



# Quality criteria for assessing Research Networks

Working group for Task 7.1: A sustainable networks of  
networks



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## Introduction to working documents for Task 7.1

Task 7.1 of the InfAct Joint Action (A sustainable networks of networks) aimed to develop criteria and procedures to judge the functioning of research networks. These criteria can be used to judge the actual quality of a network and/or its needs for further development and support. The group undertook a scoping review about expected roles and selection criteria for research networks using BRIDGE Health reports, published literature and exchanges with existing networks.

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The documents compiled here are working documents generated by the research network working group. They provide a basis for future work and could be further refined for use in this JA or other initiatives.

The first section describes a set of quality criteria that could be used to identify networks that would qualify for consideration as research networks within a sustainable health information infrastructure. The document was drafted by Peter Achterberg and modified based on comments by others in the working group.

The second section describes a set of services that could be provided by different networks. This framework has not been finalized. Its aim is to synthesize the functions that could be integrated into a research infrastructure, highlight the synergies between existing initiatives and ultimately enable the move from individual networks to a common health information and research platform.

The final section applies the quality criteria presented in the first section to five of the existing networks participating in the working group (presented in alphabetical order: ECHI, ECHO, EHES, Euro-Peristat, EuroSafe). The formats adopted for this presentation by each network differ slightly, but they cover the main quality criteria domains.

## Proposed quality criteria for assessing Research Networks

Research Networks under a future Distributed Infrastructure on Population Health (DIPoH) Research infrastructure(RI) are defined here as active networks of national and/or regional experts from several countries that perform comparative research in a specific health area (information domain).

To assess the scope, quality, impact and performance of these networks we have defined a set of criteria. By fulfilling several or all of these criteria Research Networks will also serve the overarching aims and goals of the DIPoH RI that is foreseen in the Joint Action on Health Information (InfAct).

That research infrastructure (or ESFRI/ERIC) aims to develop, support and coordinate a comprehensive, efficient, equitable and sustainable conglomerate of high quality research networks in close interaction with National Nodes. This integrated network of networks will perform high-quality comparative research that focuses on regional, national and local health and healthcare issues, to support policy making or health system improvement in a timely and effective way.

Research Networks will be the hands and feet of the research infrastructure. They will generate new data and research output, improve research methods and tools, develop standards and guidelines and contribute to international research capacity building through exchange of knowledge and expertise. The research infrastructure will support and coordinate their efforts and provide central services that assist, improve and stimulate their work.

Research networks will be relevant for the DIPoH research infrastructure if they:

- Cover a topical area (domain) that is part of the domains of the DIPoH research infrastructure, i.e. the domains of population health monitoring and/or health system performance assessment.
- Have a track record in international comparative research in that domain.
- Have a proven ability to link international experts and address information gaps in that domain.

### **Performance criteria for research networks**

Below we list a set of performance criteria for networks with examples of their operationalization. This set of criteria helps to evaluate the performance of the networks and can function as a framework for a specific research network to assess its achievements and/or possible areas for improvement.

### **Policy relevance and impact of the research**

The network:

- Covers a research area that was mentioned as being important in recent EU policy documents or EU regulations or in national or regional health policy documents of Member States (relevant).

- Provides research output and evidence that is expected by experts to be able to feed into effective and actionable health policy options and recommendations (actionable).
- Covers a research domain that has recently become a more urgent health policy priority in several countries or regions (urgent).
- Produces research reports/papers asked for by governing or healthcare managing bodies at local, regional, national or international level (effective).
- Produces new information and data from its research in a policy relevant format (policy briefs) (innovative).
- Uses its research expertise to create indicators that can be easily understood and used by health professionals, policy makers and other stakeholders (practical).
- Creates research output that evokes or contributes to health policy debates; recent policy documents refer to its publications (leading).

### **Uniqueness**

The network:

- Is the only substantial research network in a specific domain or topic area in Europe (EU/EFTA).
- Performs original research based on new data collection or compilation of data from multiple sources for secondary use to create new federated databases.

### **Sustainability**

The network:

- Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative).

### **Geographical coverage**

The network:

- Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions.
- Collects data that are representative for a significant number of EU/EFTA regions and/or countries.

### **Scientific excellence**

The network:

- Creates output with a high scientific quality as measured by publication of results in high impact journals and recognition by other experts, stakeholders and policy makers.
- Has a rigorous approach to fostering and improving the quality of its data and publications.
- Works on the harmonization of data and indicators, and on developing new methods and tools to serve its research domain in Europe.

- Has received funding from national and/or international funding organizations.
- Translates its research outcomes effectively and enables decision making to collect new or better data (can be measured by good practice guidelines, clinical recommendations, policy measures or regulations and laws that use its results).

### **Data management and access**

The network:

- Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions.
- Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility.
- Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible.
- Strives to promote the principles of open science.

### **Governance**

The network:

- Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects.
- Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities.

### **Liaising**

The network:

- Brings together data collectors, researchers and stakeholders to integrate evidence generated by the network that supports the implementation of specific interventions and policies.
- Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains.
- Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient.

### **Capacity building**

The network:

- Develops and implements forms of capacity building. This can for instance take place by organizing expert exchanges (workshops and trainings); or
- Contributes to the development and dissemination of methods and tools.

- Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building.

### **Advocacy and communication**

The network:

- Advocates for its 'domain' and the relevance of its research outcomes and policy messages.
- Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings.
- Communicates its achievements and proceedings regularly in different media.
- Participates in national and international conferences.

### **Societal impact**

The network:

- Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities.
- Creates output that generates local, regional or national discussions in media or political for a.

### **Expectations in summary**

In summary, Research Networks of the DIPoH research infrastructure will:

- Maintain, increase and exchange their scientific and technological excellence.
- Establish a critical mass in their thematic area via networking of excellent researchers, joining complementary expertise, sharing research facilities, contribute to capacity building and training of new researchers as well as developing novel professional profiles if appropriate.
- Generate new data and methods and strengthen their research capacity.
- Facilitate the integration and transfer of new knowledge.
- Undertake common research efforts and provide support, either financial or in kind over a longer period of time, allowing for more significant and sustainable outcomes and results.
- Facilitate and expand data access and sharing.
- Facilitate proactive studies, sharing standardized and innovative measures in specific disciplines.
- Develop a long lasting strong research base and regular data collection.
- Enhance communication and visibility at the European and international level.
- Deliver knowledge for policy making, anticipate scientific and technological needs and provide efficient scientific support for strategic and political decision-making in the specific field.

## Potential activities and tasks of Research Networks

Activities	Health status	Determinants of health	Health care performance
Services could include information sharing (search facilities), implementation, training and consulting	Chronic conditions Maternal and Newborn Quality of life Injuries	Health behaviours and lifestyles NCD risk factors Environmental determinants SES	
Data harmonization Pre-harmonization of survey methods Post-harmonization of survey methods Pre-harmonization of routine data sources Post-harmonization of routine data sources	**Services provided by individual networks to be filled in here**		
Data cataloguing Metadata Microdata from surveys Macrodata from surveys Microdata from routine data sources Macrodata from routine data sources Qualitative data			
Data governance Legal, ethical, data protection issues Open science Participation by users and civil society			
Data management and sharing Data linkage Data repositories Federated databases Other data transfer or sharing methods			
Indicator development Indicator development Validation of new indicators and methods Scripts/tools for indicator calculation			
Analysis and reporting Scripts/algorithms for analysis Development of analytic methods, including advanced statistics/machine learning Research on indicators Publications/reports on health/care			
Research support (external) Consultation for project design/methods Participation in other research project Provision/analysis of data for projects			
Transfer to policy-making Dissemination of results Participation in conferences and international meetings			

