European Collaboration for Healthcare Optimization	ECHO	2010-2017
European Community Health Indicators and Monitoring	ECHIM/ECHI	ECHIM JA 2009-2012, 3 ECHI projects 1998-2001, 2001-2004, 2005-2008
European Health Care Outcomes, Performance and Efficiency	EuroHOPE	2010-2014
European Health Data and Evidence Network	EHDEN	2018-2024
European Health Examination Survey	EHES	EHES pilot 2009-2012, ongoing
European Medical Information Framework	EMIF	2013-2018
European Network for Indicators on Cancer 2006-2009	EUNICE	2005-2007
European Urban Health Indicators System Part 2	EURO-URHIS 2	2009-2013
Extracorporeal life support association	ELSO	1989 to date
Family life courses, intergenerational exchanges and later life health	FAMHEALTH	2013-2018
Global Allergy and Asthma European Network	GA2LEN	2004-2015
Health Benefits and Service costs in Europe	HealthBASKET	2004-2007

Health Inequalities Indicators in the Regions of Europe	I2SARE	2008-2010
Improved access to health care data through cross-country comparisons	EuroREACH	2010-2013
Improved methodology for data collection on accidents and disabilities-Integration of European Injury Statistics	INTEGRIS	2008-2011
Individualized CVD risk assessment across Europe	EPIC CVD	1990's -2009
International Cancer Benchmarking Partnership	ICBP	2009-nr
International Research Project on Financing Quality in Healthcare	InterQuality	2010-2013
Italian nationwide longitudinal population-based study on Diabetic Ketoacidosis at Diagnosis of Type 1 Diabetes	DKA - type 1 diabetes	2016-2018
MAnagement of mental health diSorders Through advancEd Technology and seRvices – teleHealth for the MIND	MasterMind	2014-2017
Multinational MONItoring of Trends and Determinants in CArdiovascular Disease	MONICA	1980 onwards. Active period of data collection ended around 2000
Multiple Sclerosis Data Alliance	MSDA	nr
Nordic Welfare dataBASE (NOWBASE)	NOMESCO	nr
Observational Health Data Sciences and Informatics	OHDSI	2014-nr
Operations management and demand-based approaches to healthcare outcomes and cost-benefits research	MANAGED OUTCOMES	2010-2012
Personalized PREvention of Chronic DIseases consortium	PRECeDI	2015-2018
Pooling of European Data to Harmonise Translational Research in Breast Cancer	ONCOPOOL	2002-2004
Quality and costs of primary care in Europe	EUPrimeCare	2010-2012
Quality and Costs of Primary Care in Europe	QUALICOPC	2010-2013
Registry of Congenital Anomalies	EUROCAT	1979-nr
Research on Children and Adults Born Preterm	RECAP preterm	2017 up to 51 months
Socio-economic inequalities in health and mortality in 16 European cities at the beginning of the 21st century	INEQ-CITIES	2009-2012
Surveillance of rare cancers in Europe	RARECARE	2007-2010
Survey of Health, Ageing and Retirement in Europe	SHARE	2004 onwards, currently wave 8 ongoing
Tackling Health Inequalities in Europe	EUROTHINE	2004-2007
The Commonwealth Fund Multinational Comparisons of Health Systems Data	MultiCom*	1918 to date
The European Hospital Benchmarking by Outcomes in Acute Coronary Syndrome Processes	EurHOBOP	2009-2012
The European Injury Data Base	IDB	2012-nr
The Global Burden of Disease	GBD	2007-nr
The joint action on healthy life years	JA EHLEIS	2011-2014

nr, not reported; *MultiCom, acronym not reported by the RN and defined by the authors of the report;

