INFACT
Joint Action on Health Information

Deliverable 4.4 : Reports on key holders

Reports Technical Dialogues.
October 2020

Names

Escuela Nacional de Sanidad, Instituto de Salud Carlos III | Avenida Monforte de Lemos 5 |Madrid | España e-mail: InfActSpain@isciii.es|Website: www.inf-act.eu|Twitter: @JA_InfAct

This project is co-funded by the Health Programme of the European Union

Table of Contents

Executive summary 2
Key points 2
I. Introduction 4
II. Aim 4
III. Approach 4
IV. Results 5
A. Minutes of Second Technical Dialogues 5
1. Introduction (Isabel Noguer (IN), WP4, ISCIII, Spain) 5
2. Panel 1: Innovation in health information for public health policy development 5
3. Panel 2: Tools for health information support 11
4. Panel 3: Sustainable capacity building on health information 22
5. Panel 4: Proof of concept of the Distributed Infrastructure on Population Health (DiPOH) 32
V. Implications and limitations 39
VI. Conclusions and recommendations 39
References 40

Executive summary

The aim of the Technical Dialogues (TD) is to achieve technical support from National Technical experts (NTE) on the integration of InfAct outcomes into national/EU Health Information Systems (HIS). Two meetings were held on October 2019 and September 2020

In the first TD, a total of 15 EU/European Economic Area (EEA) countries gave insights including Germany, Italy, France, Netherlands, Belgium, Portugal, Austria, Spain, Norway, Finland, Serbia, Croatia, Malta, Estonia, and Ireland.

In the second TD, a total of 14 EU/EEA countries gave insights including Germany, Italy, France, Netherlands, Belgium, Portugal, Austria, Spain, Norway, Finland, Serbia, Croatia, Estonia, and Ireland.

Key points

The main recommendations of the Technical Dialogues were:

1) There was a consensus about the ***added value*** of the already advanced proposal in terms of promoting Member States (MSs) mutual learning and cooperation. In addition, InfAct outcomes were considered relevant for defining priorities and for decision makers.

2) The integration and access to different data sources, with an adequate level of quality, accuracy and robustness were considered important goals.

3) There was a concern about issues related to the application of measures from the European General Data Protection Regulation (GDPR), that could affect Health Information's interoperability, which must be tackled at national and EU level. Moreover, there are differences in the interpretation and implementation of the GDPR in different countries. To address and overcome these differences, InfAct will provide options to perform data linkage, sharing, management and reporting respecting GDPR regulation. In any case, anonymization of data was considered an important concern, for this reason an EU-consensus guidelines were encouraged.

4) NTE (National Technical Experts) asked for more specific results to properly discuss feasibility, which is a relevant issue regarding different country functional and organisational approaches.

5) With the aim of translating these results into policies, NTE highlighted the need of involvement of national data providers.

6) Regarding capacity building experiences, NTE provided insights in the framework of a stronger MSs involvement and coordination among them in terms of curricula

for public health training within Europe and a flexible approach to integrate new evidence and learning from country experiences.

7) DIPoH was considered a proposal with an important added value. The need of an EU health information infrastructure was highlighted, but its feasibility was a concern due to the financial future sustainability and country political commitment. Although it was detailed that DIPoH will be built on the current financing structures that research networks are already operating. Additional governance and financing options were presented in the ESFRI roadmap.

8) The set-up of National Nodes on Health Information was considered important for the Health Information Infrastructure, and it was considered positive that they were flexible to be adapted to the specificities of each countries. There was agreement on the added value of the national networking, but it was highlighted that the EU institutions should also participate and support it. Moreover, It was also highlighted the need of stronger EU-MSs coordination and collaboration to achieve and sustain main InfAct outcomes, since main steps to move forward to a DIPoH and NN counterparts in some countries are not functionally established.

Reports from the Technical Dialogues

List of contributors:
Teresa Gómez-García, WP4, National School of Public Health, ISCIII, Spain
Isabel Noguer-Zambrano, WP4, National School of Public Health, ISCIII, Spain
Alicia Padrón-Monedero, WP4, National School of Public Health, ISCIII, Spain
Rodrigo Sarmiento-Suárez, WP4, National School of Public Health, ISCIII, Spain

I. Introduction

The Technical Dialogues (TD), formerly called Policy Dialogues with Member States (MSs), were defined to assess how InfAct outcomes could potentially be taken up and translated into national policies and future sustainability. TD are composed by the National Experts and InfAct counterparts.

II. Aim

To achieve technical support from National Experts on the integration of InfAct outcomes into national/EU HIS (Health Information Systems). This aim pointed out at generating awareness and acceptance in decision-makers on innovative actions to improve EU HIS and translating InfAct results into policies.

The TD was a forum to exchange the results of InfAct WPs with national counterparts (technical experts in EU countries), assessing its added value and examining the possibilities on how InfAct outcomes and good practices could be shared, taken up and possibly integrated at the national level.

III. Approach

The first step of the methodological process for the TD included the elaboration and distribution of fact sheets. Fact sheets were provided in two rounds on June 2019 and July 2020 summarising relevant outcomes from WP5, WP6, WP7, WP8, WP9 and WP10.

As a second step, InfAct partners from each country selected a national expert to fulfil the following criteria, according to what has been defined in the guidelines of the national nodes

- Having knowledge and access to a regularly updated national overview of health related data collections and collecting organizations with a general sense of their timelines, national coverage, quality and reporting.
- Being directly or indirectly involved in the national process of using health data analysis and integration for health policy support, i.e. national health reporting and a more general national advisory function on health policy setting.
- Having sufficient knowledge and/or being involved in the national processes, with actors and priority setting in the area of national health data governance, technical infrastructure (TI) development and related data protection.

Finally, two meetings with national experts selected from each country were held to discuss the usefulness, added value and feasibility of translating InfAct outcomes into national and European HIS. The First one was held in Madrid on the 16th of October 2019 (See attached Minutes), with contributions from NTE of 15 EU/EEA countries. The second TD was performed online due to the COVID-19 pandemic on the 28th and 30th of October 2020, with contributions from NTE of 14 EU/EEA countries

IV. Results

A. Minutes of Second Technical Dialogues

1. Introduction (Isabel Noguer (IN), WP4, ISCIII, Spain)

The major expected outcome of InfAct and its TD were introduced and also a reminder of the main conclusions of the first TD. It was highlighted how InfAct is addressing these recommendations and views. Finally it was stressed the need of new feedback from National Technical Experts (NTE) about the new proposals presented in this second TD and their feasibility of being integrated into national HIS, which is the goal of the TDs.

2. Panel 1: Innovation in health information for public health policy development

Fact sheet Innovative use of data sources (Romana Haneef, WP9, Santé Publique France)

The main objectives of this study were: to describe the current use of data linkage at individual level and artificial intelligence (AI) in routine public health activities, to identify the related health indicators and health determinants of non-communicable diseases (NCD) and to know the obstacles to link different data sources.

We performed a survey across European countries to explore the current practices applied by national institutes of public health, health information and statistics for innovative use of data sources (i.e., the use of data linkage and/or AI) [1]. The majority of European countries use data linkage routinely by applying a deterministic method or a combination of two types of linkages (i.e., deterministic & probabilistic) for public health surveillance and research purposes. The use of AI to estimate health indicators is not frequent at national institutes of public health, health information and statistics. The complex data regulation laws, lack of human resources, skills and problems with data governance, were reported by European countries as obstacles to routine data linkage for public health surveillance and research.