Activities	Health status	Determinants of health	Health care performance
Services could include information sharing (search facilities), implementation, training and consulting	Chronic conditions      Injuries      Maternal and Newborn      Quality of life	Health behaviours and lifestyles      NCD risk factors      Environmental determinants      SES	
Production of reports/expertise Policy advice/consulting Advocacy			
Capacity building Training schools/workshops Online training materials P2P consultation Others			
Network management and governance Maintaining/reinforcing partner agreements In network communication/dissemination Holding network meetings Liaising with other networks			

## Quality criteria applied to participating networks

### ECHI - European Core Health Indicators

#### **ECHI: who, what, how?**

ECHI - European Core Health Indicators - are a The European Core (formerly: Community) Health Indicators initiative started in 1998 as a project responding to the European Commission (EC)'s call to establish a shortlist of public health indicators which would serve as the core of a European public health monitoring system. T

he ECHI work has been coordinated through a series of four EC funded projects (ECHI-I, ECHI -II, ECHIM, JA ECHIM, BRIDGE Health (WP4) and currently InfAct (WP8.2)) and provides a 'snapshot' of public health from the point of view of the public health generalist. The underlying data are derived from a variety of sources, including the EU statistical office (Eurostat), the World Health Organisation's European 'Health for all' database (HFA-DB), the Health Statistics database of the Organisation for Economic Co-operation and Development (OECD) and several specific programmes and specialised databases.

The first version of the shortlist was approved by the EC and the EU Member States (MS) in 2005. The current shortlist contains 88 indicators, covering the full domain of population health and health care (systems) and mapped to 17 (non-exclusive) policy areas. When the last JA ended, in 2012, 67 indicators had been put into practice (implemented), 14 indicators were nearly ready (work-in-progress) and 13 were not yet ready (under development). Currently, DG Sante and Eurostat maintain a tool in which the indicators can be consulted: [https://ec.europa.eu/health/indicators\\_data/indicators\\_en](https://ec.europa.eu/health/indicators_data/indicators_en). The Commission attempts to keep ECHI active, for example in Health at a Glance, in which key indicators of health and health systems are based to a large extent on the European Core Health Indicators (ECHI) shortlist. It currently is not clear how the current Commission work relates to the initial ECHI initiative and its documentation sheets. Under the BRIDGE Health project, a repository was started containing ECHI historic and contextual information: [www.echi.eu](http://www.echi.eu) (under development).

#### **What can ECHI do as a future network on health indicators (strategic role and services)?**

- "Be" ECHI; be the structure that 'oversees' the EU indicator landscape
  - in connection with National nodes
- Connect with and apply the expertise present in the various relevant other domain specific nodes
- Connect with Eurostat/OECD/WHO and other data sources about
  - implementing the indicators from the work in progress and development section
  - ensuring the shortlist data are as comparable as possible
  - the shortlist data are available and updated regularly

- Connect with MS and DG Sante about EU and MS needs/policy relevance
- Organize, structure and renew the ECHI shortlist along MS and EU policy needs
  - Consider the right balance, relevance, quality and actionability by looking for omissions, redundancies, needs for renewal of presentation or analysis
  - Design a process and criteria by which indicators can be added to or removed from the ECHI-shortlist
- Perform and publish in depth analyses covering statistical/methodological topics
- Report to the EGHI group regularly
- Ensure ECHI indicators are known to a wider audience and used in EU health reports
- Guard geographical coverage
- Establish and maintain an ECHI repository and provide structured collective memory

**What would happen if we do not arrange for a role for ECHI under a RI?**

If the ECHI shortlist is not developed to a fully implemented list, is not modernised, is not promoted, then the shortlist may no longer be supported by the MS. The EU then will no longer have the list at its disposal, losing indicators carefully selected by consensus and covering the wide range of public health issues.

Criterion	Meaning	ECHI
<b>Uniqueness</b>	Is the only substantial research network in that specific domain in Europe (EU/EFTA)	ECHI is only set covering full range of population health
	Performs original research mainly based on new data collections, i.e. data that are not part of regular statistical data that come from other sources	Does not perform “own” research
<b>Sustainability</b>	Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative)	<ul style="list-style-type: none"> <li>• ECHI data tool keeps the set alive</li> <li>• Used in “Health at a glance: Europe”</li> </ul>
<b>Geographical coverage</b>	Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions	Based on consensus by actively participating researchers from significant number of countries; currently not active anymore
	Collects data that are representative for a significant number of EU/EFTA regions and/or countries	Not active in collecting data for “own” purposes
<b>Scientific excellence</b>	Creates output with a high scientific quality as measured by the volume and impact of its publications and by its recognition by other experts,	Not currently

	stakeholders and policy makers	
	Has a rigorous approach to fostering and improving the quality of its data and publications	Not currently
	Works on the harmonization of data and indicators and on developing new methods and tools to serve its research domain in Europe	Has been taken up by BRIDGE Health and InfAct; will require alignment with Eurostat/DG Sante
	Has received funding from national and/or international funding organizations	Not specifically
	Translates its research outcomes effectively and enables decision making to collect new or better data	Not currently
<b>Data management and access</b>	Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions	Currently lies with Eurostat/DG Sante
	Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility	Currently lies with Eurostat/DG Sante
	Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible	Currently lies with Eurostat
<b>Governance</b>	Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects	Not currently
	Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities	Not currently; probably in some form with DG Sante/Eurostat
<b>Liaising</b>	Brings together data collectors, researchers and stakeholders to integrate evidence generated by the	Not currently

	network that supports the implementation of specific interventions and policies	
	Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains	Not currently
	Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient	Needs to be evaluated
<b>Capacity building</b>	Develops and implements forms of capacity building. This can, for instance, take place by organizing expert exchanges (workshops) or developing and exchanging tools and methods.	Not currently
	Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building	Not currently
<b>Advocacy and communication</b>	Advocates for its 'domain' and the relevance of its research outcomes and policy messages	Not currently
	Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings	Not currently; in some form with DG Sante/Eurostat
	Communicates its achievements and proceedings regularly in different media	Not currently; in some form with DG Sante/Eurostat
<b>Societal impact</b>	Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities	Not currently; in some form with DG Sante/Eurostat
	Creates output that generates local, regional or national discussions in media or political fora	Not currently

## ECHO: European Collaborative for Healthcare Optimization

- [www.echo-health.org](http://www.echo-health.org)

Criterion	Meaning	ECHO accomplishment
<b>Uniqueness</b>	Is the only substantial research network in that specific domain in Europe (EU/EFTA)	It has been the only one analyzing a wealth of performance validated indicators at a geographic and provider-specific level, for virtually all the hospitalizations produced in several countries over a number of years. For a detail of the indicators see here <a href="http://www.echo-health.eu/handbook/getting-indicators.html">http://www.echo-health.eu/handbook/getting-indicators.html</a>
	Performs original research mainly based on new data collections, i.e. data that are not part of regular statistical data that come from other sources	No. ECHO has done original research based on the reuse of existing data - mainly administrative healthcare data.
<b>Sustainability</b>	Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative)	It has been the case while the project was active. Now, some paper are still on the pipeline as well as some remaining products that have been already published; specifically, the ECHO digital atlases recently published and available at: <a href="http://echo-health.eu/atlas-eu/">http://echo-health.eu/atlas-eu/</a> and the formalization of the data model at: <a href="https://zenodo.org/record/3253684#.XcKQC797kb1">https://zenodo.org/record/3253684#.XcKQC797kb1</a>
<b>Geographical coverage</b>	Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions	No. ECHO was conceived as a demonstration project with a number of health care systems involved - Austrian, Danish, English, Portuguese, Slovene and Spanish, and a data collection and curation confined to the project timeline.
	Collects data that are representative for a significant number of EU/EFTA regions and/or countries	No. ECHO is no longer collecting data.
<b>Scientific</b>	Creates output with a	Yes. It was the primary objective. See here:

