Report on mapping exercise: identification of inspirational experiences

MS35

Work package 10: Assessing and piloting interoperability for public health policy

Task 10.1: Mapping exercise: identification of inspirational experiences

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Executive summary

This milestone report is the first output of the InfAct Joint Action's Work Package 10 (WP10) research on "assessing and piloting interoperability for public health policy". Specifically, the report presents results of a task one (T10.1) mapping exercise in identifying inspirational experiences, initiatives and project in cross-border sharing, linkage and management of health data.

Firstly, within the WP10, we developed and validated a conceptual and analytical framework of cross-border health data sharing, linkage and management initiatives to be used both as an inclusion criteria checklist, as well as an analytical tool.

Through online stakeholder surveying, supplemented by desk research, we collected over a hundred inspirational experiences in health data use. In total, 59 of these fulfilled our inclusion criteria and were examined in more detail.

In order to get more detailed insight into these initiatives, we did a simple analysis of system and service domains tackled, data sources used, complexity of data work, as well as products of these efforts.

As an immediate next step, tasks two (T10.2) and three (T10.3) will build on the approaches demonstrated by the inspirational examples tackling interoperability issues to characterise the panoply of solutions applied to overcome legal, organizational, technical and semantic barriers, while addressing comparisons across countries.

In parallel, the task four (T10.4) will benefit from insights gained from this analysis to propose facilitators and best approaches to set up several pilots on the proposed case studies for a future sustainable infrastructure dealing with health information in Europe. This approach will enable health data analysis across EU countries for informing health policy and conducting public health research.

We are convinced that InfAct's and WP10's work is an important step towards understanding and promoting the importance of a comprehensive approach to the concept of interoperability, which has to be an integral, sustainable and well-represented topic in any future research infrastructure dealing with health information at a European level.

Work Package 10 Research Teams from the

Croatian Institute of Public Health

CROATIAN INSTITUTE OF PUBLIC HEALTH

and the

Aragon Health Sciences Institute

IACS Instituto Aragonés de Ciencias de la Salud

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Mapping exercise

I. Introduction

Through Work Package 10 (WP10), of the InfAct (Information for Action!) Joint Action on Health Information, we are set to thoroughly describe methods and techniques used to get sound knowledge of (public) health data linkage, sharing and management, as well as reporting. We are doing so by using concepts, frameworks and practices of interoperability. As the title of the package itself suggests, goal of the WP10 is to "assess and pilot interoperability for public health policy". We structured WP10 into four tasks focused on two streams of 1) assessing (tasks 10.1, 10.2 and 10.3) and 2) piloting (task 10.4) best practices in data linkage, sharing and management. WP10 results will be reported through a number of milestone reports (starting with this one), two major WP deliverables and a series of case studies to be piloted in parallel.

Interoperability, in the broadest sense, stands for "ability to operate with others", thus can be applied to any situation where two or more entities work to achieve their goals or purpose by successfully interchanging services.[1] Institute of Electrical and Electronics Engineers (IEEE) defines interoperability as "the ability of two or more systems or components to exchange information and to use the information that has been exchanged".[2]

The European Interoperability Framework (EIF), in which we anchor our InfAct WP10 work, defines interoperability as "the ability of organisations to interact towards mutually beneficial goals, involving the sharing of information and knowledge between these organisations, through the business processes they support, by means of the exchange of data between their information and communication technology (ICT) systems".[3]

An essential starting point in InfAct Joint Action WP10 work are the interoperability layers described in the EIF:

1. legal,
2. organisational,
3. semantic and
4. technical;

a cross-cutting component of the four layers which is integrated public service governance, and a background layer of interoperability governance.

This model is depicted below in Figure 1.

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[1] Cross-border Patient Registries Initiative PARENT: Methodological guidelines and recommendations for efficient and rational governance of patient registries. 2015
https://ec.europa.eu/health/sites/health/files/ehealth/docs/patient_registries_guidelines_en.pdf
[2] Institute of Electrical and Electronics Engineers, *IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries*, New York, 1990
[3] European Commission: The New Interoperability Framework: Promoting seamless services and data flows for European public administrations. https://ec.europa.eu/isa2/sites/isa/files/eif_brochure_final.pdf
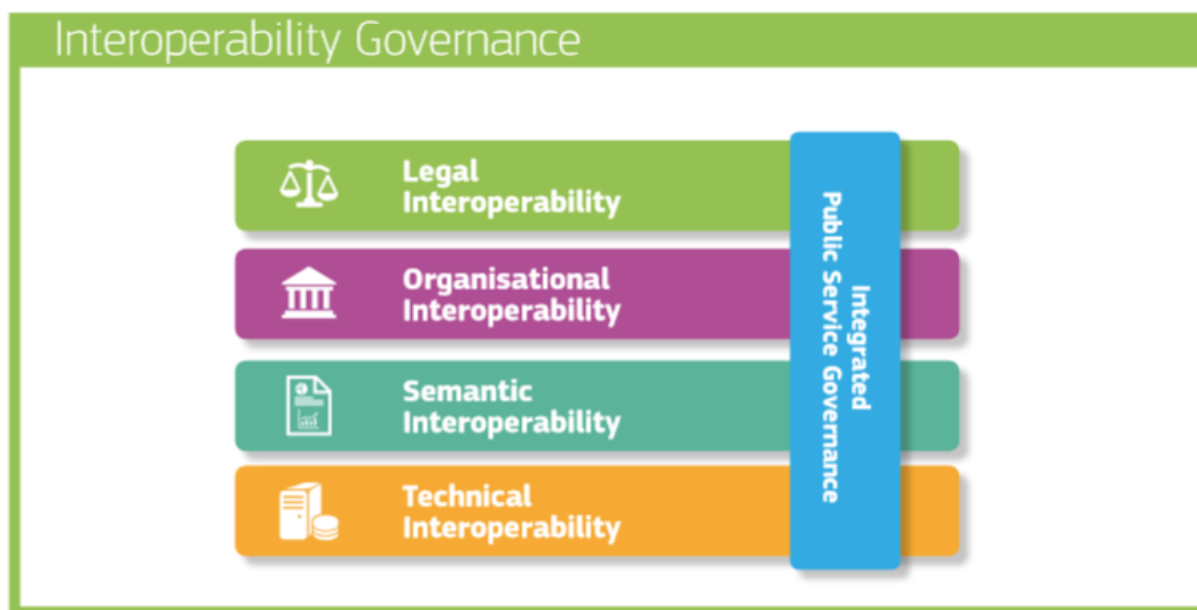
Figure 1: Interoperability model and layers[4]

BRIDGE-Health, a network of public health research networks and a predecessor to the InfAct project, posed the need of developing a European data infrastructure that can translate data, information and knowledge into support for policy making, using services based on data linkage, sharing and management, and knowledge development.

Establishing such infrastructure with data management, conceptualised and dealt with only on technical and semantic levels, is insufficient for achieving full interoperability. Our experience, working with patient registries in the scope of the PARENT (cross-border PAtient REgistries INiTiative) Joint Action project, shows that interoperability is largely understood as primarily technical, with a certain consideration given to the semantic level as well. However, these two elements are only a part of a bigger picture as described by the EIF. While the majority of registries explicitly stated that they mostly dealt with technical and semantic levels of interoperability, our research showed that some other aspects were considered as well: albeit less visible to the registry holders, they were no less important. For example, this was made clear in a study done within the scope of the PARENT project: a registry data structure was not provided by several of our respondents because their data structure was being revised to conform to new legal frameworks, which indicated that the political, legal and organizational issues were also crucial for their daily operation and data sharing practices.[5]

Our aim is to support efforts on establishing a research network that facilitates policy making, using services based on data linkage, sharing and management, and knowledge development. We are doing so through a number of sensible case studies, by piloting methods and techniques required to make this possible. For that purpose, WP10 is developing upon the building blocks defined in the EIF, while also getting inspiration from the EIF for e-Health[6].