To address these obstacles and to increase the uptake of innovative and high-performance technologies in public health activities, we propose the following recommendations:

A. Legal aspects: 1. More flexible data governance frameworks to support data linkage of different data sources should be encouraged [2], 2. Specific mandates to ensure data availability/access/capture and safe storage should be an integral part of a national/regional health information system, and 3. Differences in the implementation and interpretation of the EU-GDPR (General Data Protection Regulations) and additional national regulations should be mapped and if possible harmonized across EU-MSs [3].

B. Technical aspects: 4. More collaborations and partnerships should be encouraged to build up capacities for using new health information related technologies, to share new methods, skills, experiences and data for comparative research studies among EU national institutes of public health, health information and statistics;

C. Data Governance, 5. Initiatives to strengthen national health information infrastructure should be encouraged.

D. Organizational and structural aspects, 6. Ministries of health and research from European countries should provide their support (i.e., financial and political) for the development of integrated national health data hubs/data platforms to strengthen the national health information infrastructure.

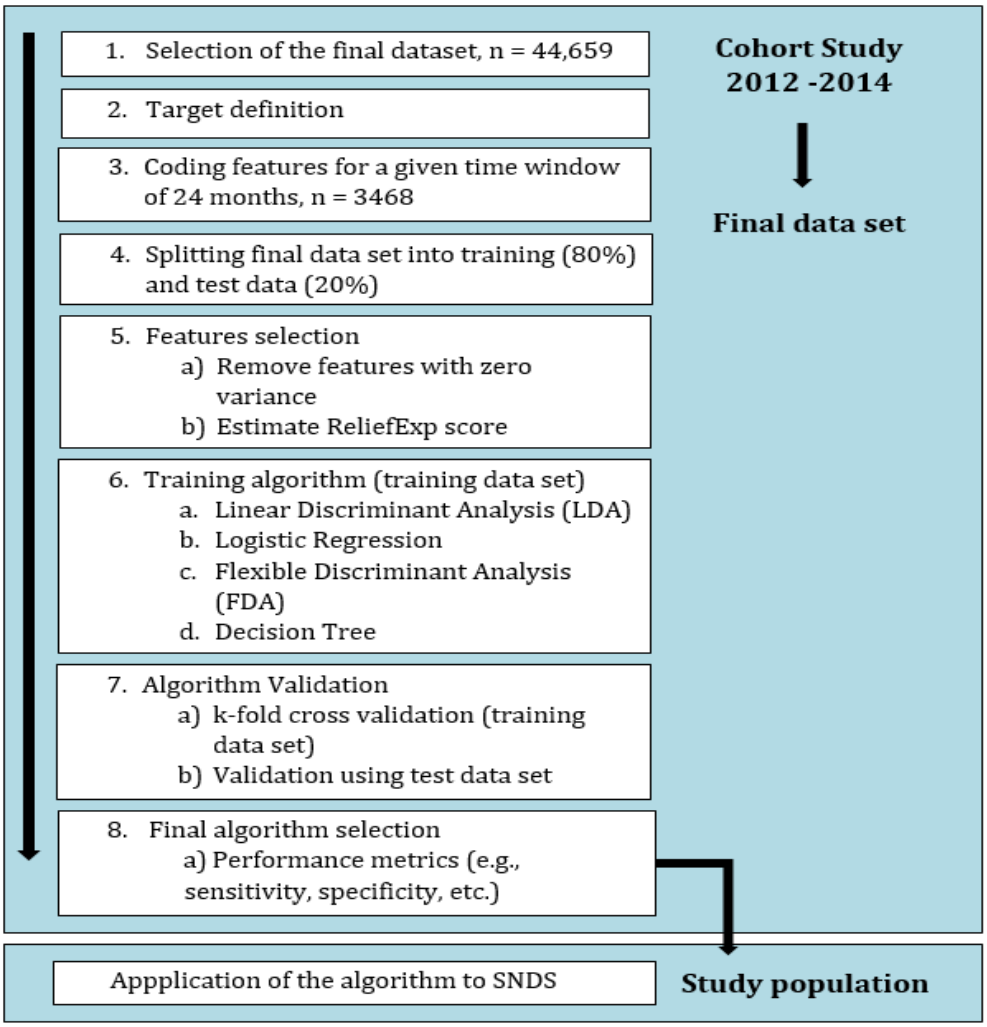
Fact sheet Use of artificial intelligence (AI) for health surveillance (Romana Haneef, WP9, Santé Publique France)

The possibility to link different data sources with each other and the use of artificial intelligence to analyse large datasets are increasing in healthcare. These innovative techniques (i.e., data linkage and/or artificial intelligence) have several advantages such as data linkage improves completeness and comprehensiveness of information to guide health policy process, whereas the artificial intelligence allows handling data with a large number of dimensions (features) and units (feature vectors) more efficiently with high precision. However, administrative linked data can be complex to use and may require advanced expertise and skills in statistical analysis. The capacity to use data linkage and/or the use of artificial intelligence to estimate and predict health indicators varies across EU-MSs. The main objectives of this study were to develop a generic approach to predict a health outcome from linked data set using machine-learning technique and to identify inspiring examples applying these innovative techniques in public health across European countries.

To develop the generic approach, we adopted a supervised machine learning approach [4]. Following steps were performed: i. selection of final data set, ii. case/target definition, iii. coding features/variables for a given window of time, iv. split final data into training and test data sets, v. features/variables selection, vi. training model/algorithm, vii. validation of model/algorithm with test data set and viii. selection of the model/algorithm.

The final data set used to develop the ML-algorithm included 44,659 participants and 3468 variables from the French Administrative Healthcare Database (SNDS) were coded similarly. Only 23 variables were selected to train different algorithms. The final algorithm was Linear Discriminant Analysis (LDA) model based on the number of reimbursements of 23 variables related to biological tests, drugs, medical acts and hospitalization without a procedure over last two years to predict the incidence of diabetes. This algorithm has a sensitivity of 62%, a specificity of 67% and an accuracy of 67% [95% CI: 0.66 – 0.68] (Figure 1).

Figure 1. Supervised Machine Learning for Developing an algorithm



16 studies were identified (12 studies related to data linkage, 2 studies applied machine learning and 2 studies used both data linkage and machine learning approaches) as

inspiring examples from ten European countries. These studies covered 14 different domains of public health. Some of these studies applied classical statistical methods such as multilevel linear regression and some of these studies used artificial intelligence such as machine learning techniques. These studies highlighted that different data collection methods, lacking completeness of information or inaccessibility to certain information were important challenges to analysing large linked datasets. Those case studies would: (i) support countries to share different experiences and to learn from each other, (ii) help countries to develop, adopt and integrate innovative approaches using data linkage and artificial intelligence to estimate health indicators, (iii) allow comparison of various approaches used for innovative use of health information across MSs, and (iv) would support to develop the methodological guidelines, for estimating health indicators using linked data and artificial intelligence. Eventually, the evidence produced by using innovative techniques would guide policymakers to make better decisions.

Fact sheet Methodological guidelines to estimate health indicators using linked data and Machine Learning Techniques (Romana Haneef, WP9, Santé Publique France)

Using data linkage and/or the use of artificial intelligence to estimate and predict health indicators varies across EU-MSs. Moreover, the estimation of health indicators from linked administrative data is challenging due to several reasons such as variability in data sources and data collection methods, availability of a large number of variables, lack of skills and capacity to link and analyse big data. Currently, there are no methodological guidelines available, which could systematically guide MSs for using linked data and machine learning techniques to estimate health indicators. Therefore, the InfAct project has proposed to develop these guidelines, which could guide those MSs who are planning to estimate health indicators using linked data and artificial intelligence with new methods/techniques.