Active networks are highlighted in green

ANNEX 2. Description of the identified research networks

RESEARCH NETWORK	BRIEF DESCRIPTION
Nordic Welfare dataBASE (NOWBASE)	NOWBASE is a shared website for Nordic Medico-Statistical Committee (NOMESCO) and the Nordic Social Statistical Committee (NOSOSCO). Aims to ensure that health and social statistics are comparable in the Nordic Countries. Gathers, presents and distributes data.
The European Injury Data Base	It is a surveillance system that provides information on non-fatal unintentional injuries such as home injuries, sports and leisure, workplace and road injuries; in addition to intentional injuries resulting from violence and self-harm.
Registry of Congenital Anomalies	Gathers, validates, analyses and disseminates data on Congenital Anomalies and its determinants at country level and regional level in EU Countries. Promotes data use in collaborative research projects.
Cancer Control using Population-based Registries and Biobanks	To facilitate research linking biobanks and cancer registries
BRidging Information and Data Generation for Evidence-based Health policy and research	To build a system to support interoperability – both technical and social – in large-scale emergency management. The BRIDGE Health project aimed to prepare the transition towards a sustainable and integrated EU health information system for both public health and research purposes
Comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of mental health care	To conduct a large-scale comparison in countries with different traditions, levels of service provision and funding systems of mental health care (Belgium, Germany, Italy, Poland, United Kingdom).
Deepening our understanding of quality improvement in Europe	The main goal of the DUQuE project is to study the effectiveness of quality improvement systems in European hospitals. This has been done by assessing the relationship of organisational quality improvement systems/management and culture, professionals' involvement, and patient empowerment with the quality of hospital care (including clinical effectiveness, patient safety and patient involvement).
Quality and costs of primary care in Europe	aimed to develop a framework to analyse Primary Care across Europe, to assess and compare Primary Care models in terms of quality and identifying costs and to provide recommendations.
Extracorporeal life support association	An international register; developed a specific dataset in order to help NICE in its assessment of ECMO
European Medical Information Framework	Tackle technical challenges when scaling up real-world health data research; improve access to human health data via providing tools and workflows to discover, assess, access and (re)use human health data
Multiple Sclerosis Data Alliance	They work with patient communities and organisations to promote the value of research and the importance of MS data.
Global Allergy and Asthma European Network	International network in allergy and asthma research to bring together institutions and researchers from across EU. The network aims to accelerate the application of research into clinical practice, meet the needs of patients and to help guide policy development. The consortium is leading European research centres specialized in allergic diseases.
The European Hospital Benchmarking by Outcomes	To provide European hospitals with a validated set of statistical functions - including determinants of in-hospital case fatality outcome indicator - to

in Acute Coronary Syndrome Processes	benchmark themselves about the quality of management of myocardial infarction (MI) or unstable angina (UA) patients and treatments aimed at removing coronary artery occlusion.
European Health Data and Evidence Network	Federated data ecosystem in Europe using OMOP common data model. Mission: to provide a new paradigm for the discovery and analysis of health data in Europe, by building a large-scale, federated network of data sources standardized to a common data model
Environmental Health Risks in European Birth Cohorts	Aims to advance knowledge on specific environment and health causal relationships in pregnancy and birth cohorts.
Best Information through Regional Outcomes: a Shared European Diabetes Information System for Policy and Practice	To build a common European infrastructure for standardized information exchange in diabetes care, for the purpose of monitoring, updating and disseminating evidence on the application and clinical effectiveness of best practice guidelines on a regular basis
Survey of Health, Ageing and Retirement in Europe	Multidisciplinary and cross-national panel database of microdata on health, socio-economic status and social and family networks of individuals aged 50 or older
Multinational MONItoring of Trends and Determinants in CArdiovascular Disease	The MONICA (Multinational MONItoring of trends and determinants in CArdiovascular disease) Project was established in the early 1980s in many Centres around the world to monitor trends in cardiovascular diseases, and to relate these to risk factor changes in the population over a ten year period. It was set up to explain the diverse trends in cardiovascular disease mortality which were observed from the 1970s onwards. There were total of 32 MONICA Collaborating Centres in 21 countries. The total population age 25-64 years monitored was ten million men and women. The ten year data collection was completed in the late 1990s, and the main results were published in the following years.
Individualized CVD risk assessment across Europe	To provide clinicians and policy-makers with evidence-based options for cost-effective individualised cardiovascular disease (CVD) risk assessment. Encompasses InterAct and EPIC-Heart (projects based on diabetes and coronary heart disease respectively) and include stroke cases
The Global Burden of Disease	GBD provides a tool to quantify health loss from hundreds of diseases, injuries, and risk factors, so that health systems can be improved and disparities can be eliminated.
Observational Health Data Sciences and Informatics	To improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care.
Improved access to health care data through cross-country comparisons	Aims to ensure comparability and harmonization of health data for cross-country research. The project will also provide a toolbox of guidance to researchers, policymakers and other stakeholders interested in cross-country research by: Identifying information sources of patient-level, disease-based data; b) Offering guidance on key data challenges such as data access, linkage and comparability; c) Highlighting gaps in existing data to encourage data collection in underrepresented areas.
European Network for Indicators on Cancer 2006-2009	To establish and operate a network, comprising primary data providers (European Cancer registries) and organizations with experience in coordination, collection, quality control, standardization, processing and dissemination of data, to provide with updated and standardized indicators of cancer.
EUROpean Cancer Registry-based study	aimed to provide an updated description of cancer survival time trends and differences across European countries, to measure cancer prevalence, and to study patterns of care of cancer patients.