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[4] *New European Interoperability Framework, EC, 2017*
https://ec.europa.eu/isa2/sites/isa/files/eif_brochure_final.pdf
[5] Valentic M., Plese B, Pristas I,Ivankovic D. Addressing the Data Linking Challenges: Interviewing for Best Practices in Patient Registry Interoperability. Methods of Information in Medicine. 2017; 56: 407-13. 10.3414/ME16-02-0029.
[6] https://ec.europa.eu/digital-single-market/news/ehealth-interoperability-framework-study-0

Based on this concept and the perceived and recognized need, WP10 is specifically:

1. Mapping and analysing cross-national inspirational case studies on public health surveillance or research, where interoperability, data linkage, data sharing and data management are present; in tasks 10.1, 10.2 and 10.3; and
2. Developing empirical work on interoperability, data linkage, data sharing and data management, for a number of case studies, using a variety of data sources from different countries; in task 10.4.

This document reports on the results of the first WP10 task, a mapping exercise with the ambition to identify inspirational experience in data linkage, sharing and management. This is a starting point for a more detailed analysis and production of guidelines and tools to be used in all future sustainable European infrastructures working with health information.

In order to achieve this, we have started by defining the inspirational experiences criteria including details on which system domains these projects and initiatives studied but also which performance areas they provided insights on, which data sources were used and whether they produced policy recommendations as an end-result. The criteria framework was tested and agreed upon among WP10 partner during the work package kick-off meeting in Zagreb, Croatia in May 2018.

Applying the criteria framework, we collected a number of inspirational experiences through a structured questionnaire distributed among InfAct and WP10 partners, but also among the broader health information community in Europe. We supplemented the results of the survey with desk research. Following the need to select a finite subset of initiatives fulfilling the established criteria for further analysis on how they approached interoperability issues, we did not aim for an exhaustive approach. However, we do foresee that this task could remain open as a continuous iterative effort to map interoperability standards arising from projects tackling data sharing and management across countries. Following the collection of inspirational experiences, we analysed them using the same criteria framework that was used as a set of inclusion criteria.

Upcoming tasks of the WP10 work will be based on the results presented in this report but also on feedback received, immediately after presenting the report, from the project partners and a wider group of stakeholders. These activities will include conducting a series of in-depth surveys, interviews and focus groups. The goal is to identify and present, in a case-study and "cookbook" format, a series of enabling and disabling factors and recommendations that make some data linking, sharing and managing efforts work better than others.

A note on the temporal component and sustainability

Although, throughout this report, we refer to the inspirational examples work in past tense, as if they were all finished, this is not always the case. Some of the examples are indeed still active today as we research and produce this report.

We believe that the issue of sustainability of projects and initiatives, like the ones analysed here, is an important one. The future European research infrastructure on health information should make sure to actively work on this topic, perhaps even including interoperability as a permanent work-area of the infrastructure. Nevertheless, we felt that this topic is mostly out of the scope of the WP10 work and have decided to semantically refer to all the work in the inspirational examples analysed, in past tense.

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II. Methods

The specific objective of the Task 10.1 "Mapping exercise: identification of inspirational experiences" was to identify a number of "best (or inspirational) practices" in the European Union Member States (EU MS) participant countries. In order to be accepted as "inspirational", the experience had to fulfil five inclusion criteria presented in Figure 2 and the following paragraph.

<u>Inclusion criteria</u>

1. The example addresses the study of health status, health determinants, and/or health systems performance;
2. The example provides insight on surveillance and/or impact or effectiveness research;
3. The example includes a variety of data sources (e.g., patient registries, population-based registries, surveys, electronic health or medical records, administrative data, etc.) from different countries;
4. The example addresses data linkage, sharing, and management (quality assurance) activities;
5. The example produces outcomes reported to public health stakeholders, particularly policy-makers.

Inspirational example:	EuroPeriStat					
Studies:	Health status			Health determinants		Health system performance
Provides insight on:	Surveilance			Impact		Effectiveness
Includes data sources:	Disease-based registries	Population-based registries	Surveys	EHRs	Administrative data	Other: N/A
Addresses:	Data linkage			Data sharing		Data management
Produces:	Policy recommendations					
Link:	http://www.europeristat.com/					

Figure 2: Inclusion criteria mapping; example of EuroPeriStat - "Better Statistics for Better Health for Mothers and their Newborns in Europe"; kindly provided by Jennifer Zeitlin; InfAct green cells represent completely fulfilling the criteria, while the orange ones represent partially doing so

<u>Collecting data</u>

Inspirational experiences were collected via two streams. Firstly, by conducting a survey among the WP10 and InfAct project partners and the wider European health information community. The wider community represents health informaticians, public health professionals, statisticians, health data stewards and health information systems governance bodies for which we knew or assumed might provide insights on inspirational experience tackling data interoperability issues in cross-country data sharing projects.

Secondly, the data was collected through desk research of projects that potentially fulfilled the inclusion criteria. For this, we mostly used publicly available information on the Health Data Navigator (HDN) site[7] and European Commission's Community Research and Development Information Service (CORDIS) database.[8]

Results obtained via the online questionnaire and desk research were in no way meant to be exhaustive. Rather, they intended to give an overview of the state-of-art in projects linking, sharing and managing health data in Europe and beyond.

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[7] http://hdn.euhs-i.eu/international-home/eu-and-international-projects/103-share
[8] https://cordis.europa.eu

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<u>Online questionnaire</u>

Survey was conducted in order to collect a representative sample of inspirational experience from EU MS for the selection of a subset and further analysis. The questionnaire was sent out to a convenient sample of 890 e-mail addresses with a request to also further share the questionnaire to professionals that might be able to contribute. Due to the quasi-snowball sampling method, the response rate cannot be calculated nor discussed. The questionnaire was first sent out on January 14th 2019, and a subsequent reminder was sent on January 24th. Data collection was finalised on January 31st 2019. LimeSurvey online surveying tool, licenced with the Croatian Institute of Public Health (CIPH), was used as a questionnaire platform, and the collected data was stored on CIPH's data servers.

The survey was titled "Collecting inspirational examples in health information interoperability". It consisted of 2 pages. On the 1st page, and in the whole questionnaire, only one question was mandatory: "What is the name of the inspirational example?"; three questions were non-mandatory: contact person for the inspirational example, project website link, and short description of the project. Questions on the 2nd page covered topics listed in the framework for inspirational experiences identification and analysis:

- If inspirational examples studied health status, health determinants, or health system performance;
- If they provided insight on available data and indicators, measurement issues, concept, data and indicators;
- Which data sources they included;
- If they addressed topics of data linkage, sharing and data management;
- If they produced any policy recommendations.

Each of these page-2 questions could be answered with "Yes", "Partially / Somewhat", "No", "I don't know" or "No answer".

The questionnaire is presented in the Appendix 1 of this report. A complete list of inspirational experiences, acquired through the questionnaire and desk research, that satisfied the inclusion criteria, are available in a table in the Appendix 2. This list also includes a short description of each experience and information on whether the example was retrieved through the survey or desk research.

<u>Desk research</u>

Desk research was conducted using publicly available information on different websites, mostly the Health Data Navigator (HDN) site and European Commission's CORDIS database. The HDN is an interactive platform for researchers, policy makers, and healthcare professionals to easily access health data and enhance cross-country analysis of European health systems o Austria, Estonia, Finland, France, Germany, Israel, Luxembourg and United Kingdom developed within the scope of the EuroREACH project[9]. CORDIS database is the European Commission's primary source of results from the projects funded by the EU's framework programmes for research and innovation (FP1 to Horizon 2020). CORDIS has a public repository with all project information held by the European Commission. It is managed by the Publications Office of the European Union on behalf of the European Commission's research and innovation Directorates-General, Executive Agencies and Joint Undertakings.