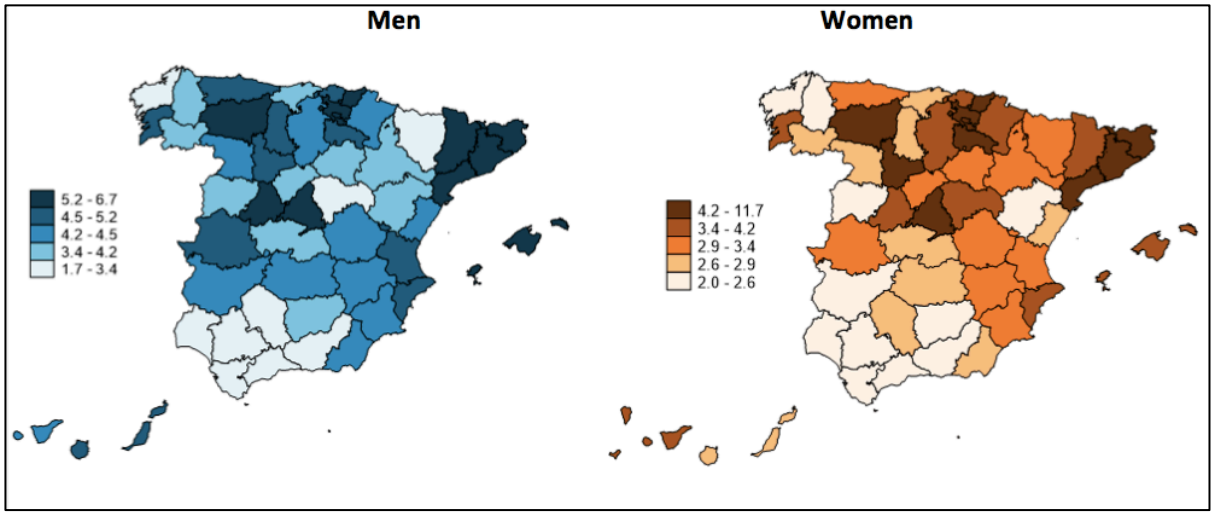
These guidelines contain the following seven important contents: (i) rationale and objective of the study, (ii) rationale for the selection of the study design, (iii) selection of the study population/sample, (iv) linked data sources available, (v) defining the study outcomes, (vi) data preparation and (vii) data analysis. A panel of experts is validating these guidelines, and the scope is to have a systematic approach to perform studies using linked data and ML-techniques for population health research, which should be also flexible to new methods used for research. The main conclusion of these guidelines is the need for high-quality research methods using linked data and ML techniques to develop a cross-disciplinary approach for improving the population health.

Fact sheet Composite health indicators for monitoring NCD: Hospital admissions and mortality ratio (Rodrigo Sarmiento, WP9, ISCIII, Spain)

The analysis of the epidemiological patterns of NCD should include an integrated study of morbidity and mortality, describing their geographic variability and, if detected, examining their causes. This study analyses the ratio of age-adjusted hospital morbidity

and mortality rates (HMR) for the following NCDs in Spain: ischemic heart disease (IHD), cerebrovascular disease (CVD), chronic obstructive pulmonary disease (COPD), and prostate, breast and lung cancer. Demographic and geographical variability was observed for all the diseases studied, in particular for CVD, with higher proportional mortality in the Southern region of the country as it is shown in the figure 2

Figure 2 Geographical distribution of hospital morbidity and mortality ratio (HMR) for cerebrovascular disease by sex, 2016



These results should be further explored with potential associated factors and it should be also analysed the specific case-management approach at the hospital level that could explain the trends observed in the HMR in Spain. The HMR is a tool that uses standardized methods and is based on routine data sources and traditional analytical procedures in public health surveillance systems. This indicator allows for a better understanding of regional variability between and within countries, and can also be useful for health planning and prevention. Composite indicators such as HMR are valuable tools to monitor burden of chronic diseases and health system performance, which is especially important in reducing the impact of COVID-19 pandemics on vulnerable populations.

Panel 1 Discussions (Moderated by Alicia Padrón, WP4, ISCIII, Spain)

AP introduced the discussions and most relevant suggestions and comments were:

IJB: Congratulated the speakers and recommend to publish all results, since it makes them more accessible to national correspondent and public health community. The first one was already published and the composite indicators final results are still pending of more in-depth analysis before being published.

IJB: Provided some comments regarding how to improve figures of the composite indicators. Those comments have been incorporated to the last version.

Luis Lapao (LL): Mentioned that they started working with AI, with Portuguese data and were worried about the amount of data found. He wondered how to manage to perform all the analyses with such a big amount of data.

RH: We used a cohort study to develop this algorithm. When validated and assessed that the performance was adequate in the cohort study then it could be applied it in the National Health database. In the National Health database you have the estimation of any health indicator on real time but whatever algorithm you have developed must be validated first. For that reason we used this cohort study, that was developed with data collected from 2012 to 2014. After all the exclusion criteria we used a sample of 44.000 to develop the algorithm for this study. It is expected that in 2 weeks we may have a draft manuscript, which is more detailed and it would be easier to understand. This generic study was a good experience for us to develop the guidelines we have been working on.

AP: Regarding the linking of data sources and its main obstacles, your survey is very clarifying for us all. It is interesting to see that for the different countries that participated in the survey there are different interpretations of the same GDPR. This is a very interesting information about a way of going forward for the countries that may have more strict regulations by assessing the national guidelines of other countries that adapt GDRP in a different manner. This could be interesting for us all. Could you add more information about this issue?

RH: There was some discussion about the implementation of GDPR is different in different countries, and of course it was perceived differently, which makes very difficult be able of linking new data sources. Thus, it is a very important point and I think some upcoming initiatives highlighted that issue, like TEDHAS and other Joint Actions. They have planned a study on the differences of GDPR' implementation in different countries and how they can be addressed. Essentially, this variability was the major problem mentioned by different country representatives.

LL: When you presented your definition of innovation, you only mentioned the AI. I would like to bring up for instance data mining. Why you just reduced the innovation only to AI?

RH: Actually, in our definition we should use data linkage and/or AI, because in some countries only data linkage is innovative, in others AI is innovative and several countries use both concepts, it depends on the country. Therefore it was not easy to define innovation taking into account all the European countries and their HIS. We agree on the fact that data mining could be innovating for some countries.

Luigi Palmieri (LP): I am coming back to data mining and AI. In my opinion data mining is to discover or to find the sources of information in an innovative way. Despite that the work presented focused on interoperability, the use of data sources to find indicators and to find an innovative way, need to think beforehand in data mining as a previous step to find out the use of different sources of information. I think it also involves innovative technology and innovative methodology but the work of interoperability is a second step after you find out all the sources of information.

IV: I have a comment also about GDPR and I think it is also good to have guidelines or methodologies to recommend the MSs how to create methods for anonymization that can link all this process, because we have in our HIS individuals already identified. For example, in Portugal we have the National Health Number, for each person, and it is applied in hospital dataset, primary care dataset, etc. So when we talk about the integration of different databases, the first problem that we have is to create anonymization of this numbers but at the same time to create a link that can make the linkage between them. We are not able to do anonymization at individual databases, we need to have a key to integrate all the data. It is important to work more on this process, because investigators reassure that it is difficult to have integrated data, due to the fact that sometimes the anonymization does not allow to make a posterior linkage of data. As an example; we perform the anonymization of the drug datasets and the anonymization of the datasets for healthcare, but we are not able to integrate them. Creating some guidelines would help in the process to reduce these limitations.

RH: About Luigi's comment, I agree with Luigi on the importance of data mining. Beforehand you supervise your algorithm and you see what are the most important and useful variables you will use to predict or estimate your outcome, I think this is the data mining approach. Basically, making it more efficient and quick.