excellence	high scientific quality as measured by the volume and impact of its publications and by its recognition by other experts, stakeholders and policy makers	<a href="http://echo-health.eu/category/publications/scientific-publications/">http://echo-health.eu/category/publications/scientific-publications/</a> On the other hand, ECHO methods and outputs have contributed to the development of the OECD health care quality indicators project, to the discussion on the HSPA senior group in Santé, and to the scoping debate on the JAF. ECHO was also part of a STOA workshop in the European Parliament
	Has a rigorous approach to fostering and improving the quality of its data and publications	Yes. It was the case during the project: see here the report on data quality <a href="https://echo-health.eu/echo-atlas-reports/">https://echo-health.eu/echo-atlas-reports/</a>
	Works on the harmonization of data and indicators and on developing new methods and tools to serve its research domain in Europe	Yes, this was the case within the context of the project. Details on the methods followed on indicators development and validation are here: <a href="http://www.echo-health.eu/handbook/">http://www.echo-health.eu/handbook/</a> It was of particular relevance the mapping and crosswalks built to allow interoperability across five taxonomies (ICD9th, ICD10th, OPCS, NOMESCO, ASCHI). The wealth of indicators developed and validated are open access here: <a href="http://www.echo-health.eu/handbook/getting-indicators.html">http://www.echo-health.eu/handbook/getting-indicators.html</a> and reusable files here: <a href="https://zenodo.org/record/3530510#.XcLKF797kb0">https://zenodo.org/record/3530510#.XcLKF797kb0</a>
	Has received funding from national and/or international funding organizations	7 <sup>th</sup> Framework program and Health program throughout Bridge-Health project.
	Translates its research outcomes effectively and enables decision making to collect new or better data	The project had an explicit translational strategy, involving national stakeholders. A core activity was the development of national reports (Atlases) that were used to steer national debate with those stakeholders. See here the national reports: <a href="https://echo-health.eu/category/echo-atlas">https://echo-health.eu/category/echo-atlas</a>
<b>Data management and access</b>	Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions	No. It was a demonstration project initially designed according to a specific timetable (42 months).
	Generates	Generated an interoperable centralized data

	repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility	model: see here <a href="https://echo-health.eu/echo-atlas-reports/">https://echo-health.eu/echo-atlas-reports/</a> Data sharing, data access, and data use were agreed with partners according to legislation on data protection issues. Currently, two countries have already withdrawn their data, as per data sharing contract provisions.
	Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible	No. The data that remain stored and maintained in the central repository are subject to legal provisions that impede third party uses. All the project outputs are open to any public.
<b>Governance</b>	Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects	The Consortium agreement, bilateral contracts with data authorities in each participant country, and internal documents within the consortium clearly established the governance mechanisms for data access and use. No provisions were defined for third parties access to raw data.
	Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities	No. It used to be the case, while the project was active.
<b>Liaising</b>	Brings together data collectors, researchers and stakeholders to integrate evidence	It used to be, as Local Stakeholders were part of the translational tasks, both in the face validation of the indicators and in the within country policy dialogues around the research outputs. This kind of activity ended once the project was over.

	generated by the network that supports the implementation of specific interventions and policies	
	Liases with other networks, organizations and key stakeholders that cover complementary and related research and policy domains	ECHO methods and outputs have contributed to the development of the OECD health care quality indicators project, to the discussion on the HSPA senior group in Santé, and to the scoping debate on the JAF. Scarce formal exchange has been carried out with other projects, like EUROHope. Currently, leading WP on data reuse within an INTERREG SUDOE project with regions from France, Portugal, and Spain (ICTUSNet).
	Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient	Although ECHO is over, the methodological developments are current, and publicly available either to build a network or contribute in any other initiative.
<b>Capacity building</b>	Develops and implements forms of capacity building. This can, for instance, take place by organizing expert exchanges (workshops) or developing and exchanging tools and methods.	It was out of the scope of ECHO. However, ECHO developed and made public a handbook on methods. <a href="http://www.echo-health.eu/handbook/">http://www.echo-health.eu/handbook/</a>
	Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building	A singular task in ECHO was the semantic validation of different classification systems using for that purpose local clinical and coding experts in each participant country. No capacity building exercise was made for this purpose, as it was not needed.
<b>Advocacy and communication</b>	Advocates for its 'domain' and the relevance of its research outcomes and policy messages	ECHO methods and outputs have contributed to the development of the OECD health care quality indicators project, to the discussion on the HSPA senior group in Santé, and to the scoping debate on the JAF. ECHO was also part of a STOA workshop in the European Parliament
	Organizes or	ECHO is still present in international conferences -

	participates in international meetings with experts and counterparts to exchange their methods and findings	see here <a href="https://echo-health.eu/category/publications/presentations/">https://echo-health.eu/category/publications/presentations/</a>
	Communicates its achievements and proceedings regularly in different media	No.
<b>Societal impact</b>	Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities	It has not been the case. Currently, ECHO analytical tools are under the scrutiny of the IT marketplace, as part of a EU funded project UTILE - <a href="https://www.health-breakthrough.eu/partners/">https://www.health-breakthrough.eu/partners/</a>
	Creates output that generates local, regional or national discussions in media or political fora	It was part of the project aims to feed discussion using those aforementioned policy dialogues with high-level stakeholders.

## EHES: European Health Examination Survey

(<http://www.ehes.info>)

Criterion	Meaning	EHES accomplishment
<b>Uniqueness</b>	Is the only substantial research network in that specific domain in Europe (EU/EFTA)	To our knowledge EHES is only of its kind. SHARE is collecting some, very limited health data on elderly and EHIS (Eurostat) questionnaire based data on health issues. These are not overlapping but supplementing each others.
	Performs original research mainly based on new data collections, i.e. data that are not part of regular statistical data that come from other sources	EHES is not centrally doing much research on nationally collected data, due to lack of sustainable resources. Individual countries are doing a lot of research on their data. Data comes from health examination surveys which are not part of regular statistics.
<b>Sustainability</b>	Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative)	During the active funding period, harmonization of data collection procedures was prepared and capacity building for countries was active. Now, when no sustainable funding exists, this is more limited.
<b>Geographical coverage</b>	Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions	No. EHES network covers most of EU MSs + few other counties. At the national level data is been collected on about 50% of them. <a href="http://www.ehes.info/national/national_hes_status.htm">http://www.ehes.info/national/national_hes_status.htm</a>
	Collects data that are representative for a significant number of EU/EFTA regions and/or countries	No/Yes. Data collection done at the national level but not collected into EU level database. <a href="http://www.ehes.info/national/national_hes_status.htm">http://www.ehes.info/national/national_hes_status.htm</a>
<b>Scientific excellence</b>	Creates output with a high scientific quality as measured by the volume and impact of its publications and by its recognition by other experts, stakeholders and policy makers	Yes. EHES Manuals have been widely used and are also used by WHO on their work together with their own material from WHO STEPs.
	Has a rigorous approach to fostering and improving the quality of its data and publications	Yes. Data quality and harmonization is the main aim of the network. EHES Manuals promote harmonization and new material is added to the EHES website whenever available. <a href="http://www.ehes.info/manuals.htm">http://www.ehes.info/manuals.htm</a>