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[9] http://www.euroreach.net/compendium

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The desk research search was conducted on January 30th and January 31st 2019. CORDIS website was searched with the following filters[10] "Collection: Projects" and "Domain of Application: Health". The search retrieved 1348 results.

The projects were deemed as inspirational if they fulfilled the aforementioned inclusion criteria. The inspirational examples retrieved through this research are available in Appendix 2 of this report.

Analysis of inspirational examples

The exploratory purpose of this analysis was to:

a.   get an overview of the European health data sharing, linking and managing landscape in the last decade; and to
b.   facilitate the choice of approximately 10 to 15 experiences to be examined in more detail in the continuation of the WP10 work through tasks 10.2 and 10.3.

Inspirational experiences, identified either through questionnaire or desk research, were analysed against the aforementioned criteria. This was done in order to get a better understanding of the profile of data linkage, sharing and management initiatives.

The answers received via the questionnaire were not further checked nor changed by the authors of this report. Information about the inspirational examples were retrieved from the projects' websites where available. If project website was not available, information available on HDN or CORDIS site were used.

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https://cordis.europa.eu/search/en?q=contenttype%3D%27project%27%20AND%20exploitationDomain%2Fcode%3D%27health%27&p=1&num=10&srt=contentUpdateDate:decreasing

III. Results

Questionnaire

During two-and-a-half-week data collection period, total of 48 completed questionnaires were received. Some of the responses provided more than one inspirational experience. Finally, once accounting for those, the questionnaire resulted in 60 project and initiative examples deemed inspirational by the respondents.

Out of these 60 experiences received, 32 were analysed to be unsuitable according to the inclusion criteria by the questionnaire analysts. 22 out of 32 did not deal with cross-border data work but were rather confined within a single country. Ten out of 32 experiences did address cross-border data activities, but did not deal with data linkage, management nor data sharing.

Using the analysis framework and inclusion criteria, the questionnaire resulted in 28 inspirational examples to be taken forward.

Desk research

Desk research resulted in collecting 42 examples. One example was rejected because it did not deal with neither health determinants, status, nor health system performance. Ten examples did not address data linkage, sharing nor management. This means 31 examples were accepted as inspirational through desk research.

In total, we analysed 59 inspirational experiences collected through an online questionnaire (n=28) and desk research (n=31); Figure 3.
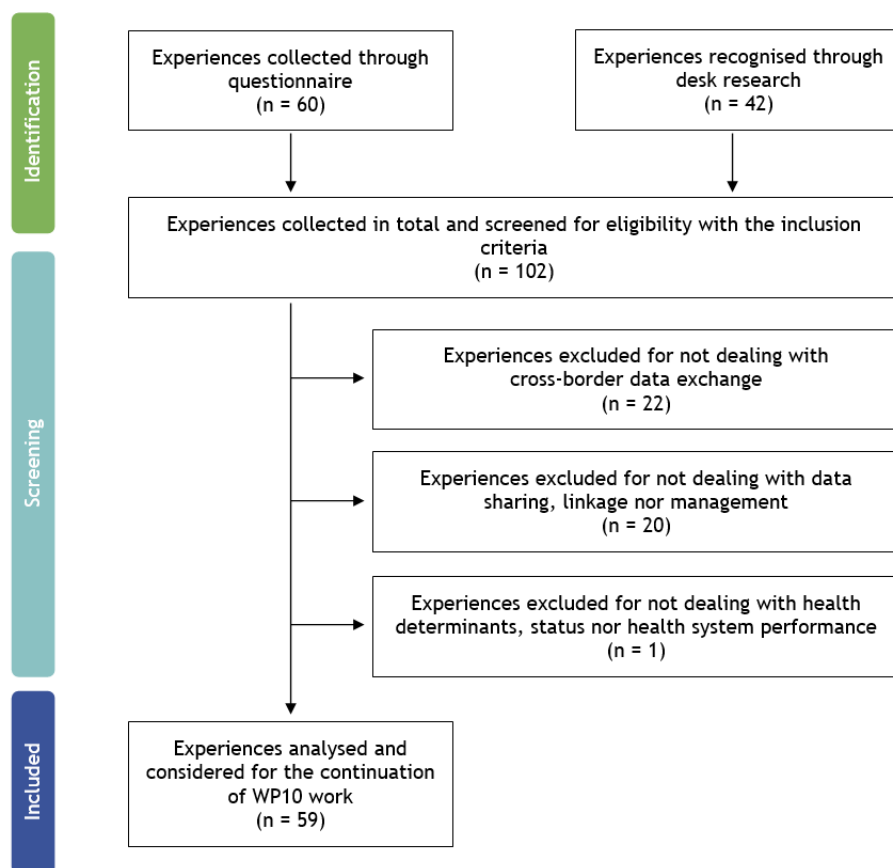

Figure 3: A flow diagram of data collection and screening

Inspirational experiences analysis

Thematically, inspirational experiences dealt with a range of topics and areas related to health information. A short description of each inspirational experience is provided in the Appendix 2 at the end of this report. In terms of domains, majority of inspirational examples did study at least one, and more often two or all three, of the domains recognised as being relevant for international data management: health status (45/59; 76%), health determinants (32/59; 54%) and health system performance (36/59; 61%). Details in Fig. 4.

This inspirational example studied:

	I don't know	No	No answer	Partially / Somewhat	Yes
Health Status	0	5	5	2	45
Health Determinants	2	13	5	7	32
Health System Performance	4	6	5	8	36
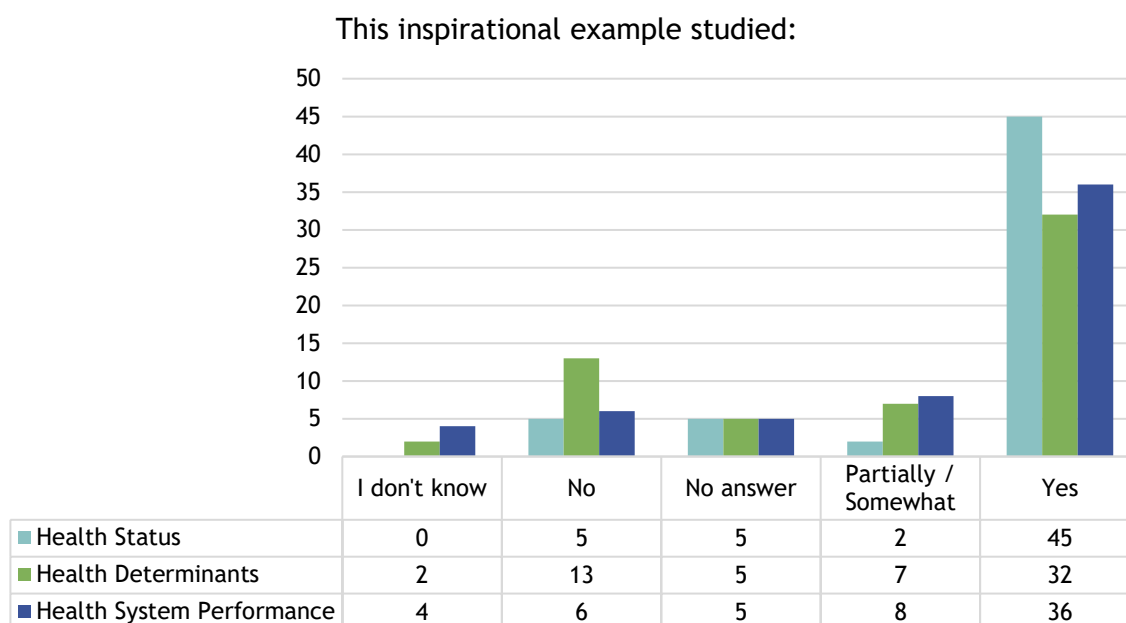
Figure 4: Domains of inspirational experiences' work

Inspirational examples were also comprehensive in covering topics related to health system performance domains with almost two-thirds of projects dealing with data related to quality of care and patient experience (38/59; 64%) and effectiveness (37/59; 63%). Half of them also worked with surveillance data (30/59; 51%). Details in Figure 5.