3. Panel 2: Tools for health information support

Fact sheet: Health data collection methods and procedures (Luigi Palmieri, WP8, ISS, Italy)

To reduce gaps and inequalities of health information across MSs, T8.1 aims at:

i) Identifying European projects/studies providing Health Monitoring and Health System Performance Assessment data

ii) Summarizing existing knowledge and definitions of health data, indicators, standardised data collection methods, availability and accessibility procedures covering different health data sources across EU/EEA MSs

iii) Developing a report on health information collection methods, quality assessment, accessibility and availability procedures in and across MSs.

The main activities conducted in the framework of T8.1 included: (i) In a first phase, the implementation of a scoping review of international organizations and selected EU research networks to identify HI data and metadata characteristics, and (ii) In the second phase, the development of a questionnaire based on five main topics: *source of information*, *methodology*, *quality*, *data availability*, and *data accessibility, which was* administered to all representatives of the InfAct partner countries (28 MSs and 4 associated countries).

The survey collected information on data related to 91 projects/studies from 18 EU countries, and the most important results were: a) only 1/3 of the projects share data

with EU research networks, b) less than half of the projects follow meta-data reporting standards for data description, c) less than 1/3 of the projects evaluate all quality criteria defined by Eurostat and ECHO, and d) microdata are never accessible in open access and macrodata are accessible in 1/3 of the projects. ***Basically, these results demonstrate that evidence produced by research is not always available, comparable or usable for research purposes and policy-making***. The survey has generated knowledge on standardised health data collection methods and procedures for health monitoring and health system performance assessment in the EU and also provided information on accessibility and availability of health data across EU countries. The research output will contribute to the development and the sustainability of a research infrastructure by providing information on standardized data collection methods and procedures and facilitating sharing and comparability of health data across EU countries.

Fact sheet: Guidance for health reports (Martin Thissen, WP8, Robert Koch Institute, Germany)

Health reporting should provide up-to-date data and information on the population‘s health status and its determinants, as well as on healthcare services in the countries (or regions). Establishing a discussion base for health policy is a key objective of health reporting (‘data for action’).

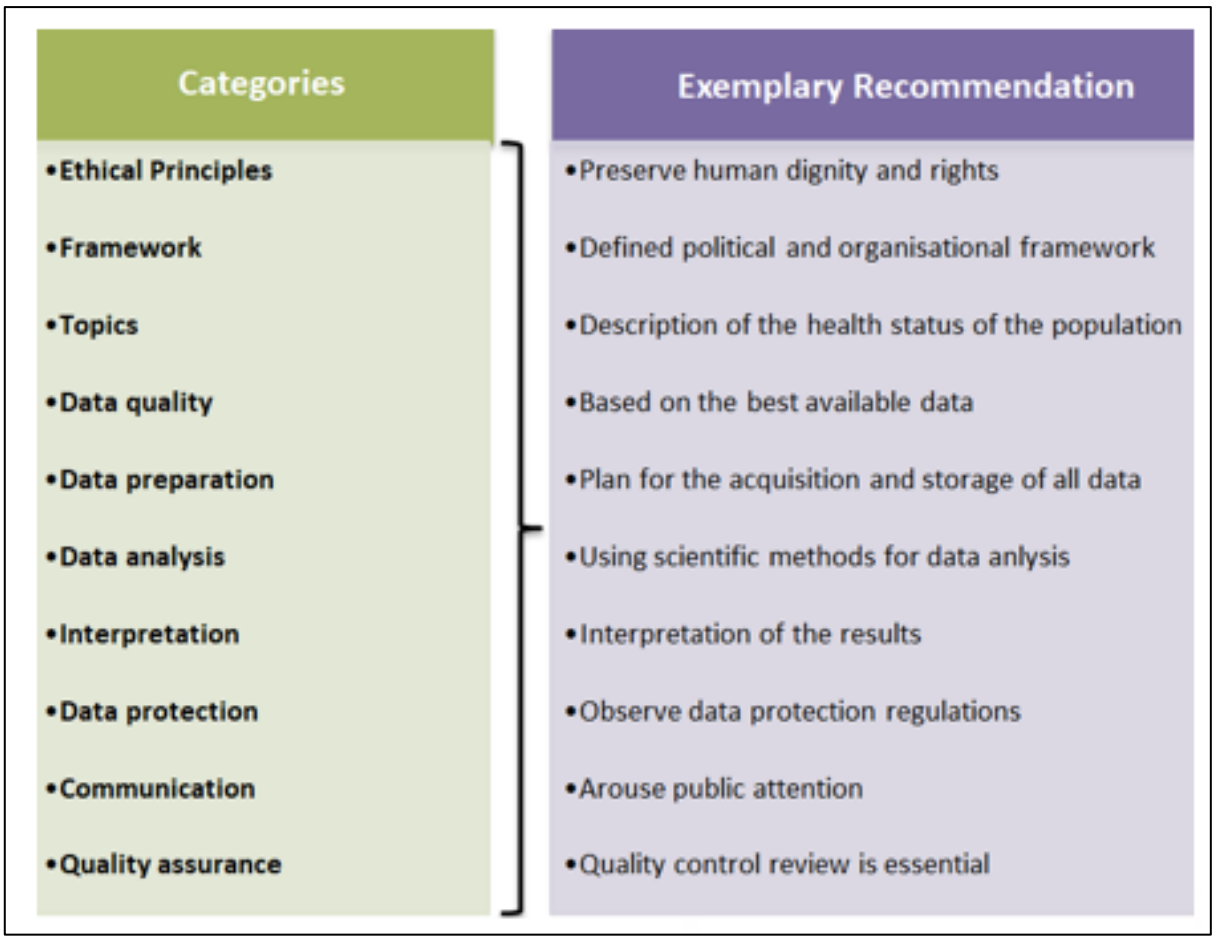
A web-based desk research was conducted among InfAct countries to generate a comprehensive overview of different national health reporting formats and their respective target groups. A guidance document for MSs and regions for health reports was drafted to facilitate making health information adequately available while reducing inequalities in health reporting across the EU.

The key messages from the web based desk research were:

- *Health reporting practices and quality in EU MSs are heterogeneous*
- *‘Health reporting’ is not a commonly used terminology in all analysed countries*
- *Public health reports are the most frequently used health reporting format*
- *The general public and scientists or researchers are the most frequently stated target groups of health reporting formats.*
- *Health reporting formats should be tailored to the needs and competencies of the target groups.*

A total of 8 categories for health reports with a variety of quality criteria were identified: scientific standards, report framework, presentation of results, subject of the report, database, data evaluation, interpretation and recommendations and prospective approach. The report provides general recommendations for national health reporting, making it a useful tool for other health report formats as well

Figure 3 Example Guidance for health reports



The guidance document strengthens HIS sustainability because

- Aims to facilitate the generation of standardised and comparable health reports across the EU.
- Will be presented at relevant conferences and a scientific paper will be published to spread the findings.
- Should be circulated at national level and disseminated to the national nodes to reach relevant stakeholders.
- Could contribute to capacity building if included in training programmes.
- It is applicable at national as well as international level and could be integrated into EU HIS to enhance sustainability.

Fact sheet: A sustainable ECHI shortlist (Mariken Tijhuis, WP8, RIVM, Netherlands)

The European Core Health Indicators (ECHI) shortlist provides a 'snapshot' of European public health and care. It is the result of consecutive EU-wide projects starting in 1998, representing a collective MS effort and was first implemented in 2012. It currently contains 88 indicators. DG Sante maintains a webpage and an interactive tool, which is filled by Eurostat. Using ECHI to internationally compare public health aspects adds value to the national HIS. Despite the recognition of its importance by health information experts at the EU and national level, there are no formal updating procedures nor is there a formal and sustainable form of governance. Therefore, InfAct aims to provide suggestions and recommendations that may benefit and improve the future of the ECHI shortlist.