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Better Statistics for Better Health for Mothers and their Newborns in Europe	The objective is to establish a high quality, internationally recognized and sustainable European perinatal information system.
Research on Children and Adults Born Preterm	To improve health, development and quality of life of very preterm or very low-birth-weight children and adults by combining European cohort studies.
The joint action on healthy life years	To contribute to the first partnership of Innovation Union, which focuses on active and healthy ageing and with the target of increasing by 2 years the average number of healthy life years by 2020. Provides information on various health indicators that are comparable among EU countries and further develops the EHLEIS system to allow rapid access to up-to-date health expectancies.
Socio-economic inequalities in health and mortality in 16 European cities at the beginning of the 21st century	To identify socio-economic inequalities in health and mortality in Europe and to examine urban health policies developed to tackle such inequalities in health.
Surveillance of rare cancers in Europe	Aim is to provide an operational definition of "rare cancer" and a list of cancers meeting that definition.
Health Inequalities Indicators in the Regions of Europe	To produce a health profile for each region of the European Union, to create a typology of those regions of Europe and a typology of sub regional territories in a selection of countries and regions. Main objective is to assist decisionmakers in developing their health policies, through better understanding in health statuses and health inequalities at regional and subregional levels.
European Community Health Indicators and Monitoring	Aims to create a comparable health information and knowledge system to monitor health at EU level to support policy making. Currently uses over 60 indicators in 5 main themes. These indicators give an overview of health and health systems across Europe.
European Health Examination Survey	Population based and objective surveys which provides data on many health indicators to support policy-making, preventive activities and research. Aims to ensure high quality and comparability of health data by standardized procedures.
European Collaboration for Healthcare Optimization	Aimed at building a common knowledge infrastructure, based on existing datasets. Aims to bring together national hospital databases from several European countries.
European Cardiovascular Indicators Surveillance Set	Goal was to develop health indicators and recommendations for monitoring the burden and distribution of cardiovascular disease (CVD). Manual of Operations for the implementation of population-based registers of acute myocardial infarction/acute coronary syndrome, stroke and of CVD surveys was the main result.
European Health Care Outcomes, Performance and Efficiency	To evaluate the performance of European health care systems in terms of outcomes, quality, use of resources and costs. The project focuses on five important disease groups: acute myocardial infarction (AMI), ischemic stroke, hip fracture, breast cancer and very low birth weight and very preterm infants (VLBWI).
Quality and Costs of Primary Care in Europe	Aims to analyse and compare how primary health care systems in 34 countries perform in terms of quality, costs and equity
EU Public Health Outcome Research and Indicators Collection	Aimed at building a consortium of participating countries to cooperate on benchmarking the outcomes of selected health performances and exchange information on quality standards, best practice and effectiveness in public health by developing and maintaining EU networks
Comparative Effectiveness Research on Psychiatric Hospitalisation by Record	To identify factors related to re-hospitalisations by comparing psychiatric re-hospitalisation rates and identifying their predictors in unselected patient