This inspirational example provided insights on:

	I don't know	No	No answer	Partially / Somewhat	Yes
Surveillance	0	13	5	11	30
Quality of care and patient experience	1	5	5	10	38
Effectiveness	1	4	5	12	37
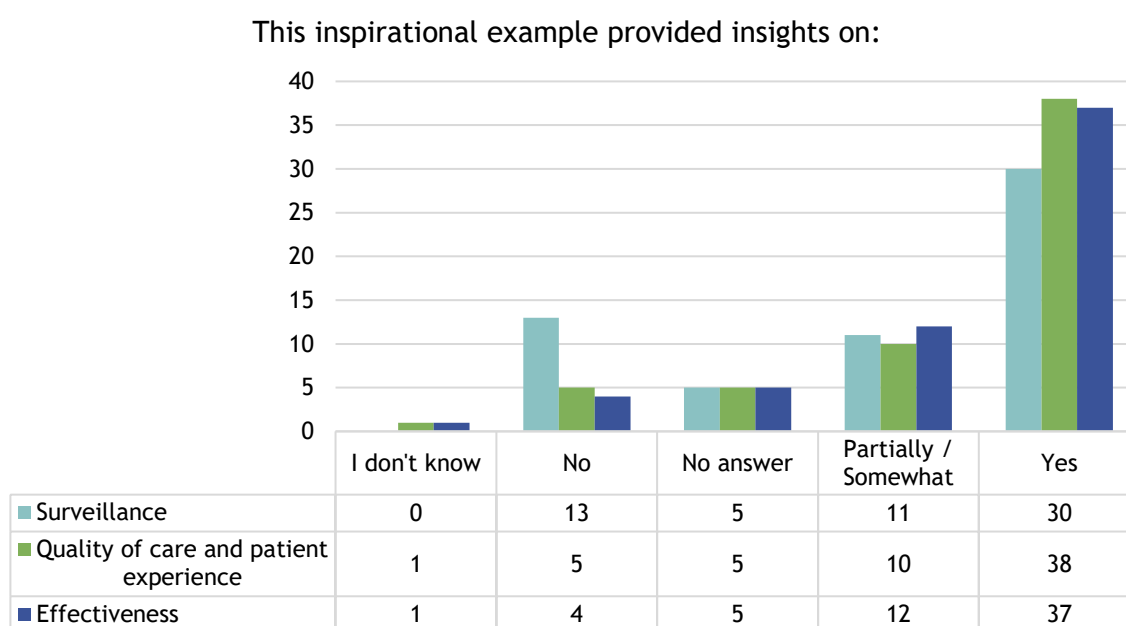
Figure 5: Health system domains tackled by inspirational experiences

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Data sharing, linking and management efforts in the inspirational examples collected used a variety of data sources. Almost two-thirds of the initiatives used population-based registry (37/59; 63%) and administrative data (37/63; 63%) while half (also) used disease-based registry (27/59; 46%), survey (26/59; 44%) and EHR (25/59; 42%) data. Details in Figure 6.
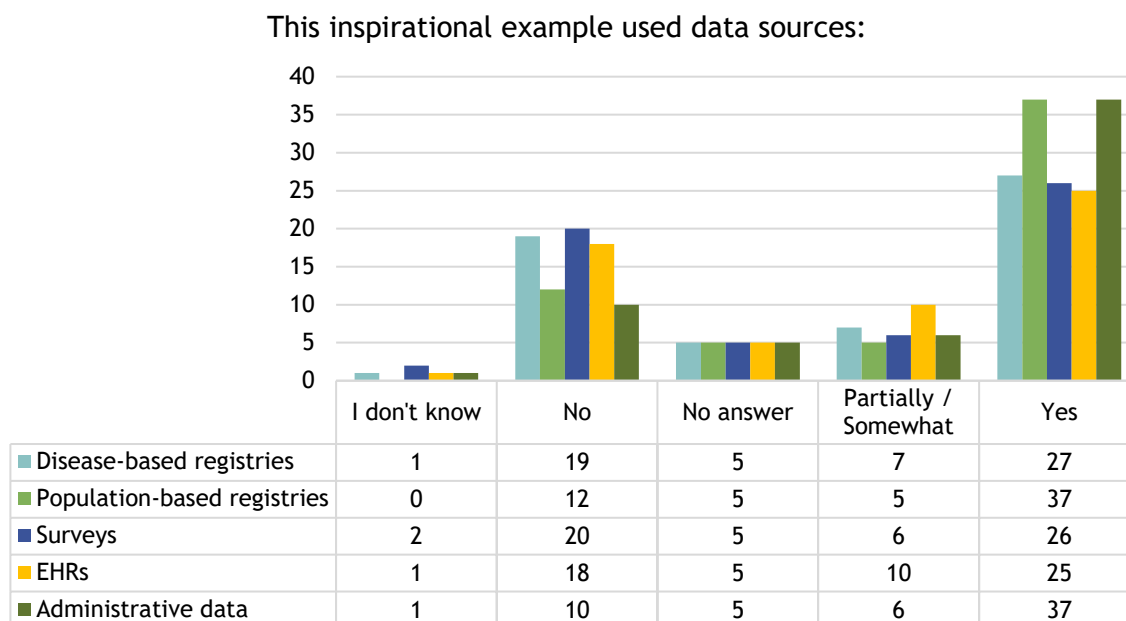
This inspirational example used data sources:

	I don't know	No	No answer	Partially / Somewhat	Yes
Disease-based registries	1	19	5	7	27
Population-based registries	0	12	5	5	37
Surveys	2	20	5	6	26
EHRs	1	18	5	10	25
Administrative data	1	10	5	6	37

Figure 6: Data sources used by inspirational experience examples

Other data sources reported to have been used include: "biobank data", "data on patients' satisfaction and patients' complaints (healthcare quality of experience and doctor-patient relationship)", "data on health care coordination and transitions", "geographical information (GIS) regarding the statistical and administrative area units (NUTS - nomenclature of territorial units for statistics - and organisational healthcare areas)"; "environmental data", "cities' resource allocation information", and "qualitative: interviews and focus groups with health care providers and organisational representatives".

Due to heterogeneous efforts and implementation methods of collecting patient reported outcome (PROM) and experience (PREM) data, these could have been listed under more than one category (i.e. survey or EHR data) and some respondents also listed these separately under "other data sources used".

Three quarter of initiative dealt with data linkage (43/59; 73%), two-thirds with data sharing (41/59; 69%) and a bit more over a half with data management (32/59; 54%). It seems that, in the linkage, sharing and managing cascade, as the complexity of activities increases the rate of dealing with these "methods" goes down, as seen in Figure 7.