InfAct identified 4 focus areas to provide practical suggestions (messages):

1. **Technical updates of the metadata (documentation sheets)**

InfAct reviewed all the ECHI documentation sheets, summarized the findings into draft recommendations and asked a group of experts to review them.

Message: *the documentation sheets need to be reviewed regularly (e.g. every 3 years) and disseminated in an easily accessible way.*

2. **Modernising the content and/or structure of the list**

InfAct collected ideas for new indicators in the shortlist, developed the idea to change the structure of the shortlist and included a flexible subset to accommodate emerging information needs.

Message: *Content and suitability of the list needs to be reviewed regularly (e.g. every 3 years)*

3. **Improving the visibility**

InfAct prepared an ECHI information repository as a source of structured ECHI collective memory and input for the web portal under the RI (temporarily to be found via ECHI.eu under a website maintained by RIVM). InfAct prepared a communication plan to increase ECHI visibility. This includes infographics, an example of which can be found on the ECHI information repository.

Message: *ECHI visibility and communication plan will help MSs/AC and EU get more out of ECHI and stimulate performing international comparisons.*

4. **Procedures and governance**

InfAct drafted update procedures based on criteria that were developed by the previous ECHI projects. It also prepared a draft governance structure, with roles and responsibilities for both EU structures and MS. InfAct organised a meeting with DG Sante and ESTAT to discuss progress and possibilities to increase sustainability.

Message: *"Adoption" of the ECHI by EC and MSs/AC would benefit their health information systems.*

In order to be a useful indicator set at the heart of European HIS, ECHI needs to be embedded in a sustainable infrastructure, robust, stable and visible, and yet flexible to current developments. I would like to have your suggestions in the following aspects of ECHI shortlist

- How to continue with updated documentation sheets, how to disseminate them?
- Do we need a new more flexible format? For example:
    - A stable overview of European Public Health (n=~70 indicators)
    - A flexible subset addressing urgent information needs (n=~10 indicators)
- Which new topics should be included in the ECHI (stable/emerging)? Which topics can go out?
- Who should ideally be responsible for the ECHI? (Role for EC, MS, DIPoH?)

Fact sheet: Interoperability (Jakov Vukovic, WP10, CIPH, Croatia)

The aims of WP10 in interoperability are:

- 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
- 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

Semi-structured in-depth interviews were conducted with key opinion leaders from different European cross-border projects that dealt with sharing, linking and managing health data with the goal of better understanding the enablers and the barriers to the cross-border linkage and sharing of health data through four interoperability layers (legal, organisational, semantic and technical). Transcripts of the semi-structured interviews were analysed qualitatively by framework analysis.

Achieving interoperability with health data is a long process with many obstacles. Most key opinion leaders emphasize legal and semantic interoperability layer as a main barrier, while technical interoperability is no longer seen as a barrier unless practicing physicians and patients are involved. Other barriers emphasized by key opinion leaders were lack of funding, differences in health data in countries with decentralized governments and different interpretations of the GDPR that varied between countries, between different regions of a country and between different institutions. Other enablers, which were emphasized by key opinion leaders, were univocal health data in countries with centralized governments, pre-existing legislation for a specific topic in certain countries and continuation to a work done by pre-existing project.

Piloting the development of a distributed infrastructure where the pillar of the European Interoperability Framework (EIF) and the FAIR principles and assessing the feasibility of complying with GDPR and Ethical principles, adapting to the organizational specificities of each data hub, assuring semantic interoperability across hubs and developing technological interoperability. Three case studies (Monitoring resilience, Costs of dementia, Stroke care pathway) were piloted as to capture different requirements in the development of a distributed infrastructure on population health research where any study design could be conducted.

Table 1: Inspirational case studies for piloting interoperability

Case study	Aim	Data sources	CDM (Main entities)	Software distribution	Hubs
Monitoring resilience	Elaboration of a population health indicator	Insurance data PC HER Prescriptions Hospital stays	Individuals Insurees Residences	Data model specification (v1.0)	Wales NHS (UK) Aragon (ES)
Costs of dementia	Identification of 1-year follow up contacts and associated costs	Insurance data PC HER Prescriptions Hospital stays ER data RHB contacts Billing data	Individual patient Care provider Time stamps	Data model specification (v0.1)	Aragon (ES) France (FR)
Stroke care pathway	Discovery of the actual care pathway for acute stroke	Insurance data	Individual patient	Complete solution Docker with	Aragon (ES) Marche (IT) Norway

	patients	ER data Hospital data	Care provider Contacts Time stamps Events	open source Log builder and process mining analysis (1.10)	(NO) HU Zagreb (HR) Latvia (LV)

Results from assessing and piloting interoperability would serve as a basis for publishing recommendations that are derived from key opinion leaders from different European cross-border projects dealing with sharing, linking and managing health data. It would also enable better optimization and utilization of health information systems across Europe and would facilitate the development of health information and research infrastructure based on cumulative experiences and know-hows from key opinion leaders.

Panel 1 Discussions (Moderated by Rodrigo Sarmiento, WP4, ISCIII, Spain)

RH: I have a question for Luigi Palmieri. It is very important the process of data collection. Did you see different variability in the data collection systems in different countries? Do you propose some recommendations to harmonise the data collection methods? Can you comment on that? It is a key point when linking different data sources.

LP: No, by the moment we provide the picture of the situation just to stress that there are a lot of differences, a lot of barriers to data sharing and integrating health information. Obviously the recommendations should be technical The first step it is to have a picture and to show that there is a need to have systems that deal with this technical issues and give specific recommendations for sharing specific data.

IJB: I have a question for Martin of the Robert Koch, you mentioned cross-border linkage and data sharing, I think what you mean is cross-border data sharing because most citizens of one country will have their data inside the country so you only need to do that link within the country

MTh: Yes, I agree with you, I was not explained that part clearly

IJB: What also strikes me of all the presentations is that there is no mention of the possibilities of using anonymous data or synthetized data that has been modified from the original data base, which is something that might be worth looking into. In Statistics Norway they have macrodata available for researchers, but they are no longer related to single individuals. So, this is a question to all presenters, have you ever thought harmonising individual data to synthetic data as a proxy to original individual data?

IV: I am going to pick up the question that I made in the first session, I was expecting to hear something about this here, but I agree that it was not mentioned the anonymization of data and I think there is a very important topic in a way to improve the exchange inside countries and also at European level. I know that in Portugal there is a repository of clinical information and it is already anonymized, and it is useful for researchers so this allows to do the research and investigation in health. My question is do you have some recommendations to improve more this work?

RH: I agree with Inger and Isaura on this important point, there are different ways to anonymize data. In our Project we did not focused on that but there are independent projects, which work on that issue. I think that it is important that we recommend guidelines on anonymising data for research that would be useful for future research.

LL: I also agree with Romana. We have developed an information system for primary care and at the beginning we decided to have both, we have the database of the system and we have an anonymised database for research. We have to guarantee the quality of data and at the same time to have anonymised data for research I agree that this question should be included in the recommendations.

LP: I agree with Luis and Romana for the comments.. Obviously anonymising data, macrodata is important but I think metadata description, catalogues for metadata and description for richer domains of data, should be the first step to know how to produce the data and how to organise it in order to be shared with all other countries. I think one of the roles of a centralised HIS should be to give the main rules on how to provide data in order to be easier to share with other countries, even though there are lot of issues that must be solved deriving from the use of these data for all countries.