	Works on the harmonization of data and indicators and on developing new methods and tools to serve its research domain in Europe	See above.
	Has received funding from national and/or international funding organizations	EU Public Health Programme in 2009-2012 and 2015-2017
	Translates its research outcomes effectively and enables decision making to collect new or better data	Main focus on methods. National level activities focus more on evidence-informed policy making.
<b>Data management and access</b>	Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions	Not currently due to lack of funding.
	Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility	Data repository outline has been prepared and tested during the pilot phase but due to lack of sustainable funding is not up and running at this moment. Also data sharing rules have been prepared. <a href="http://www.ehes.info/publications/Blueprint_data_reporting_systems.pdf">http://www.ehes.info/publications/Blueprint_data_reporting_systems.pdf</a>
	Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible	Not at the moment. This is part of the data plan if sustainable funding would be available. Cannot be done on temporary project funds.
<b>Governance</b>	Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects	Management structure for EHES has been defined as well as roles of different network partners.
	Organizes regular meetings and implements processes and procedures by which decisions are made among the	Not at the moment. Network received occasional e-mail contacts from coordinator.

	participants that deal with governance, strategy and priorities	
<b>Liaising</b>	Brings together data collectors, researchers and stakeholders to integrate evidence generated by the network that supports the implementation of specific interventions and policies	No at the moment.
	Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains	Follows what is happening in Europe on the field of health examination surveys and health monitoring. No formal contacts.
	Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient	Collaboration is always considered if possibilities arise.
<b>Capacity building</b>	Develops and implements forms of capacity building. This can, for instance, take place by organizing expert exchanges (workshops) or developing and exchanging tools and methods.	During the active funding phase, there was a lot of capacity building activities: training seminars, written protocols, online availability of training materials, laboratory quality control programme, personal consultation. At the moment, online materials are still available and personal consultation will be provided on small scale.
	Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building	Site visits were performed to evaluate each of the pilot studies and after wards few individual full-size studies. Laboratory quality control programme was running during the pilot phase. There is specific instructions for data checking for quality on the EHES Manual.
<b>Advocacy and communication</b>	Advocates for its 'domain' and the relevance of its research outcomes and policy messages	??
	Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings	Many EHES network members present their work on conferences and meetings.
	Communicates its achievements and proceedings regularly in different media	Web site updated when new information comes up and promoted also through social media (Twitter).

<b>Societal impact</b>	Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities	Not at the moment on European level. Countries within network do this at the national level.
	Creates output that generates local, regional or national discussions in media or political fora	Not at the moment on European level. Countries within network do this at the national level.

## Euro-Peristat: better statistics for better health for mothers and newborns

www.europeristat.com

Research networks will be relevant for the research infrastructure on Health Information if they:

<ul style="list-style-type: none"> <li>Cover a topical area (domain) that is part of the domains of the research infrastructure on Health Information, i.e. the domains of population health monitoring and/or health system performance assessment</li> </ul>	Maternal and child health are priority domains
<ul style="list-style-type: none"> <li>Have a track record in international comparative research in that domain</li> </ul>	Yes >60 scientific publications using Euro-Peristat data by our team + others using the data downloaded from our website.
<ul style="list-style-type: none"> <li>Have a proven ability to link international experts and address information gaps in that domain</li> </ul>	Existing network of countries, including data providers, from 31 European countries. Active collaboration with stakeholders, including user groups and professional societies, as witnessed by their participation in Euro-Peristat meetings (EBCOG, EFCNI)

### Performance criteria for research networks

#### Policy relevance and impact of the research

<ul style="list-style-type: none"> <li>Covers a research area that was mentioned as being important in recent EU policy documents or EU regulations or in national or regional health policy documents of Member States (relevant).</li> </ul>	>5,000,000 births per year in Europe. Maternal and child health are areas specifically targeted in H2020. Priority in most European countries, New life course focus in research on health highlights periods of pregnancy and infancy.
<ul style="list-style-type: none"> <li>Provides research output and evidence that is expected by experts to be able to feed into effective and actionable health policy options and recommendations (actionable)</li> </ul>	Yes, benchmarking on a set of 30 indicators. Very valuable for establishing policy priorities (as stated in our previous evaluations with stakeholders). Maternal and child health indicators used in many countries to underpin policy changes.
<ul style="list-style-type: none"> <li>Covers a research domain that has recently become a more urgent health policy priority in several countries or regions (urgent)</li> </ul>	Population risk factors increasing. In some EU countries, stagnating mortality rates. Stark disparities in outcomes across EU countries. Also, demands from women for less medical intervention in pregnancy and childbirth and better outcomes.
<ul style="list-style-type: none"> <li>Produces research reports/papers asked for by governing or healthcare managing bodies at local, regional, national or international level (effective)</li> </ul>	Data from reports are routinely used by healthcare bodies. Can provide specific analyses of data - country representatives provide

	context.
<ul style="list-style-type: none"> <li>• Produces new information and data from its research in a policy relevant format (policy briefs) (innovative)</li> </ul>	Information disseminated in reports, presentations at conferences and publications at the moment. With more resources, a broader range of formats could be used
<ul style="list-style-type: none"> <li>• Uses its research expertise to creates indicators that can be easily understood and used by health professionals, policy makers and other stakeholders (practical)</li> </ul>	Yes
<ul style="list-style-type: none"> <li>• Creates research output that evokes or contributes to health policy debates; recent policy</li> </ul>	Yes (examples are past debates in the Netherlands, current debates in France on stagnating mortality, improvements of health info in many countries)
<ul style="list-style-type: none"> <li>• documents refer to its publications (leading)</li> </ul>	Euro-Perstat is widely cited

## Uniqueness

The network:

<ul style="list-style-type: none"> <li>• Is the only substantial research network in that specific domain in Europe (EU/EFTA)</li> </ul>	<p>Yes on perinatal health indicators based on routine sources (although other aspects of perinatal health - congenital anomalies, cerebral palsy - covered by other networks - EUROCAT, SCPE, both at JRC)</p> <p>Note also that WHO, OECD, Eurostat compile some of the same indicators, but without the detail on risk groups which allows us to make indicators comparable. The data are therefore less reliable. We have worked with OECD to improve validity of their infant mortality indicator.</p>
<ul style="list-style-type: none"> <li>• Performs original research mainly based on new data collections, i.e. data that are not part of regular statistical data that come from other sources</li> </ul>	<p>Yes, all of our research is based on data we have collected.</p> <p>In addition to data collected in reports, we have undertaken one-off studies (on risk factors for mortality, preterm birth and growth restriction).</p>

## Sustainability

The network:

<ul style="list-style-type: none"> <li>• Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative)</li> </ul>	<p>Yes, since 1999</p> <p>&gt; 20 plenary meetings over this period (between 30-60 participants at each meeting)</p>
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## Geographical coverage

The network:

<ul style="list-style-type: none"> <li>Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions</li> </ul>	All EU countries participate
<ul style="list-style-type: none"> <li>Collects data that are representative for a significant number of EU/EFTA regions and/or countries</li> </ul>	Iceland, Norway and Switzerland

## Scientific excellence

The network:

<ul style="list-style-type: none"> <li>Creates output with a high scientific quality as measured by the volume and impact of its publications and by its recognition by other experts, stakeholders and policy makers</li> </ul>	- Number of publications + impact (journals read by public health and clinicians in field). Participation in other international initiatives (stillbirth series, Lancet, etc).
<ul style="list-style-type: none"> <li>Has a rigorous approach to fostering and improving the quality of its data and publications</li> </ul>	Many of research articles focus on quality and comparability of indicators
<ul style="list-style-type: none"> <li>Works on the harmonization of data and indicators and on developing new methods and tools to serve its research domain in Europe</li> </ul>	Same as above. Indicators are updated each time before collection. Experimenting with new ways of transferring data.
<ul style="list-style-type: none"> <li>Has received funding from national and/or international funding organizations</li> </ul>	Public Health Programme Each institution finances own participation in data collection and interpretation Participant in H2020 research bids
<ul style="list-style-type: none"> <li>Translates its research outcomes effectively and enables decision making to collect new or better data</li> </ul>	Several countries have improved data collection - linked in part to Euro-Peristat showing that they were lagging behind (Cyprus, France) - the fact that Euro-Peristat was seen as a European initiative is very important for this impact.