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This inspirational example addressed

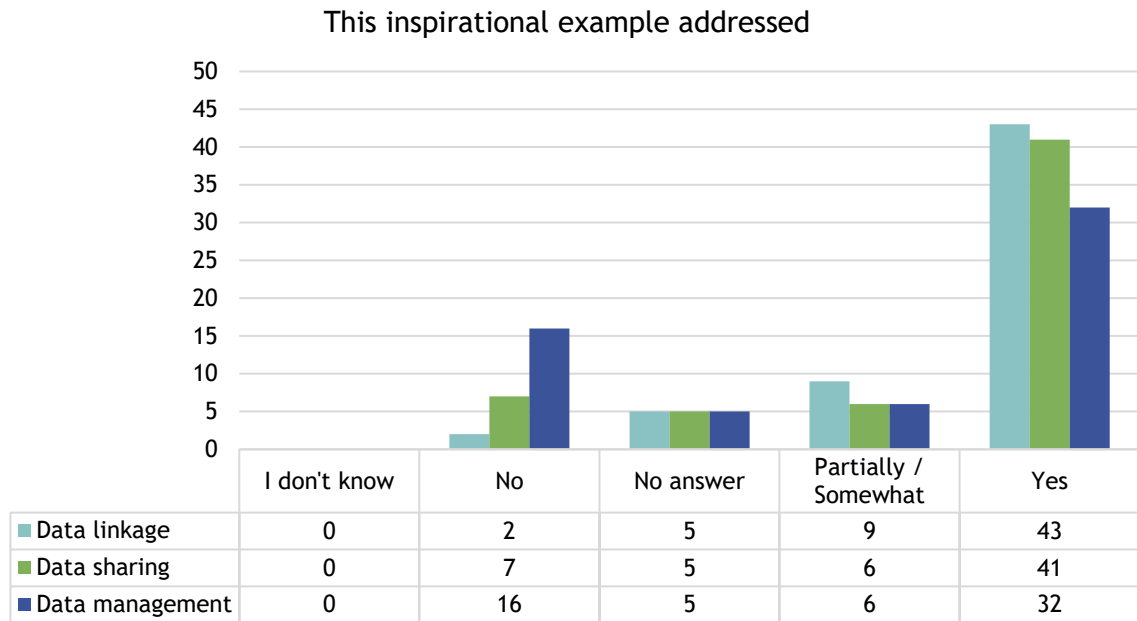|	I don't know	No	No answer	Partially / Somewhat	Yes
Data linkage	0	2	5	9	43
Data sharing	0	7	5	6	41
Data management	0	16	5	6	32

Figure 7: Data manipulation activities by inspirational examples

Almost three-quarter of examples (43/59; 73%) produced policy recommendations based on the data linkage, sharing and management work, while additional 10% (6/59) did that "partially / somewhat", as shown in Figure 8. Based on the short descriptions of the project, also available in the Appendix 2, it is clear that a lot of projects and initiatives had policy-involved work as part of their mandate, even in the "definition" of the project.

This inspirational example produced:

	I don't know	No	No answer	Partially / Somewhat	Yes
Policy recommendations	4	1	5	6	43
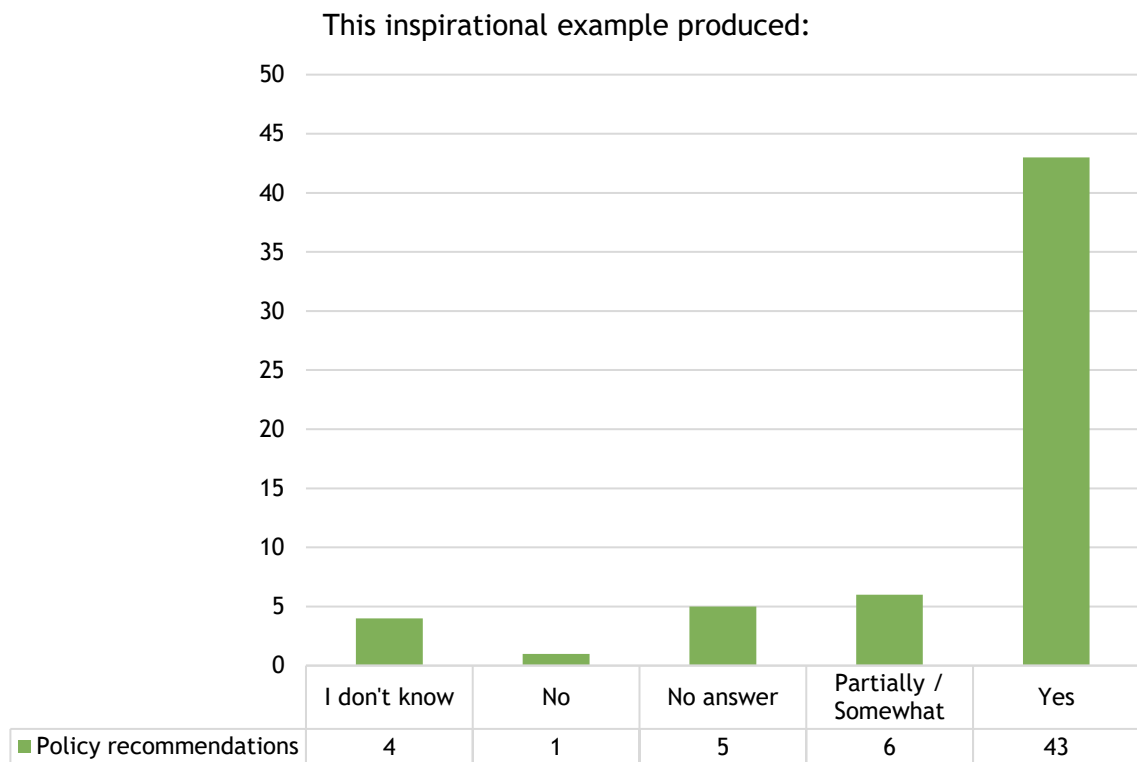
Figure 8: Whether inspirational experiences produced policy recommendations?

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Discussion on implications for further WP10 work, future sustainable structure on health information and EU Member States

This report presents the outputs of task one (T10.1) the InfAct Joint Action WP10 in assessing and piloting interoperability for public health policy, identifying inspirational examples of initiatives or experiences in cross-border sharing, linkage and management of health data.

As an immediate next step, tasks two (T10.2) and three (T10.3) will build on the approaches demonstrated by the inspirational examples tackling interoperability issues to characterise the panoply of solutions applied to overcome legal, organizational, technical and semantic barriers while addressing comparisons across countries. A summarised schematic representation of the double-stream WP10 work is visible below in the Figure 9.

In parallel, the task four (T10.4) will benefit from insights gained from this analysis to propose facilitators and best approaches to set up several pilots on the proposed case studies for a future sustainable infrastructure dealing with health information in Europe, enabling health data analysis across EU countries for informing health policy and conducting public health research.
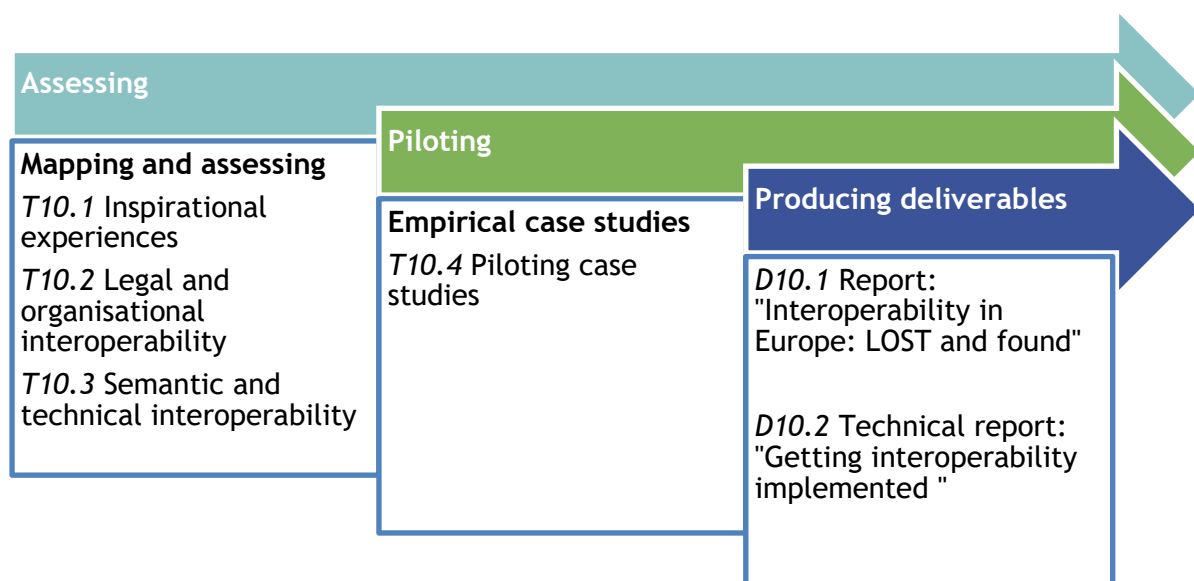
Assessing