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Linkage of Large Administrative Data Sets	populations from six European countries with different health care systems (Austria, Finland, Italy, Norway, Romania and Slovenia)
Cancer Registry Based project on Haematologic Malignancies (HMs)	This project aims to bridge the gap between clinical research and public health information systems. It will be based on the EUROCARE-3 and EUROPREVAL networks and will profit form the collaboration of EUROCHIP project. Main objective 1. Revision of HMs coding procedures used by cancer registries, ensuring strict adherence to ICD-0 morphology codes, and making them consistent with nosologic categories currently used by clinicians. A panel of haematologists and epidemiologists will be constituted for this purpose. 2. Improve public health use of clinical data. Indicators of clinical activity for HMS by country, will be provided, through integration of data from population cancer registries and clinical networks on HMs.
International Cancer Benchmarking Partnership	The project has demonstrated differences in survival between countries and has suggested some possible causes of these differences, and ruling out possible causes
The Commonwealth Fund Multinational Comparisons of Health Systems Data	Data collected by OECD are used to compare healthcare systems and performance on a range of topics (e.g. spending, hospitals, physicians, etc.). Data across eleven industrialized countries are presented: Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States.
MAnagement of mental health diSorders Through advancEd Technology and seRvices – teleHealth for the MIND	The project created guidelines and pathways for using videoconference for collaborative care and treatment of depression. The guidelines are based on the previous pilot projects. The aim of the project was to use VC (videoconference) in collaborative settings between GPs and specialists. Additionally, the need for the use of it in direct treatment and cCBT (computerised cognitive behavioural therapy) was realised. Main healthcare users can be psychiatric departments, health care organisers, e-health clinics, mental health outpatient services etc.
Pooling of European Data to Harmonise Translational Research in Breast Cancer	The proposal is to obtain a large Data Set of Breast cancers, from Breast Units representative of the presentation of the disease in Europe. No such large tumour set, with carefully compiled and checked long-term clinical follow-up and with standardised histological and other measurements of tumour factors, exists in Europe. The Data Set will provide a critical mass, invaluable in translational research for relating tumour factors to clinical outcomes. The Consortium for the project provides a European Network of Excellence in Breast Cancer. At the conclusion of the project this will be expanded by other Units. In turn this will provide a huge Data Set with associated Quality Assurance of the data.
Developing a Child Cohort Research Strategy for Europe	Aims to improve child health across Europe by developing an integrated strategy for mother-child cohort research in Europe by evaluating data from existing cohorts, registers and relevant European databases, identifying gaps in knowledge, developing recommendations for targeted research action at the European level.
Improved methodology for data collection on accidents and disabilities-Integration of European Injury Statistics	To develop and evaluate a data model for the integration of routine and more detailed hospital data on injuries, namely through linking the official HDR (hospital discharge registers) with the EUIDB (EU Injury database). The goal of the integrated data model would enable hospitals to generate standard injury data with minimal additional efforts. To identify possible risk factors and strengthen injury prevention by understanding statistics from already existing databases.
Italian nationwide longitudinal population-based study on Diabetic	The project provides information on DKA at diagnosis of type 1 diabetes for planning prevention interventions

Ketoacidosis at Diagnosis of Type 1 Diabetes	
European Association for Injury Prevention and Safety Promotion	Promotes safety of European citizens by enhancing safety of products and services, raises awareness of injury risks at home and in leisure and offers cost effective measures to prevent injuries.
Committee of Nordic Assisted Reproductive Technology and Safety	To investigate the health of children born after assisted reproduction (ART), and the safety of ART in four Nordic countries: Denmark, Finland, Norway and Sweden.
EUropean Best Information through Regional Outcomes in Diabetes	The vision of the EUBIROD Network is to support and facilitate the integration of all diabetes data sources already available, in order to improve all policies against diabetes and to reduce its direct implications across the whole range of non-communicable diseases. An active collaboration of systematic data collection and monitoring of diabetes complications and health outcomes across Europe. The EUBIROD is an informal and voluntary collaboration, which advocates of the rights of the people with diabetes, (non)governmental organizations, scientific societies, associations of health professionals and individual citizens. EUROBIROD network builds on the finished EUROBIROD project 2008-2012).
Operations management and demand-based approaches to healthcare outcomes and cost-benefits research	The MANAGED OUTCOMES proposal explores the assumption that healthcare outcomes and costs are affected by the efficiency of service production, the time/location constrained regional structure of healthcare delivery, and the degree to which people are empowered to participate in the co-production of their care. These relationships are insufficiently understood and need to be studied to meet the objectives of the new European health strategy. More optimized health systems should be planned on the grounds of citizens' expectations for both effective outcomes, and for access and quality of healthcare delivery.
Tackling Health Inequalities in Europe	The Eurothine project is a large international project aimed to improve the description of health inequalities in Europe and to enhance the evidence-base for policies to reduce inequalities in health. Its two principal objectives were: 1) to prepare international overviews that provide bench-marking data on inequalities in mortality, morbidity and health determinants to participating countries; 2) to assess evidence on the effectiveness of policies and interventions to tackle health inequalities, and to make recommendations on strategies for reducing health inequalities in participating countries
Personalized PREvention of Chronic DIseases consortium	Health care is increasingly adopting a more personalised medicine (PM) approach involving individually tailored patient care. The project aims to foster collaboration on PM research and training with attention to prevention of chronic diseases. A set of recommendations in research and consortium was carried out to policy-makers, scientists and health care industry.
Health Benefits and Service costs in Europe	The project developed and tested an innovative approach of cost analysis at the micro-level that allow for international comparisons.
Family life courses, intergenerational exchanges and later life health	To uncover how family life courses influence health and well-being in later adulthood, whether family related strengths or disadvantages relevant to health offset or compound socio-economic sources of disadvantage, and the extent to which these associations are influenced by societal factors.