Hanna Tolonen (HT): I agree with Luigi that the first step is to get metadata information published from the data available in the country, because this is the key way to access to the data. For the anonymisation we have to remember that purely anonymised data means we do not have a key to the identifiers anywhere. You want to keep your identifiers somewhere for future use. So, as long as identifiers are somewhere we are talking about de-anonymised data and GDPR is in place Thus, making distinctions between anonymised and de-anonymised data is very important for future recommendations as well

IV: I agree with the last intervention because as it is important to have the data and to link with different kind of databases, for example is you have anonymised primary healthcare then we need to make some connection with secondary care, for instance acute myocardial infarction you can create studies with the treatment and then with the items in the hospital system and if these information is anonymised and separated it is impossible to do the study. I agree then that it is different anonymisation and de-anonymisation, when there is a link where we can find information related to that patient. On the other hand I like all the interventions and in the overall I think all these work, all these fact sheets might improve the quality of reports and the way a report is developed in order to get better information for decision makers. I think it is an added value all the work that you have been done and that it was presented here today so I think you should

continue your work to have recommendations and disseminate it to researchers of several institutes, universities, etc

Ivan Pristas (IP): I have a brief comment to the discussion, thanks you to all the presenters for their great presentations and I am looking forward to the results of the project. Obviously, legal and organisational dimensions of interoperability, although very often neglected seem to be taking a more important role in data linkage and joint information management, specifically not only because of the data protection but because of new technology arrivals. More and more artificial technology will be deployed in order to produce health information and in order to be able to explain all the black boxes that are going to be produced, so we'll have to be more involved in not completely anonymised data, either for cross-border sharing or for EU level data linkage purposes. Hopefully tackle the barriers of legal interoperability that are approaching will be supported by our Joint Action recommendations as well.

LL: A short question to Mariken, how can we be sure that our recommendations about ECHI will be successful because we need to -, make sure that Europe addresses and picks ECHI in a serious way. What are your big recommendations in order to do this

MT: I think we need to work together with the European Commission. That is why we try to build a relationship with them and they actually put an effort to look at our recommendations for the ECHI metadata. Now we need to find a way to develop a governance. For me the key is setting up the procedure, to make sure that it will be clear who does what, and hopefully the European Commission would have some money to support that. It is really a lot of work to keep the list updated both in terms of metadata and in term of policy-relevant contents

LL: In order to have a European health information we need ECHI and it is a fundamental pillar for HIS European strategy, why the European Commission is not so much on it?MT: I think that is a really complicated question that we have to discuss with the Commission, I think that there a very dedicated people at DG Sante and EuroPeristat, but there are other indicator sets such as Chid health that can be comparable. Actually some of the colleagues from this group made a comparison between the 2 lists. We will include it in the report as well

RS: Would anyone like to comment on Mariken suggestions? (i) how to continue with updated doc sheets, how to disseminate them?, (ii) does it need a flexible format?, (iii) which new topics should be in the ECHI, and (iv) who should be responsible for the ECHI?

RH: In question ii) when you talk about a flexible format can you give an example?

MT: ECHI list needs to be more focused on the time we are living in, sometimes we need health information and sometimes, for example during COVID-19 crisis there was a need of comparable information of ICU beds or excess mortality, so ECHI could be also a platform where we could come together, that would be a different way of approaching things, not the stable monitoring point of view so that is why we split up in an A (stable overview of European Public Health with 70 indicators) and a B (a flexible subset addressing urgent

health information needs with 10 indicators). This is just an idea to get the ECHI more modern.

RH: Yes, I agree it should be more flexible. The information needs might change in 2 months and I think is important to comply with changes over time.

IN: Regarding ECHI, what do you think about having a more close involvement of the national public health institutions, that are the one's that currently provide health data and health information. I think a closer involvement should be better to perform and to better distribute information among decision makers for these ECHI indicators.

MT: I agree, in the governance structure that we have been trying to develop we also would like to involve more on one hand the national statistical offices and the working group of the public health statistics, and on the other hand the national nodes on health information.

AP: It is a great proposal and I agree that having less indicators for special situations and sudden changes on population health status is important. For example mental health problems are fast evolving during this crisis of COVID-19. They require quick evidence based political decisions and a flexible ECHI format could help with that. What are the indicators that you want to include for these situations?

MT: One of them could be excess mortality and actually the question is open, do you have suggestions? I think mental health could comply with our requirements in this case and we are still collecting ideas

RS: Any of the national experts have comments on the feasibility to integrate this outcomes into national health information systems? Your opinion is very valuable for us

IN: NTE opinion is very important since you will provide advice to InfAct partners and to the high level representatives of the Assembly of Members

IJB: I think there are other systems like the BoD and in Norway we have indicators that each municipality can look into in their own data and statistics provided by the national health institute. If there are only slight differences between the ECHI set and the indicators already provided by our public health institute it might be easier to compare and integrate. I think it is better to assess the current systems before introducing a new one.

IN: The BoD is an important group of indicators, Romana would you like to comment something on that?

RH: Most of the European countries were not estimating their own BoD indicators so one initiative was to raise awareness among European countries about being able to estimate their own indicators. In this context we organised two workshops last year, one was about the concept of BoD and the second workshop was about their implication, of indicators, on health policy. So we worked on that and I think it was a very good response from European countries, they were motivated to initiate their BoD at national level and to integrate BoD indicators into national HIS. This is an ongoing initiative for all the countries. In October

20 and 21 there is another workshop where 4 countries that are estimating their own BoD studies will share their experiences (Scotland, Germany, Netherlands, Belgium). All the countries are also on board on the European Burden of Disease Network COST action and in France we also initiated this project, at first with the support of IHME but in the future we would like to have the estimation of our own indicators at subnational level.

RS: Thanks for the comment, in fact we distributed the fact sheet on BoD but did not include it in the agenda as we discussed last time in the First Technical Dialogues.

RH: Regarding the fact sheet, we asked countries to compare IHME results with their results from the National Health Statistics and to identify the main differences. Most of the countries were unable to comment on that because they are not applying BoD methodology. This work is on validation and is one of the deliverables form WP9 we have to provide an overview on BoD estimates for European countries and based on this we will write some recommendations if any country wants to do their own BoD study, so what would be the steps in terms of strategy, methodology and so on. These recommendations will be shared in October's workshop.

HT: Linking metadata information is important and it is also important what kind of metadata countries already have available and published and incorporate it in the European catalogue of the metadata of the data. For the indicator set is also important to compare how these indicators overlap with other international indicator sets and national indicator sets as well. In Finland there are more than 1000 indicators calculated regularly and adding 100 more can pass the limit countries are willing to do. And also for the indicators if we can demonstrate that they can be used for benchmarking at European level that Commission is using them, we will support the countries to understand why they need to calculate those ECHI indicators as well.

IN: I found interoperability very important and regarding the situation we are living with COVID-19 and the GDPR problem with contact tracing and the new technologies that are coming really fast, how to tackle this issue? The new technologies can provide new tools to help to address this issue?

JV: The new technologies could help to deal with GDPR there are some approaches in that sense. In the interviews some advances through smart phones applications ask the patients if they authorise the use of such data, so it is possible to approach this problem in some way.

IJB: GDPR is not a problem but a reality that we have to deal with, no one wants to be in a situation on which all data is shared, we want to preserve privacy. Son in our work environment we have relate to GDPR and it's meant to protect. Of course we want to do good research and we want to cooperate within countries, but still we have to relate to data protection as an important issue.

IP: In a way I agree with Inger, in traditional health data collection systems, data ownership it's not within institutions just holding the data. GDPR is protecting, WHO issued a statement regarding COVID-19 where there is not any epidemiological excuse for geolocations of persons. The ideas is to track persons but with fairly acceptable use of the

data, considering data protection, to trace patients without geolocations and that's why it is really important to have legal and organisational interoperability in mind with regards to GDPR

RS: Thanks all of you for the interesting discussion, many of this issues I guess will be raised again in the following panels when we discuss the proof of concept for a sustainable structure and also capacity building.