Mapping and assessing

T10.1 Inspirational experiences

T10.2 Legal and organisational interoperability

T10.3 Semantic and technical interoperability

Piloting

Empirical case studies

T10.4 Piloting case studies

Producing deliverables

D10.1 Report: "Interoperability in Europe: LOST and found"

D10.2 Technical report: "Getting interoperability implemented "

Figure 9: Work Package 10 work summarised

Our simple scoping exercise, through both surveying and desk research, already collected a lot of inspirational experiences, showing that the European landscape of projects and initiatives linking, sharing and managing health data among countries is very vibrant but even more diverse. Despite the non-exhaustive approach, we did manage to list a significant number of inspirational experiences for our future WP10 work. We also managed to get an overview of geographic, funding, thematic and governance-style "spread" of these efforts. This analysis, unfortunately outside of the WP10 scope, would be interesting to pursue further.

Another result of our review, which will not feed directly into the future WP10 work but is of great significance to potential future European infrastructure dealing with health information, is the dispersion and limited duration of these efforts. Evidence of projects communicating and collaborating among themselves, despite dealing with similar topics and data, is scarce. Also, a minority of the efforts analysed here operate as on-going projects with sustainable governance structures.

The analysed inspirational experiences did show a rather comprehensive approach to dealing with all domains of data exchange - sharing, linking and management of data. Health system domains-wise projects also did holistically address health status, determinants and system performance measures. Experiences also looked at both quality and effectiveness data and, to a bit lesser extent, at surveillance data.

With administrative and population-based registry data being most often used in these efforts, there is a slight but interesting preference for some less purely clinical data sources, which might indicate differences in data availability and/or quality, but also might lead to conclusions about legal and semantic data issues. These kinds of findings will be invaluable in our future work on analysing a subset of these data sharing efforts and looking into enablers and barriers in cross-border data use.

Another interesting finding, which we will look into more detail, is that, in the linkage, sharing and managing cascade, as the complexity of data "manipulation" activities increases, the rate of initiatives dealing with these "methods" decreases.

A predominant majority of examples produced policy recommendations of some sort. It will be interesting to research into more detail what kind of policy work was done and to what effect.

There are multiple efforts, among several work packages within the InfAct Joint Action project, to collect and analyse examples of previous or current pan-European initiatives in using, linking, sharing and managing health data. Namely, work packages eight, nine and ten. Each of the work packages is using a different definition of what an inspirational or useful experience is, in line with its own research scope and question(s), and also focusing on different perspectives of working with health data (interoperability, innovative use of data, use of existing and new indicators...). In order to fully use the synergistic potential of multiple research streams within InfAct, it would be very interesting to consolidate these efforts and perhaps consider a joint report or even a repository of (analysis) results. Any future research- and/or operational-based infrastructure dealing with health information on an EU level would benefit from such a resource (idea: an updated and expanded Health Data Navigator-style repository).

Interoperability has to be an integral, sustainable and well-represented topic in any future European Research Infrastructure dealing with health information. Such an infrastructure should not only use the products and frameworks of other sectors' work on the topic,

but should also aim to be a relevant player in future European work on exploring, defining, advancing and implementing interoperability.

WP10 work is an important step towards understanding and promoting the importance of a comprehensive approach to considering and applying the concept of interoperability as well

as its four indivisible levels: legal, operational, semantic and technical. Besides the personal and institutional capacity building role, by the end of its mandate, WP10 plans to produce a series of assessment and piloting deliverables that will be used as a practical tool for professionals in Europe and beyond working with data sharing, linking and management across borders.

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Acknowledgements

This work would not have been possible without the valuable inputs from colleagues and friends around Europe responding to our online survey. Among hundreds of emails, you chose to open this one and take the time to contribute to our work. Thank you! ✱

We would also like to thank Rafaela for her proofreading help. Thanks, Raf! ✱

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Report on mapping exercise: identification of inspirational experiences
Work package 10: Assessing and piloting interoperability for public health policy

Appendix 1: Mapping exercise questionnaire

Invitation letter (e-mail)

Subject: *InfAct Joint Action – Work Package 10 short questionnaire*

Dear Madam or Sir,
we are contacting you on behalf of InfAct (Information for Action!) Joint Action Work Package 10.

You are receiving this invitation because we have recognised you as an important and an insightful member of the European public health information community.
We kindly ask you to help us identify inspirational examples (projects, initiatives and networks) that have linked, shared and managed public health surveillance or research data across countries.

Information collected here will help us get an overview of the European health information interoperability landscape and incorporate these findings into the future sustainable European research infrastructure on health information.

Filling out this questionnaire is anonymous and will take no more than 2-3 minutes of your time.

Survey link: http://survey.hzjz.hr/limesurvey/index.php?r=survey/index&sid=825811

Please, feel free to share this email or the survey link to other colleagues that you think might be able to contribute.

We thank you in advance!

Best regards,
Croatian Institute of Public Health InfAct Work Package 10 Research Team

Online questionnaire (browser based)

Introduction page

InfAct Joint Action work package 10 task 10.1 short survey

What is InfAct?

InfAct (Information for Action!), the Joint Action on Health Information, is a 3-year project funded by the European Commission involving 40 partners in 28 European countries. It builds on the BRIDGE Health project and other initiatives in the area of health information.

By country collaboration through 10 work packages, InfAct aims to streamline health information activities across Europe. It builds towards a sustainable and solid infrastructure on EU health information and strengthens its core elements based on capacity building, health information tools and political support.

Read more about InfAct at https://www.inf-act.eu

What is this very short survey about?

There is a need for a holistic European model and data infrastructure to translate data, information and knowledge into support for policy making. Based on the building blocks of the European Interoperability Framework (EIF) and inspired by the EIF for e-Health, InfAct WP10 aims to map, structure and pilot interoperability levels as a support for policy making using services based on data linkage, sharing and management, and knowledge development.

We are looking for your insights on (the existence of) inspirational examples (projects, initiatives and networks) around Europe (and beyond) that have linked, shared and managed public health surveillance or research data across countries.

Filling out this survey will take no more than 2-3 minutes, per inspirational example.

Of course, we will appreciate if you decide to share more than one example with us.

Basic information page

Think about, but don't be limited to, best examples that you know of, according to (some of) the following criteria:
- *addresses the study of health status, health determinants, and/or health systems performance;*
- *provides insight on surveillance and/or impact or effectiveness research;*
- *includes a variety of data sources (e.g., patient registries, population-based registries, surveys, electronic health or medical records, administrative data, etc.) from different countries;*
- *addresses data linkage, sharing, and management (quality assurance) activities and*
- *produces outcomes reported to public health stakeholders, particularly policy-makers*

Q1
What is the name of the inspirational example?

Q2
Can you provide us with an email / phone contact of person we could ask more about this inspirational experience? This can, of course, also be you.

Q3
A website link, if available, would also be nice.

Q4
What did the project / initiative do (or is still doing) in one or two sentences?