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Diagnosis-Related Groups in Europe - Towards Efficiency and Quality	Analysis of the national DRG-based hospital payment systems by using qualitative and quantitative research methods.
European Urban Health Indicators System Part 2	The project aims to identify urban health problems, and for the first time to compare health statuses between the different cities in Europe. This is done by developing, testing and validating a set of comparable urban health indicators. The aim is to provide information for policy-makers to prioritise topics in urban health issues, policies and interventions.
International Research Project on Financing Quality in Healthcare	To investigate the effect of different financing methods and incentives on quality, effectiveness and equity of access to health care in four patient groups affected by: pharmaceutical care, hospital care, outpatient care and integrated care.

ANNEX 3. Risk factors under consideration and indicators elaborated by the research networks

RESEARCH NETWORK	RISK FACTORS, HIGH-RISK CONDITIONS AND HEALTH BEHAVIORS	ELABORATED INDICATORS
B.I.R.O.	Glycaemia; blood pressure; lipids; microalbuminuria; smoking; alcohol; drug abuse/dependence; diet; socio-economic factors	Incidence; prevalence; structural quality; process quality; outcome measures
BRIDGE	Anthropometry, blood pressure, total and HDL cholesterol and glucose/HbA1c	Incidence; prevalence; performance measures; outcome measures
CCPRB	Familial risks; genetic determinants	Incidence
CoNARTaS	Born after assisted reproduction (ART)	Incidence
CEPHOS-LINK	Health and social system variables	Performance measures
COFI	Health and social system variables	Performance measures
DUQuE	Socio-economic factors; environmental risk factors	Performance measures; outcome measures
EUPHORIC	nr	Performance measures; outcome measures
EUBIROD	Diabetes	Prevalence; incidence; outcome measures
EHDEN	All health related risk factors	na
EMIF	Project-specific	Project-specific
EUNICE	Age; environmental risk factors; disease-specific factors	Mortality; prevalence; incidence
ELSO	nr	Outcome measures
OHDSI	All health related indicators	Outcome measures; incidence; prevalence, data quality indicator
EUPrimeCare	Socio-economic factors; environmental factors	Outcome measures
MultiCom	Socio-economic factors; environmental factors	Performance measures, outcome measures
INEQ-CITIES	Socio-economic factors, life-style factors, risk factors related to the 15 conditions	Avoidable mortality rates, socio-economic indicators
EuroDRG	Health status, health intervention, demographics characteristics	na
EUROCISS	Blood pressure, hypertension, lipids, hypercholesterolemia, tobacco smoking, BMI, physical activity	Prevalence; incidence; case fatality; attack rate; hospital discharge rate; hospitalisation rate; disability adjusted life years; potential years of life lost; activities of daily living
ECHIM/ECHI	ECHIM: 60 indicators under 5 main themes; ECHI: 88 indicators under 5 themes	Prevalence; incidence; mortality; attack rates; performance measures; outcome measures; economic evaluations; policies
FAMHEALTH	Socio-economic factors	outcome measures; performance measures
GA2LEN	Environmental risk factors, exposure factors related to allergy and asthma	na
HealthBASKET	nr	Performance measures; outcome measures
EuroREACH	na	na
INTEGRIS	Risk factors for injuries causing mild injuries, mortality or disability	Injury disability indicators