## Data management and access

The network:

<ul style="list-style-type: none"> <li>Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions</li> </ul>	Every 5 years, but core data collection should really be carried out annually
<ul style="list-style-type: none"> <li>Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility.</li> </ul>	Data in appendices to reports. Data for 2010 in excel sheets on website; with funding, full data could be provided.

<ul style="list-style-type: none"> <li>Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible</li> </ul>	<p>Yes, as witnessed by scientific articles by others using our data</p> <p>More funds are needed to support this feature, though</p>
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## Governance

The network:

<ul style="list-style-type: none"> <li>Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects</li> </ul>	<p>For the moment, light management structure because very little funding.</p> <p>Executive Board for decisions Scientific Committee (one person per country) Country teams (all people involved in data collection and interpretation in the country)</p>
<ul style="list-style-type: none"> <li>Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities</li> </ul>	<p>Regular meetings are held.</p> <p>Decision-making procedures are not formalized (no active consortium agreement, voluntary participation).</p>

## Liaising

The network:

<ul style="list-style-type: none"> <li>Brings together data collectors, researchers and stakeholders to integrate evidence generated by the network that supports the implementation of specific interventions and policies</li> </ul>	<p>Yes, as witnessed by composition of country teams and participation of stakeholders in meetings.</p>
<ul style="list-style-type: none"> <li>Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains</li> </ul>	<p>Yes, links with Eurocat, SCPE (and euroneonet, when this existed). Founding member of ROAM on migration and reproduction.</p>
<ul style="list-style-type: none"> <li>Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient</li> </ul>	<p>Yes, congenital anomalies and cerebral palsy are a good example.</p>

## Capacity building

The network:

<ul style="list-style-type: none"> <li>Develops and implements forms of capacity building. This can for instance take place by organizing expert exchanges (workshops) or developing and exchanging tools and methods.</li> </ul>	<p>We have had several thematic workshops as part of our meetings, for instance on:</p> <ul style="list-style-type: none"> <li>Data linkage</li> <li>Recording of births/deaths at the limits of viability</li> </ul>
<ul style="list-style-type: none"> <li>Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building</li> </ul>	<p>When there is a new partner, there is a meeting to go through all the indicators and the data collection instrument. All submitted data are checked and there</p>

	is a back-and-forth with providers to make sure that indicator definitions are understood/used correctly. This has a capacity building effect.
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### Advocacy and communication

The network:

<ul style="list-style-type: none"> <li>Advocates for its 'domain' and the relevance of its research outcomes and policy messages</li> </ul>	Yes, some advocacy by coordination and members. Could be expanded. Also in liaison with user groups (presentation at European Parliament last week, for example).
<ul style="list-style-type: none"> <li>Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings</li> </ul>	Yes, routinely invited to international conferences.
<ul style="list-style-type: none"> <li>Communicates its achievements and proceedings regularly in different media</li> </ul>	Newsletter with >2000 subscribers

### Societal impact

The network:

<ul style="list-style-type: none"> <li>Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities</li> </ul>	We have received media coverage, however, it is country-specific.
<ul style="list-style-type: none"> <li>Creates output that generates local, regional or national discussions in media or political fora</li> </ul>	Yes, this too. Also, country-specific. When articles or reports come out depending on the context, issue, etc..



<ul style="list-style-type: none"> <li>Cover a topical area (domain) that is part of the domains of the research infrastructure on Health Information, i.e. the domains of population health monitoring and/or health system performance assessment</li> </ul>	<p>Yes. Injuries (unintentional and intentional ones) count for a substantial share of mortality and morbidity as well as related health services. Evidence based prevention actions have to address mainly external causes and circumstances, which are hardly registered in medically oriented data stocks and therefor require dedicated registers and researchers.</p> <p>The European Injury Data Base (IDB) is the only relevant European data source that contains standardized cross-national information on the external causes of injuries treated in emergency departments (EDs) in the EU. The database provides information on accidental injuries such as home injuries, sports and leisure, workplace and road injuries; in addition to intentional injuries resulting from violence and self-harm.</p> <p>The importance of injury surveillance systems, such as the IDB have long been recognized across the EU. The World Health Organisation (WHO) document "Injury Surveillance Guidelines" [1] clearly outlines why injury surveillance systems are indispensable.</p>
<ul style="list-style-type: none"> <li>Have a track record in international comparative research in that domain</li> </ul>	<p>Yes. The IDB system is based on long-lasting experiences from various countries over more than two decades. Studies based on IDB data are regularly presented during international conferences as the series of WHO-endorsed World conferences and our European conferences on injury prevention.</p> <p>The IDB system has been internationally standardized only a few years ago (JAMIE-project 2013-2016) and it is not yet fully implemented in all EU countries. The track record of publications on international comparative studies is yet limited, but growing.</p> <p>There are many scientific publications, policy reports and many specific IDB-data reports on</p>

	<p>specific issues (e.g. products, types of injuries, settings in which injuries occur) using EU IDB data, produced by our team and others using the data downloaded from our website [2-6,6-20]. Further reports available at following link:  <a href="http://www.eurosafe.eu.com/key-actions/injury-data/reports">http://www.eurosafe.eu.com/key-actions/injury-data/reports</a></p>
<ul style="list-style-type: none"> <li>• Have a proven ability to link international experts and address information gaps in that domain</li> </ul>	<p>Yes. The IDB data dictionaries are closely linked to the WHO classification systems such as the as ICD-10 and ICD-11. Our team has fulfilled a leadership role in developing the International classification of External Causes of Injury (ICECI) which is acknowledged as an international classification related to the WHO Family of international health and disease related classification (<a href="https://www.who.int/classifications/icd/adaptations/iceci/en/">https://www.who.int/classifications/icd/adaptations/iceci/en/</a>).</p> <p>The IDB advisory board (constituting the Austrian Road Safety Board, Brandenburg authority of Environment/ Health and Consumer protection, Danish Institute of Public Health, Dutch Consumer Safety Institute, Centre de Recherche Public de la Santé Luxembourg, Italian Ministry of Health, and Centre for E-Health Research at Swansea University) oversees an established network of IDB experts and data providers, from 26 European countries. Annual network meetings and training events provide opportunities for international experts to share knowledge, address information gaps, and to develop and maintain IDB standards.</p>

**Performance criteria for research networks**

**Policy relevance and impact of the research**

<ul style="list-style-type: none"> <li>• Covers a research area that was mentioned as being important in recent EU policy documents or EU regulations or in national or regional health policy documents of Member States (relevant).</li> </ul>	<p>Yes. 37.8 million people attend ED departments across the EU, 5.3 million of which are admitted to hospital[19]. Further injuries and violence are the leading cause of death among people aged 5-44 years and are responsible for 14% of all disability adjusted life years (DALYs) lost in the WHO EU Region[21].</p> <p>The need for enhanced investments in injury surveillance and prevention had been clearly</p>
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profiled e.g. by the Council Recommendation on the "Prevention of Injury and the Promotion of Safety" (2007/C 164/01)[22]. This Recommendation concludes among other things that: Injuries are, after cardiovascular diseases, cancer and respiratory diseases, the fourth most common cause of death in the Member States; Many survivors of severe injuries suffer life-long impairments; and that Injuries, while being largely avoidable, are the main cause of chronic disability among younger people, and lead to significant losses in healthy life years. Injury prevention is a priority in most European countries.

Council of the European Union: Regulation on Community statistics on public health and health and safety at work, which aims to harmonize reliable health information which supports Community actions as well as national strategies in statistics in the field of public health. Annex I to the Regulation identifies "accidents and injuries" as one of the core subjects to be covered within this common framework [24].