4. Panel 3: Sustainable capacity building on health information

AP: Welcome again to this 2nd session of the Technical Dialogues. We are grateful with your participation as EU national experts. This TD will provide us your feedback about the feasibility and added value of infAct outcomes.

Fact sheet Prioritising health information at national level (Anselm Hornbacher, WP5, Robert Koch Institute, Germany)

The aim was to ensure that health information at European and national levels supports public health policy action (agenda-keeping) and points to emerging public health issues (agenda-setting). How health information for national health reporting is prioritized in EU-MS and associated countries? Is prioritization guided by:

- Pre-defined criteria?
- National and international frameworks or health targets?
- Stakeholder recommendations?
- Any other factors?

Can "good-practice"-approaches to prioritizing health information be identified?

We employed an online two-round Policy Delphi survey which was distributed to EU and associated countries' representatives – mainly public health and health information experts – participating in the Joint Action InfAct.

The results of a literature review formed the basis of the Delphi survey. The 1st round contained mainly open-ended questions and was used to generate qualitative information on national health information prioritisation strategies. Full-text responses from the 1st round were developed into closed questions for the 2nd round, focusing on prioritisation approaches, criteria and stakeholder involvement. Participants were asked to rank these questions according to the degree of "desirability", "feasibility", "importance" and "confidence", based on their expert opinion.

A total of 119 experts in 33 countries were contacted; we received 19 fully and 11 partially completed questionnaires for the 1st round of the Delphi survey. Experts from 13 countries agreed to be invited to the 2nd round; of these, six completed the 2nd survey. At the time of this writing, the analysis of both rounds is being finalised. From the results, a guidance document will be drafted for presentation to the InfAct partners with a view to adopting a consented final version.

Preliminary results have shown that: (i) A Pan-European framework for the prioritisation of health information is missing, (ii) formal, horizontal and centralised approach is the more desirable and considered to be more feasible, (iii) mixed stakeholders meetings for criteria development to identify barriers is desirable.

The expected outcome of the Delphi survey is a list of good-practice-approaches to health information development and guidance for prioritisation at national level. The document will include criteria, methods and structured prioritisation processes as well as stakeholder involvement. We also aim to draw insights into the inclusion of good-practice-approaches in the prioritisation of health information in the respective countries, as well as analyse the connection between health information and health targets, both national and international. Guidance for prioritisation of health information for national health reporting enhances comparability of health information systems across the EU and associated countries. The guidance could be further developed into a health information prioritisation strategy at the European level for establishment of an EU-HIS.

Fact sheet Contributions for a Health Information Training Program (Luis Lapao, WP6, IHMT, Portugal)

To cope with the challenges associated with strengthening Health Information capacity, health professionals require health information capabilities complying with their tasks. Nowadays, it widely recognized that most health and management functions require specific health information skills (or eSkills).

Given that the European Health Information panorama is mainly a challenge of heterogeneous capacity rather than of lack or low capacity, the definition of a strategic plan for health information aimed to respond to the need of reducing inequities across all MSs and include all relevant stakeholders and resources.

It was considered necessary to have a sustainable capacity building programme in health information that focused on the following areas: data analysis and interpretation, especially interoperability of data sources, derivation of European Core Health Indicators (ECHI) indicators and foresight/scenario analysis; transfer from data to policy, especially policy translation tools and data presentation; data collection methods, sources of data, metrics and indicators, especially issues related to health examination surveys; and data privacy and ethical issues, especially how to deal with requirements of EU General Data Protection Regulation (GDPR).

We started with a survey to look for health information inequalities and we identified the needs in terms of availability of health information training, country participation in capacity building activities and priority themes for a Capacity Building Training Program.

The aims of the Capacity Building program are European centred approach, choice of contents, practical case-based approach and pedagogic approach, benefits of the contributions from InfAct work and health information glossary. The main objective is to increase knowledge on availability and use of standardised health information methods and common practices within MSs. The modules of the training course will include: data collection sources, methods and indicators, data analysis and interpretation, transfer from data to policy and data privacy and ethical issues. A pilot course on Health Information starting in October will be used as a tool for piloting our Capacity Building Training Program. The target audience will be professionals working on health information related context, with 2-3 years of experience in public health services. The face to face component consists on 40 hours with theoretical approach and 40 hours of autonomous work.

Our recommendations for sustainability of the European Health Information Training Program (EHITP) are:

1- EHITP should be a flexible structure of courses and other capacity building activities, modules and training plans, covering all the areas related to HI and easily tailored to tackle the different specificities.

2- Under the EHITP, MSs and European Institutions should develop initiatives according to specific needs, then contributing to a European perspective of HI.

3- Modules provided by different organizations (ECDC, EMCDDA, IARC, Eurostat, OECD, WHO, etc) should be considered on the training initiatives, as well as already available academic and non-academic structures specialized on training on Health Information

4- The programme must be tested through a pilot course and the evaluation of this initiative should contribute to the consolidation of a roadmap for capacity building in HI

5- More research is needed on HIS topics and their relationship with public health activities, as well as on the training of professionals for their use

Fact sheet Health Information Training Course and Roadmap for sustainability (Luis Lapao, WP6, IHMT, Portugal)

For the pilot course we received 51 applications (21 countries, 20 from Europe and 1 from Brazil) and we selected 25 participants (from 20 countries) based on curriculum, letter of application and geographic origin.

The course consists of a week of both face-to-face and virtual sessions. These include theoretical and practical classes, group work among trainees and discussion of practical cases and projects on HIS in which trainees and trainers are involved.

Each day will be dedicated to a HIS specific topic:

- Day 1: Health information Data collection, sources, metrics and indicators:
- Day 2: Health Data analysis and interpretation:
- Day 3: Transfer from health data to policy and clinical practice:
- Day 4: Interoperability and record linkage
- Day 5: Data protection (DGPR) and ethical questions for HI

Every participant will do the quality assessment of the course after each session.

The results of the pilot course will help InfAct to define the roadmap for a capacity building program.

The activities developed at WP6 enable to reach the following issues on sustainability of HI in Europe:

1- CONCEPTS: Efforts should be made to clarify concepts regarding the professions around public health activities.

2- RESEARCH: More research is needed on HIS topics and their relationship with public health activities, as well as on the training of professionals.

3- CAPACITY BUILDING: A sustainable capacity building programme in HI should be stablished, aiming to increase knowledge on availability and use of standardized Health Information methods and common practices within MSs.

4- EUROPEAN STRATEGY: EHITP should be a flexible structure of courses and other capacity building activities, modules and training plans, covering all the areas related to Health Information easily tailored to tackle the different needs. Under the EHITP, MSs and European Institutions should develop initiatives, according to specific needs and, at the same time, that contribute to a European perspective of HI.

5- EUROPEAN FLAGSHIP TRAINING: In this flagship programme, the following thematic areas should be considered as priorities: data analysis and interpretation, interoperability of data sources, European Core Health Indicators (ECHI) indicators and foresight/scenario analysis; transfer from data to policy,; data collection methods, sources of data, metrics and indicators, especially issues related to health examination surveys; and data privacy and ethical issues, especially how to deal with the requirements of GDPR.

6- COLLABORATION: Collaboration among European MS and Institutions is critical for the sustainability. Training modules provided by different organizations (ECDC, EMCDDA, IARC, Eurostat, OECD, WHO, etc) should be considered on the training initiatives, as well as academic and non-academic structures specialized in training on Health Information.