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EPIC CVD	Collection and screening of genetic biomarkers, assessment of CVD risk factors	Incidence
ICBP	nr	Prevalence; incidence; outcome measures
InterQuality	na	Performance measures; outcome measures
DKA - type 1 diabetes	Glycaemia; diabetes; socio-economic factors	Prevalence; outcome measures; epidemiological association measures (relative risk, odds ratio)
MasterMind	Lifestyle related mental health factors	na
MONICA	Blood pressure, hypertension, lipids, hypercholesterolemia, diabetes, BMI, obesity, smoking, socio-economic factors	Prevalence; incidence; attack rate; mortality rate
MSDA	Disease specific	na
PRECeDI	Genomics diseases/conditions	na
ONCOPOOL	Disease specific	na
SHARE	Income and wealth, health, health care, work & retirement, social networks	Outcome measures, performance measures
EUROTHINE	Obesity, smoking, alcohol consumption, physical activity, socio-economic factors	Prevalence; incidence; mortality related to unhealthy lifestyles and socio-economic factors (health inequalities indicators)
EurHOBOP	Life-style related factors	In-hospital mortality related to: 1. Coronary angiography; 2. Thrombolysis; 3. Percutaneous intervention; 4. General myocardial infarction patient management. 5. General unstable angina patient management
IDB	Home accidents, sports and leisure injuries, workplace accidents and road accidents and on injuries due to violence and self-harm	Estimated incidence rate and national cases
JA EHLEIS	Age related risk factors	Morbidity and disability; prevalence; life and health expectancy indicators
EURO-URHIS 2	Non-communicable diseases, communicable diseases, socio-economic factors, environmental risk factors	Prevalence; outcome measures; mortality and morbidity
ENRIECO	Inventory of existing birth cohorts and health data, exposure data, biological samples, environmental exposure response functions	na
EHES	All health related risk factors	Prevalence
EUROCAT	Teratogenic exposure, pregnancy-related, lifestyle and environmental risk factors	Prevalence; perinatal mortality; fetal death, rate of pregnancy termination; data quality indicators
EuroCARE	nr	Prevalence; incidence, attack rates, outcome measures
Euro-Peristat	Four main themes: 1. fetal, neonatal and child health, 2. maternal health, 3. population characteristics and risk factors, and 4. health services	Prevalence; incidence; mortality
HAEMACARE	Rare haematological tumours	Prevalence; incidence; survival on haematologic tumors; indicators of clinical activity
CHICOS	Early childhood's effect on health later in life	Prevalence; attack rates; outcome measures
EUROSAFE	Unintentional and intentional injuries, work related injuries	Incidence; hospital admissions; fatalities and accident and emergency cases
ECHO	Socio-economic factors, hospitalizations	Prevalence; attack rates; outcome measures

EuroHOPE	AMI, stroke, hip fracture, breast cancer and low-birth-weight infants	Prevalence; incidence; attack rates; mortality; hospital comparison (Nordic hospital comparison study); performance measures for five conditions: AMI, stroke, hip fracture, breast cancer and low-birth-weight infants
I2SARE	Socio-economic factors, biological factors and health behavior	Number of health professionals; number of healthcare services; demographic and socio-economic; mortality; morbidity; indicators related to risk factors (obesity, overweight, smokers aged 15 and over)
NOMESCO	All health related issues	Prevalence; incidence; attack rates; performance measures; outcome measures
MANAGED OUTCOMES	Type 2 diabetes, stroke, hip osteoarthritis and dementia	Incidence; performance measures; outcome measures
QUALICOPC	All health related issues	Indicators of system design and organization of primary care; outcome measures
RECAP preterm	All health related issues	Prevalence; health outcomes
RARECARE	Health status, risk factors for all rare cancers	Incidence; survival; prevalence and mortality for all rare cancers
GBD	All health related issues	Prevalence; incidence; attack rates; mortality; disability

AMI, acute myocardial infarction; BMI, body mass index; CVD, cardiovascular disease; GBD, Global Burden of Disease; nr, not reported; na, not applicable.

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