"European Community Health Indicators and Monitoring" (ECHIM) and the list of health indicators as agreed with the member states' competent authorities under the Health Information programme. The home and leisure injury indicator 29b is being defined as injuries that have occurred in and around home, in leisure time and at school resulting in an injury that required treatment in a hospital. These data are expected to be provided from national hospital discharge information systems as well as national injury surveillance systems in line with the IDB methodology [26].

The Council Conclusions on 'Modern, Responsive and Sustainable Health Systems' [25] provided a new boost by inviting the Commission and Member States to "cooperate with a view to establishing a sustainable and integrated EU health information system, built on what has been already achieved through different groups and

	EU co-funded projects” .
<ul style="list-style-type: none"> <li>Provides research output and evidence that is expected by experts to be able to feed into effective and actionable health policy options and recommendations (actionable)</li> </ul>	<p>Yes. The IDB provides experts with several options for accessing it’s data: public access (IDB Minimum Data Set) and restricted access (IDB Full Data Set) via EC IDB website (<a href="https://webgate.ec.europa.eu/idb/">https://webgate.ec.europa.eu/idb/</a>), an interactive tool via the Eurosafe website (<a href="http://www.eurosafe.eu.com/look-at-the-figures">http://www.eurosafe.eu.com/look-at-the-figures</a>) and the EC ECHI web-gate (<a href="https://ec.europa.eu/health/indicators/echi/list_en">https://ec.europa.eu/health/indicators/echi/list_en</a>).</p> <p>Furthermore, information requests and analyses can be conducted at a cost.</p> <p>IDB-MDS is recommended as a data source in the ECHI-list (European Community Health Indicators, ECHIM, 2011). Relevant injury related indicators include 29b (register-based home and leisure injuries) 30b (register-based road traffic injuries) and 31 (work related injuries). Other important indicators delivered by IDB-MDS are on all ED treated injuries, on injuries due to self-harm and assault. IDB-FDS data support product safety actions (risk assessment of products, standardization and consumer information).</p> <p>Some publications based on IDB data are listed in the references below [2-21]. See also <a href="http://www.eurosafe.eu.com/key-actions/injury-data/reports">http://www.eurosafe.eu.com/key-actions/injury-data/reports</a>.</p> <p>Many more policy reports and short data reports using EU IDB FDS data produced by Swansea team and are available at following link:  <a href="https://cumulus.hiru.swan.ac.uk/index.php/s/630c5796a5e39458f744762e17c957a9/">https://cumulus.hiru.swan.ac.uk/index.php/s/630c5796a5e39458f744762e17c957a9/</a> use password: IDBAnalyses2015.</p>
<ul style="list-style-type: none"> <li>Covers a research domain that has recently become a more urgent health policy priority in several countries or regions (urgent)</li> </ul>	<p>Yes. Prevention shall be cost-efficient, which requires to monitor cost-relevant indicators like medical treatments. IDB data provides relevant information for the domain of injury prevention and safety promotion.</p> <p>Child safety is still a priority of health policy. New products and services provide new risks which need to be monitored and analyzed.</p>

	<p>Health surveys do not cover children &lt;15 years. Only IDB data provide necessary information.</p> <p>Fighting child maltreatment and violence against women became an urgent health policy priority. IDB data allow for the assessment of the magnitude of the problems as well as the analysis of circumstances for targeted prevention.</p> <p>Aging of European societies makes healthy aging a priority. Injuries among senior citizens (mainly due to falls) are one of the main threads to life and autonomous living of old persons.</p> <p>Road traffic safety monitoring shall be based not only on fatalities, but also on severe injuries and permanent disabilities (<a href="https://ec.europa.eu/transport/road_safety/specialist/statistics_en">https://ec.europa.eu/transport/road_safety/specialist/statistics_en</a>). This requires data from hospitals like IDB data.</p>
<ul style="list-style-type: none"> <li>• Produces research reports/papers asked for by governing or healthcare managing bodies at local, regional, national or international level (effective)</li> </ul>	<p>Partly. For most publications and data queries it cannot be assessed, if they have been explicitly requested by healthcare managing bodies.</p> <p>The IDB-coordinators were invited to participate in the advisory committee that assisted DG-Santé in drafting a Council recommendation on Injury prevention and the promotion of safety, by providing data from various sources including IDB.</p> <p>IDB data is being used for papers and reports at national level, allowing members to establish inter-country comparison, f. e. by producing league tables of nations related to overall injury risks as well as the risk of injury in specific domains or by specific injury causes and/or in specific age groups.</p>
<ul style="list-style-type: none"> <li>• Produces new information and data from its research in a policy relevant format (policy briefs) (innovative)</li> </ul>	<p>Yes. There are numerous examples in member states, which have IDB implemented (e.g. AT, NL, SE, PT). A list of exemplary policy briefings at European level, which are mainly based on IDB data, can be found at the WHO-Europe web-site at</p>

	<p><a href="http://www.euro.who.int/en/health-topics/disease-prevention/violence-and-injuries/publications/policy-briefings-on-strategies-and-best-practices-for-the-reduction-of-injuries">http://www.euro.who.int/en/health-topics/disease-prevention/violence-and-injuries/publications/policy-briefings-on-strategies-and-best-practices-for-the-reduction-of-injuries</a>.</p> <p>Information disseminated in reports, presentations at conferences, online tools, and publications. With more resources, a broader range of formats could be used.</p>
<ul style="list-style-type: none"> <li>• Uses its research expertise to creates indicators that can be easily understood and used by health professionals, policy makers and other stakeholders (practical)</li> </ul>	<p>Yes. Most indicators have been already mentioned above: Register-based injury incidence (non-fatal injuries treated in Emergency departments of hospitals) in various “domains of prevention” as home and leisure, road traffic, workplace, self-harm and assault.</p> <p>IDB data allow further for the calculation of disability adjusted life years. An exemplary report demonstrating the practical output of the network (Injuries in the EU) can be found at <a href="http://www.eurosafe.eu.com/key-actions/injury-data/reports">http://www.eurosafe.eu.com/key-actions/injury-data/reports</a>.</p>
<ul style="list-style-type: none"> <li>• Creates research output that evokes or contributes to health policy debates; recent policy documents refer to its publications (leading)</li> </ul>	<p>Partly. The IDB system has been internationally standardized only a few years ago (JAMIE-project 2013-2016) [23] and it is not yet fully implemented in all EU countries. The track record of publications evocating health policy debates is growing and in early stage of policy considerations and action planning.</p> <p>Based on IDB-reports, a number of countries have developed a national accident prevention strategy, such as Austria, the Netherlands and the UK.</p>

## Uniqueness

The network:

<ul style="list-style-type: none"> <li>• Is the only substantial research network in that specific domain in Europe (EU/EFTA)</li> </ul>	<p>Yes. Some injury data can be obtained within individual EU countries - but most of these data is limited by size, scope and comparability. The IDB is the only systematic, comparable injury surveillance system, to collect and collate comparable data on non-fatal, register based injuries from countries across the EU. Further, what information is available in countries tends to</p>
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	focus on fatal injuries which are only the tip of the iceberg. For every person killed, countless others are seriously injured or even left permanently disabled. The IDB complements information of fatalities by providing information on the most cost-relevant treatments in hospitals.
<ul style="list-style-type: none"> <li>Performs original research mainly based on new data collections, i.e. data that are not part of regular statistical data that come from other sources</li> </ul>	Yes. All of our reports and publications are based on IDB - a selection of our publications are referenced [2-21]. No other comparable surveillance system exists in Europe to monitor non-fatal injury trends and causal factors.