Report on mapping exercise: identification of inspirational experiences
Work package 10: Assessing and piloting interoperability for public health policy

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Additional information page

Q5

The inspirational experience studies or studied:	Yes	Partially / somewhat	No	I don't know	No answer
Health status					
Health determinants					
Health system performance					

Q6

This inspirational example provides or provided insights on:	Yes	Partially / somewhat	No	I don't know	No answer
Surveillance					
Quality of care and patient experience					
Effectiveness					

Q7

This inspirational example uses or used data sources:	Yes	Partially / somewhat	No	I don't know	No answer
Disease-based registries					
Patient-based registries					
Surveys					
EHRs					
Administrative data					
Does this inspirational example use (or used) any other data sources?	If yes, please specify:				

Q8

This inspirational example addresses or addressed:	Yes	Partially / somewhat	No	I don't know	No answer
Data linkage					
Data sharing					
Data management					

Q9

This inspirational example produces or produced:	Yes	Partially / somewhat	No	I don't know	No answer
Policy recommendations					

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Appendix 2: Complete list of inspirational experiences

Inspirational experience	Short description Provided by the respondents or acquired through desk research	
B.I.R.O.	Best Information through Regional Outcomes (2005-8) developed a shared European Diabetes Information System (SEDIS) that produces diabetes health reports generated automatically from a common dataset used by participating regions (Italy, Austria, Scotland, Norway, Romania, Malta and Cyprus).	(2)
BRIDGE	BRIDGE Health stands for BRidging Information and Data Generation for Evidence-based Health policy and research. The BRIDGE Health project aims to prepare the transition towards a sustainable and integrated EU health information system for both public health and research purposes.	(2)
CCPRB	Cancer Control using Population-based Registries and Biobanks (2004-2009) facilitating research linking biobanks and cancer registries.	(2)
CEPHOS-LINK	Making comparisons of re-hospitalisation rates using routine data began in the 1960's, revealing large differences observed between countries. However, the actual reasons behind these differences are not entirely clear. It is important to distinguish how much of the variation in re-hospitalisation rates can be explained by methodological artefacts, and how much is "real" representing actual differences in patient population, health system dynamics and so on. The CEPHOS-LINK project aimed to clarify these discrepancies striving to identify factors related to re-hospitalisations by comparing psychiatric re-hospitalisation rates and identifying their predictors in unselected patient populations from six European countries (Austria, Finland, Italy, Norway, Romania and Slovenia), all with differently organised health care systems.	(1)
COFI	Comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of mental health care assessing mental health policies on organisation of mental health care and evaluate outcomes, costs and patient experience of care in 5 European countries: Belgium, Germany, Italy, Poland and United Kingdom.	(2)
The Commonwealth Fund Multinational Comparisons of Health Systems Data	In this project, they use data collected by the Organization for Economic Cooperation and Development (OECD) to compare health care systems and performance on a range of topics, including spending, hospitals, physicians, pharmaceuticals, prevention, mortality, quality and safety, and prices. We present data across eleven industrialized countries: Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States.	(1)
CoNARTaS	The Committee of Nordic Assisted Reproductive Technology and Safety. The Committee of Nordic ART and Safety (CoNARTaS) was established in 2008 by initiative from members of the European IVF Monitoring group in the European Society of Human Reproduction and Embryology (ESHRE). The collaboration includes researchers from the University of Copenhagen (Denmark), University of Helsinki and THL National Institute for Health and Welfare (Finland), Norwegian University of Science and Technology (Norway), Centre for Fertility and Health, Norwegian Institute of Public Health and University of Gothenburg (Sweden). Initially, the main aim is to study the neonatal and infant health of children born after ART as well as the health of the treated women.	(1)
DUQuE	Deepening our understanding of quality improvement in Europe (2009-2014) was a cross-sectional study, goal: to study the effectiveness of quality improvement systems in European hospitals.	(2)
EARS-Net	EARS-Net is based on routine clinical antimicrobial susceptibility data from local and clinical laboratories reported to ECDC by appointed representatives from the Member States.	(1)
ECHIM	European Community Health Indicators and Monitoring (2009-2012) Goal: to develop and implement health indicators and health monitoring in the EU and all EU Member States. Not enough info.	(2)
ECHO	European Collaboration for Healthcare Optimization - ECHO aimed at building a common knowledge infrastructure, based on existing datasets, which ultimately allowed international healthcare performance	(1)

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	comparisons. ECHO set about the task of bringing together patient-level data from Denmark, England, Portugal, Slovenia and Spain, as well as, contextual information -demographic, socioeconomic, and healthcare supply data. This knowledge infrastructure allows the evaluation of more than 40 performance indicators, carefully developed to avoid inappropriate cross-country comparisons. The ECHO knowledge infrastructure allows the study of several performance dimensions (equity, effectiveness, safety and efficiency) at international, national, regional, and even provider level.	
European Health Data and Evidence Network	Federated data ecosystem in Europe using OMOP common data model.	(1)
European Health Information Gateway - WHO Europe	The European Health Information Initiative is a WHO network, which develops the European Health Information Gateway, works in six strategic areas, one of which is improving access to and disseminating health information. Other strategic work areas are a) gathering and analysing data that deepen the understanding of health and well-being, with a focus on indicators; b) building capacity; c) strengthening health information networks; d) supporting the development of health information strategies; and e) communication and advocacy.	(1)
JA EHLEIS	2011-2014 Goal: 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. It aims to provide a central facility for the coordinated analysis and synthesis of life and health expectancies to add the quality dimension to the quantity of life lived by the European populations	(2)
Extracorporeal life support association	An international register; developed a specific dataset in order to help NICE in its assessment of ECMO https://www.nice.org.uk/guidance/ipg391/documents/extracorporeal-membrane-oxygenation-for-severe-acute-respiratory-failure-in-adults-overview2	(1)
European Medical Information Framework	Tackle technical challenges when scaling up real-world health data research.	(1)
EPIC CVD	Investigate the interplay of genetic, biochemical and lifestyle factors on the risk of coronary heart disease. Use data from an existing large-scale multi-cohort observational study to compare existing risk scores across diverse European populations and develop new scores.	(2)
EPIS System	The Epidemic Intelligence Information System (EPIS) is a web-based communication platform that allows nominated public health experts to exchange technical information to assess whether current and emerging public health threats have a potential impact in the European Union (EU).	(1)
EUBIROD	European Best Information through Regional Outcomes in Diabetes (2008-2011), implemented European Diabetes Register through the coordination of existing national/regional frameworks and the systematic use of the BIRO technology. Main product: Diabetes Report (each EUBIROD Diabetes Report is entirely comparable across the whole collaboration).	(2)
The European Injury Data Base (IDB)	The IDB is an injury surveillance system containing publicly available, standardised, cross-national information on the external causes of injuries treated in emergency departments (EDs) across Europe. The database 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. It is an invaluable surveillance system, serving as a basis for benchmarking and designing appropriate prevention policies across Europe.	(1)
EUNICE	European Network for Indicators on Cancer 2006-2009, GOAL: 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.	(2)
EUPHORIC	EU Public Health Outcome Research and Indicators Collection (2004-2008) oriented to policy authorities and policy makers and 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.	(2)