## Sustainability

The network:

<ul style="list-style-type: none"> <li>Actively performs research, e.g. by collecting comparable data, producing research papers or reports, harmonizing data collections and organizing network meetings and exchange of good practices. It has been doing this for several years (sustainable, active, collaborative)</li> </ul>	Yes. The network has been strengthened from 2011-2014 as part of the JAMIE project (Joint Action on Injury Monitoring in Europe) and then from 2014 - 2017 as part of the BRIDGE project (BRIdging Information and Data Generation for Evidence-based Health Policy and Research). An IDB manual, data dictionaries, annual network and training events, and quality checking systems, ensure consistency across participating countries. Since 2017, the IDB network and monitoring system continue to operate, sadly without any EU co-funding.
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## Geographical coverage

The network:

<ul style="list-style-type: none"> <li>Consists of actively participating researchers and/or data collectors that represent a significant number of European countries or regions</li> </ul>	<p>Yes. Up to 26 European countries are active in the Network (e.g. annual meetings), have contributed data to IDB and have used data at national level (see IDB-Network Members in ANNEX).</p> <p>In particular active are countries which are presented in the IDB Advisory Board (Austrian Road Safety Board, Brandenburg authority of Environment/ Health and Consumer protection, Danish Institute of Public Health, Dutch Consumer Safety Institute, Centre de Recherche Public de la Santé Luxembourg,</p>
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	Italian Ministry of Health, and Centre for E-Health Research at Swansea University).
<ul style="list-style-type: none"> <li>Collects data that are representative for a significant number of EU/EFTA regions and/or countries</li> </ul>	Yes. There are estimated injury rates (based on IDB-MDS) available for 26 European countries (including Iceland, Norway and Turkey), although not for every year. The sample of IDB-FDS data is considered as sufficiently representative for the entire single market.

### Scientific excellence

#### The network:

<ul style="list-style-type: none"> <li>Creates output with a high scientific quality as measured by the volume and impact of its publications and by its recognition by other experts, stakeholders and policy makers</li> </ul>	Partly. The IDB system has been internationally standardized only a few years ago (JAMIE-project 2013-2016) and it is not yet fully implemented in all EU countries. The track record of scientific publications is yet limited but growing, pending on the number of national implementations and their quality.
<ul style="list-style-type: none"> <li>Has a rigorous approach to fostering and improving the quality of its data and publications</li> </ul>	Yes. The IDB continually strives to improve the quality and comparability of data in its system - work is listed in detail in the IDB manual <a href="http://www.eurosafe.eu.com/uploads/inline-files/IDB_operating_manual_Jan%202017_0.pdf">http://www.eurosafe.eu.com/uploads/inline-files/IDB_operating_manual_Jan%202017_0.pdf</a> , which is implemented in all countries that deliver data to the EU level database. IDB complies with ECHI quality standards (see IDB Reference Metadata in Euro SDMX Metadata Structure [28].  In course of the annual data uploads also the quality of national implementation is being systematically assessed and assessment reports are published (as upload metadata reports). See also <a href="http://www.eurosafe.eu.com/key-actions/injury-data/reports">http://www.eurosafe.eu.com/key-actions/injury-data/reports</a> .
<ul style="list-style-type: none"> <li>Works on the harmonization of data and indicators and on developing new methods and tools to serve its research domain in Europe</li> </ul>	Yes. As mentioned already. The IDB operating manual is maintained and updated regularly. The six bi-annual reports on Injuries in the EU reports demonstrate the efforts for harmonizing data, data collection methodologies, data retrieval tools, analysis and reporting (see f.i.: <a href="http://www.eurosafe.eu.com/uploads/inline-files/EuropeSafe_Master_Web_02112016%20%28">http://www.eurosafe.eu.com/uploads/inline-files/EuropeSafe_Master_Web_02112016%20%28</a>

	2%29.pdf).
<ul style="list-style-type: none"> <li>Has received funding from national and/or international funding organizations</li> </ul>	<p>Yes. IDB members fund their data collection activities within their own countries. Standardization, adaptation of national systems and exemplary applications have been subsidized by EU funds from the EU Health Programme during 2011-2017. For the time being, there is no co-funding at EU-level.</p>
<ul style="list-style-type: none"> <li>Translates its research outcomes effectively and enables decision making to collect new or better data</li> </ul>	<p>Yes. Quality of national implementation of injury data collection systems is assessed annually in the course of the IDB data upload (Implementation score card reports).</p>

### Data management and access

The network:

<ul style="list-style-type: none"> <li>Regularly collects timely, new data that are comparable between and representative for EU/EFTA countries and/or regions and as far as possible comply with European and/or international quality standards and definitions</li> </ul>	<p>Yes. Data is collected from participating countries annually. Data collected in two standardized formats: IDB-Full Data Set (FDS) and IDB-Minimum Data Set (MDS). Each data package is accompanied by metadata (quality statement) which gets published in a so-called upload-report (data quality report).</p> <p>Conversion guidelines and tables, quality checks, and consistency standards reported in detail in the IDB manual [27].</p> <p>IDB-MDS data from which national injury rates (European Core Health Indicators) are derived, comply with ECHI quality standards (see IDB Reference Metadata in Euro SDMX Metadata Structure [28]).</p>
<ul style="list-style-type: none"> <li>Generates repositories and/or data platforms that allow easy access to comparable (aggregated) data and/or indicators and meta-data in agreement with criteria for good data governance, privacy and accessibility.</li> </ul>	<p>Yes. An MDS public access tool and a FDS restricted access tool available on European Commission website  <a href="https://ec.europa.eu/health/indicators_data/idb_en">https://ec.europa.eu/health/indicators_data/idb_en</a>.  IDB-based European Core Health Indicators (ECHI-29b -Home and Leisure Injuries) can be retrieved at  <a href="https://ec.europa.eu/health/indicators/echi/list_en">https://ec.europa.eu/health/indicators/echi/list_en</a>.  Eurosafe have developed a public access tool for home and leisure injuries:  <a href="http://www.eurosafe.eu.com/look-at-the-figures">http://www.eurosafe.eu.com/look-at-the-figures</a></p> <p>Swansea University is in the process of developing an IDB-Burden of Injury Tool.</p> <p>In particular for public health professionals, health and safety administrations at the national and EU</p>

	levels, members of parliaments, business and consumer interest groups, and media at EU level, an EU IDB clearinghouse service is available.
<ul style="list-style-type: none"> <li>Makes data collected by the network available for other researchers and policy makers outside the network ready for easy access with as little publication delay as possible</li> </ul>	Yes. See above. Usually, IDB data from participating countries get published at the EU-web-gate with a delay of 15 months, i.e. data from 2017 by March 2019.

## Governance

### The network:

<ul style="list-style-type: none"> <li>Has clearly defined aims and objectives and a transparent governance structure, including a management board, explicit coordinating roles and a clear process to make decisions and take on board new network participants and take on new research projects</li> </ul>	<p>Yes. Aims, activities, membership, decision making process, role of assembly, board and coordinator etc. are clearly laid down in the bylaws of the IDB-Network.</p> <p>Currently, the European Association for Injury Prevention (EuroSafe) coordinates the network in collaboration with the IDB Advisory Board (Austrian Road Safety Board, Brandenburg authority of Environment, Health and Consumer protection, Danish Institute of Public Health, Dutch Consumer Safety Institute, Centre de Recherche Public de la Santé Luxembourg and Centre for E-Health Research at Swansea University).</p> <p>The 'Joint action on monitoring injuries in Europe' (JAMIE) initiative and then 'BRidging Information and Data Generation for Evidence-based Health policy' (BRIDGE Health) initiative brought together 26 member states and their competent authorities, signing up for a joint commitment to enhance injury surveillance efforts.</p> <p>There are also clear rules on data protection in accordance with EU laws. See <a href="http://www.eurosafe.eu.com/key-actions/injury-data/toolbox">http://www.eurosafe.eu.com/key-actions/injury-data/toolbox</a>.</p>
<ul style="list-style-type: none"> <li>Organizes regular meetings and implements processes and procedures by which decisions are made among the participants that deal with governance, strategy and priorities</li> </ul>	Yes. Annual meetings (or Skype-conferences) are held with IDB network members and the advisory board members.

## Liaising

The network:

<ul style="list-style-type: none"> <li>• Brings together data collectors, researchers and stakeholders to integrate evidence generated by the network that supports the implementation of specific interventions and policies</li> </ul>	<p>Yes, as evidenced by the wide array of participants in our annual IDB network member meetings with National Data Administrators from each of the participating countries. Almost all EU member states' governments have designated an internal unit or an affiliated agency with the task of exploring the possibilities of enhanced national injury surveillance efforts and to participate in EU level exchange. These designated centres are the data owners and represent their country in the EU Network of National Data Administrators (NDAs) for the IDB exchange. IDB regularly publishes policy reports and presents analysis findings at international conferences.</p>
<ul style="list-style-type: none"> <li>• Liaises with other networks, organizations and key stakeholders that cover complementary and related research and policy domains</li> </ul>	<p>Yes. Through EuroSafe, the IDB-network is liaised with:</p> <ul style="list-style-type: none"> <li>-WHO-Global programme and its Network for Violence and injury prevention;</li> <li>-International Collaborative Effort on Injuries (ICE), research network;</li> <li>-ANEC, EU-level coordinating body for consumer product standards and regulation;</li> <li>-European Public Health Association and its Injury prevention section;</li> <li>-European Child safety Alliance;</li> <li>-European Prevention of falls network (ProFound);</li> <li>-European Federation of National Associations of Orthopedics and Traumatology (EFORT);</li> <li>-European Platform of European Elderly (AGE)</li> </ul>
<ul style="list-style-type: none"> <li>• Will not take up research that other networks are already doing well, but is willing to collaborate with other networks if feasible, relevant and efficient</li> </ul>	<p>Yes. The IDB has been developed in order to fill in serious gaps in information on non-fatal injuries, especially injuries that occur at home, in sports and at schools. It proved also to provide essential for providing data that is complementary to existing data sources for road traffic accidents (relying traditionally on police reports) and accidents at work (relying traditionally on reports from health and safety inspectorates).</p>

## Capacity building

The network:

<ul style="list-style-type: none"> <li>• Develops and implements forms of capacity building. This can for instance take place by organizing expert exchanges (workshops) or developing and exchanging tools and methods.</li> </ul>	<p>Yes. EuroSafe and the IDB Advisory Board:</p> <ul style="list-style-type: none"> <li>- Function as the secretariat of the network and representative towards the Commission services;</li> <li>- Assist IDB-NDAs in implementing and maintaining comparable national systems;</li> <li>- Collect and check data for upload at European level;</li> <li>- Develop and maintain standards and tools for the system, e.g. the IDB- Manual, the Coding Manual and software support tools;</li> <li>- Organize annual network meetings and training events;</li> <li>- Promote the use of the database at the European level.</li> </ul>
<ul style="list-style-type: none"> <li>• Engages in quality support among its members, i.e. by performing site visits or quality audits, including the provision of advice that serves research capacity building</li> </ul>	<p>Yes. Quality audits are undertaken prior to the data being uploaded to the IDB. Such measures include:</p> <ul style="list-style-type: none"> <li>- Checking the representativeness of selected hospitals by identifying the distribution of age, sex, mechanism of injury;</li> <li>- Continuous supervision of coding staff regarding selection of patients, and accuracy and completeness of coding;</li> <li>- Submitted data also has to pass formal checks for completeness on compulsory elements, absence of duplications and consistency with the Data Dictionary, before being uploaded to the IDB.</li> </ul> <p>For FDS-data additional measures are implemented:</p> <ul style="list-style-type: none"> <li>- Continuous training, supervision of coding staff and on-going feedback on questions relating to coding accuracy (in particular regarding products/substances)</li> <li>- Cross-checking of codes entered with the accompanying narrative free-text, together with identifying inconsistencies between data variables.</li> <li>- A few countries also carry out validity audits e.g. cases are coded by the national IDB-team in addition to the local team, and codes are compared to identify the number of true positives/ false positives/ false negatives and an overall "completeness score".</li> </ul> <p>Each data file is also accompanied by</p>

	information as to the origin, content and quality of the data.
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## Advocacy and communication

The network:

<ul style="list-style-type: none"> <li>Advocates for its 'domain' and the relevance of its research outcomes and policy messages</li> </ul>	<p>Yes. Through EuroSafe, the IDB Network produces:</p> <ul style="list-style-type: none"> <li>-regular factsheets and policy briefings on specific injury topics (<a href="http://www.eurosafe.eu.com/publication/policy-briefing">http://www.eurosafe.eu.com/publication/policy-briefing</a>);</li> <li>-quarterly Newsletters with updates on research, policies and actions in fields of injury prevention (<a href="http://www.eurosafe.eu.com/newsletters">http://www.eurosafe.eu.com/newsletters</a>)</li> <li>-bi-annual conferences on injury prevention and safety promotion (<a href="https://www.veiligheid.nl/eurosafe-conference">https://www.veiligheid.nl/eurosafe-conference</a>);</li> <li>-Active engagement in consultations organised by European Commission on respectively health information policies and consumer safety policies</li> <li>-contacts with members of European Parliament</li> <li>-national level advocacy and lobby through the IDNB-members by coaching and alerting members of the network.</li> </ul>
<ul style="list-style-type: none"> <li>Organizes or participates in international meetings with experts and counterparts to exchange their methods and findings</li> </ul>	<p>Yes. Research findings and proceedings of methodology are regularly presented at international conferences as the WHO-endorsed biannual World-conferences for injury prevention and the biannual European conferences for injury prevention</p> <p>IDB coordinators regularly attend international expert meetings as the International Collaborative Effort on Injury Statistics (ICE) and Methods meetings.</p> <p>The network itself performs annual meetings or skype-conferences for exchanging experiences and implementing revisions of methodology.</p>
<ul style="list-style-type: none"> <li>Communicates its achievements and proceedings regularly in different media</li> </ul>	<p>Yes. through websites (e.g. EC website <a href="https://ec.europa.eu/health/indicators_data/idb/">https://ec.europa.eu/health/indicators_data/idb/</a> and Eurosafe website <a href="http://www.eurosafe.eu.com/key-actions/injury-data/aims-network">http://www.eurosafe.eu.com/key-actions/injury-data/aims-network</a>), journal publications, reports (<a href="http://www.eurosafe.eu.com/key-actions/injury-data/reports">http://www.eurosafe.eu.com/key-actions/injury-data/reports</a>).</p> <p>At EU-level there are a quarterly newsletter ("IDB E-Update") addressing all network-partners, and the quarterly Eurosafe newsletter ("Eurosafe News") informs regularly on achievements of the</p>

	network, with >2000 subscribers.
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### Societal impact

The network:

<ul style="list-style-type: none"> <li>Creates output (articles, reports) that receive a high degree of positive media coverage in several European regions and/or countries and/or within professional communities</li> </ul>	<p>Yes. Public information based on IDB data gets much media attention in several countries (e.g. NL, AT, DE, LU), where influential agencies for injury prevention exist. In particular, IDB data have been extremely influential to improve child safety throughout Europe during past years, e.g. through providing evidence for improving standards for toys and child care articles [29].</p>
<ul style="list-style-type: none"> <li>Creates output that generates local, regional or national discussions in media or political fora</li> </ul>	<p>Yes, this too. Also, country-specific. A particular usage of IDB data is for so-called safe community programmes (WHO endorsed programme), which require local injury data in order to guide local injury prevention programmes as well as for the European Child Safety Alliance (ECSA) and its 32 country members.</p>

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