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EUPrimeCare	2010-2012, 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.	(2)
EuroCARE	EUROpean Cancer Registry-based study (1978 to 2007) on survival and care of cancer patients 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.	(2)
EUROCAT	EUROCAT is the registry of Congenital Anomalies at JRC ISPRA. 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.	(1)
EUROCISS	European Cardiovascular Indicators Surveillance Set (2000-2007). 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.	(2)
EuroDRG	EuroDRG (Diagnosis-Related Groups in Europe - Towards Efficiency and Quality) analysed the national DRG-based hospital payment systems by using qualitative and quantitative research methods. Beyond the project, the EuroDRG team still collaborates in ongoing research and upcoming publications. In addition to the countries mentioned above, Denmark, Hungary and Italy were analysed within the HealthBASKET project which was the forerunner of the EuroDRG collaboration.	(2)
EurHOBOP	EurHOBOP, the European Hospital Benchmarking by Outcomes in Acute Coronary Syndrome Processes, was a three-year study initiated in 2009 with the aim to provide European hospitals with a validated set of statistical functions - including determinants of in-hospital case fatality outcome indicator - to benchmark themselves about the quality of management of myocardial infarction (MI) or unstable angina (UA) patients and treatments aimed at removing coronary artery occlusion.	(2)
EuroHOPE	European Health Care Outcomes, Performance and Efficiency. EuroHOPE - European Health Care Outcomes, Performance and Efficiency - evaluates 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).	(1)
Euro-Peristat	Better Statistics for Better Health for Mothers and their Newborns in Europe. We use routine data to evaluate maternal and newborn health in Europe. We have just published a report on births in 2015 which is available on our website. We also use these data to produce peer reviewed scientific articles and make our data available to other researchers who also have used it for scientific publications. >60 publication have been based on Euro-Peristat data.	(1)
EuroREACH	Improved access to health care data through cross-country comparisons. Health Data Navigator EuroREACH 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.	(1)
EUROTHINE	Tackling Health Inequalities in Europe (2004-2007) aimed to improve the description of health inequalities in Europe and to enhance the evidence-base for policies to reduce inequalities in health.	(2)
EURO-URHIS 2	European Urban Health Indicators System Part 2 (2006-2008) looking at health issues for people living in urban areas to allow for the better planning of health services and initiatives, goal to develop, test and validate a set of comparable urban health indicators	(2)
EWRS (Early warning and response surveillance)	The Early Warning and Response System of the European Union is a tool with restricted access for monitoring public health threats in the EU. Access and posting are confidential and only accessed by ECDC, the Member States and the Directorate General Health and Food Safety (SANTE).	(1)

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FAMHEALTH	Family life courses, intergenerational exchanges and later life health. The overall aim of this research programme is 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.	(2)
GA2LEN	the Global Allergy and Asthma European Network (2004-2010) most widespread international network in allergy and asthma research. Project meetings still going on.	(2)
HAEMACARE	Cancer Registry Based project on Haematologic Malignancies (2005-2008). Goal was to reach a consensus for classifying the existing morphology codes (of haematological tumours) into disease groups that were as similar as possible to those used in clinical studies, and compatible with WHO classifications.	(2)
HCAI	Antimicrobial resistance and healthcare-associated infections (AMR/HCAI); ECDC.	(1)
HealthBASKET	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.	(2)
I2SARE	Health Inequalities Indicators in the Regions of Europe. Goal: 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. It uses 37 selected indicators covering different aspects of health (mortality, morbidity, socio-economic determinants, health risk factors, health care resources, etc). Health profiles enable both the assessment of population health within an area and comparison with others.	(2)
International Cancer Benchmarking Partnership	ICBP research is trying to unpick the reasons for existing international cancer survival variation. The project has demonstrated differences in survival between countries and has suggested some possible causes of these differences, as well as ruling out some possible causes.	(1)
GBD	The Global Burden of Disease (2007-2010) complete systematic assessment of global data on all diseases and injuries.	(2)
INEQ-CITIES	Socio-economic inequalities in health and mortality in 16 European cities at the beginning of the 21st century. The central aim of INEQ-CITIES was to identify socio-economic inequalities in health and mortality in Europe and to examine urban health policies developed to tackle such inequalities in health. To achieve these aims, a methodological approach was applied to study cross-sectional ecological mortality data from 16 European cities.	(1)
INTEGRIS Integration of European Injury Statistics	The overall goal is to develop and evaluate a data model for the integration of routine and more detailed hospital data on injuries, namely thru linking the official HDR with the EUIDB.	(2)
InterQuality	International Research Project on Financing Quality in Healthcare (2010-2013) established 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.	(2)
MANAGED OUTCOMES	Operations management and demand-based approaches to healthcare outcomes and cost-benefits research (2010-2012) Goal: development and dissemination of theoretically rich but practical conceptual models and a toolkit of the healthcare service production system.	(2)
MasterMind	Summative evaluation of large-scale implementation and upscaling of Internet interventions for common mental disorders in 15 regions in Europe using a standardised evaluation framework based on the MAST model.	(1)
MONICA	Multinational MONItoring of Trends and Determinants in CArdiovascular Disease. 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.	(2)
Multiple Sclerosis Data Alliance	Tackle sociological as well as technical challenges when scaling up real-world health data research in the field of multiple sclerosis.	(1)
Nordic Welfare dataBASE (NOWBASE) - NOMESCO	NOWBASE is tasked with: working to ensure that health and social statistics in the Nordic Countries is comparable between countries; gathering statistics	(1)

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	within this field (health and welfare) and presenting these statistics and making them widely available.	
OECD work on health care quality through the Working party on Health Care Quality and Outcomes.	Collects data from OECD member countries related to quality of health care. Data collection methodologies are aligned as much as possible in order to get internationally comparable data. It compiles and develops country-level statistics on many health care quality and outcomes indicators. Additionally, it compiles statistics on various other dimensions related to Health expenditure and financing, Health Status, Non-Medical Determinants of Health, Health Care Resources, Health Workforce Migration, Health Care Utilisation, Health Care Quality Indicators, Pharmaceutical Market Long-Term Care Resources and Utilisation, and Social Protection.	(1)
Observational Health Data Sciences and Informatics (OHDSI)	This project aims at improving health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care. Promoting observational research to produce a comprehensive understanding of health and disease and configuring and supporting a comprehensive international multipurpose common data model enabling the design and implementation of multinational observational studies based on EHRs and administrative health data at a broader scale; also, by facilitating software tools materialising new methodological approaches on observational research. This project is responsible for the development and support of the OMOP Common Data Model and a multipurpose Common Evidence Model for Health and Healthcare Science.	(1)
ONCOPOOL	Pooling of European Data to Harmonize Translational Research in Breast Cancer (2002-2005) retrospectively compiled database of primary operable invasive breast cancers treated in the 1990s in 10 European breast cancer units. Scarce info.	(2)
PRECeDI	Personalized PREvention of Chronic DIseases consortium. The aim of the PRECeDI consortium is to promote knowledge transfer between academic and non-academic entities that can lead to a proper integration of –omics information into public health interventions. The main goal of this platform is to cover an existing gap in the evidence-base use of the –omics approach in the prevention of chronic diseases, by sharing knowledge, building synergies and expertise and encouraging an exchange of best practice among top level institutions. In the long run, the results of the consortium activities will enhance the scientific basis for an appropriate implementation of the –omics applications into true benefits for population health.	(1)
QUALICOPC	Quality and Costs of Primary Care in Europe (2010-2013) evaluated primary care systems in Europe against criteria of quality, equity and costs, aimed to answer which elements of structure and organization of primary care are associated with access to high quality services against affordable costs and also by what mechanisms primary care structure and organisation are related to overall health care system goals.	(2)
RARECARE	RARECARE, Surveillance of rare cancers in Europe (2007-2010), was intended to help define indicators, collect and analyse data on rare cancers on a sustainable, long-term basis.	(2)
RECAP	Research on Children and Adults Born Preterm. Attempt to combine data from 1) follow-up studies of children and adults born very preterm (<32 weeks) or at very low birth weight (<1500 g); 2) Nordic registry data on studies following up the health and well-being in children and adults born preterm in Nordic populations.	(1)
The Study of Health, Ageing and Retirement in Europe	Both studies gather data about ageing and various socio-demographic, economic and health related variables.	(1)
TESSY	The European Surveillance System (TESSy) is a highly flexible metadata-driven system for collection, validation, cleaning, analysis and dissemination of data. Its key aims are data analysis and production of outputs for public health action. All European Union Member States (28) and EEA countries (3) report their available data on communicable diseases (49) as described in Decision No 2119/98/EC to the system.	(1)

- Source: (1) InfAct T10.1 Survey; (2) Desk research

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