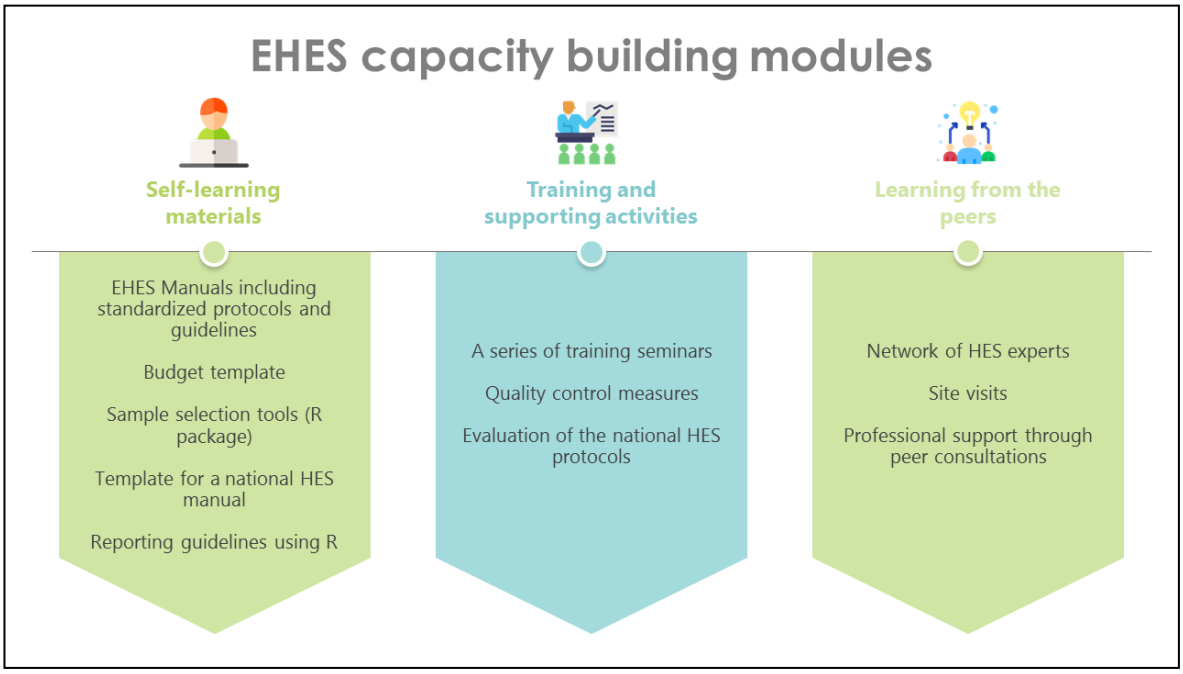
7- LEARNING: Including a cycle of learning. Guidelines and recommendations are produced and contribute to an improved version of the capacity building programme. The evaluation of this initiative will contribute to the consolidation of a roadmap for capacity building in health information.

Fact sheet Capacity building under European Health Examination Survey (EHES) (Hanna Tolonen, WP6, THL, Finland)

EHES is a collaboration between organizers of national health examination surveys in Europe (HES). EHES support capacity building in the EU MSs and aims to ensure high quality and comparability of the surveys. All members are represented in the network.

EHES capacity building activities are targeted mainly for national survey organizers following the idea 'train the trainers' and peer-support. The EHES capacity building activities can be classified in three categories: 1) material for self-learning, 2) training and supporting activities and 3) learn from your peers and are shown in detail in the figure

Figure 4. Capacity building under the EHES



For cross-country comparisons, knowledge to use standardized protocols is essential. Currently, EHES network is exists but without sustainable funding. Therefore many capacity building activities have been run down or are functioning based on good will of the network members. To revive these activities, a small sustainable funding for the coordination activities would be needed.

Panel 3 Discussions (Moderated by Alicia Padrón, WP4, ISCIII, Spain)

AP: We open now the discussion panel. Please let us know the question and to whom it is addressed

Alan Cahill (AC): I just have a question for Hanna, and I am curious about how can HES can operate or continue to work at all through the COVID-19

HT: Thanks Alan, that is really an important question. I know that in many countries the HESs, which actually requires many physical contact with people, have been on hold due to the COVID-19 crisis, since we do not have the people to come into the examination clinics and we cannot do it at home visits. I think that Germany is one of the countries that is planning to get started whenthe situation gets better. In Finland we are in the same situation, we planned our next survey for 2020 but we will have to postpone it if needed because of COVID-19.

Stefanie Seeling (SS): From Germany we were hoping to start in March 2020 and we had to stop it even though there were some appointments made with participants and now there is no new date for restarting. It seems to be wise to wait a little longer before start planning again.

RH: I have a question for Luis. You will also focus on data analysisWwhich specific contents you have included?

LL: We have a comprehensive program, the program is online. As far as I remember there is a session on new innovative indicators and other one on trends and projections on health and health determinants, but you can check it at the website

Herman Van Oyen (HVO): This is the pilot course which focused on one particular topic. If you think in the term of the coming into 5 to 10 years then you will have also other topics and more technical and methodological issues that can also be tackled.

LL: To answer the question of Romana, in data analysis and interpretation we have a session on comparability of different data sources and another session on new innovative data sources

Rana Charafeddine (RCh): I have also a question, now this course is online, it would be online later on or it is just for COVID-19 situation?

LL: What we agree is that we are going to record the sessions and they will be available for the InfAct community

RCh: In the future there will be no course to be given as live sessions?

LL: One of the tasks is to evaluate the course and to develop the roadmap for sustainability. We will learn from this new experience, but we are already thinking about a new version of the course for next year because we have a big demand

IJB: I think that 50 participants is quite small. Norway has done courses of several hundreds of participants. I think, and I also noticed that there are no applicants from the Nordic countries so I would like to know how the information about the course was distributed

LL: There were applicants form Finland, actually, and also from Lithuania and Latvia. Anyway, the issue of COVID-19 did not allow to communicate the course information earlier. With the time we had, 51 applicants is amazing and we expect to have more next time.

IJB: How did you distribute the information about the course?

LL: The information was distributed mainly through the InfAct network, ASPHER and other social networks.

IJB: If you had contact with the epidemiology societies like the Norwegian Society for Epidemiology they could have made it through their website, and maybe they are similar networks in every country,. Thus, I think if you had distributed the information in another way you would have had a lot more applicants. Clearly it was not the main goal because you have only 20 spots but I still think that perhaps you should consider another way of making courses like this available to a lot more people, because it is less costly. My suggestion is to have online courses, face to face course and a combination of face-to-face and online courses.

LL: Thank you Inger and I think one of our weakness of the course was the promotion of the training but due to COVID-19 we had to overcome the delays. Also, we would have liked to have it face to face but we had to shift to online mode

IJB: Of course, this discussion we are having right now is better face to face but we had to do it online because of COVID-19, but we also get to know each other. Online courses are online networks and I think it will be more important in the future, and also after the COVID-19 situation

RCh: How do you evaluate the course?

LL: We evaluate it in different ways, we evaluate the sessions, by the lecturers and the participants. In addition, the participants must write down an essay or report about the training and we have a group within our team that is independent and is reviewing all the process, the design, the organisation, etc. We will also have an external evaluation. These are the different tools that we have to evaluate the course

IJB: Will you issue a certificate for the course?

LL: We are going to issue a certificate that will detail the number of hours, etc

IJB: Perhaps you should consider some kind of follow-up after a time period. Maybe after half a year or more then you can contact the participants again and ask them about it

LL: Thanks for your suggestion, I think this feedback is very important, I remember doing it also for a similar course that I gave 10 years ago.

SS: I would like to quickly explain for Germany that we have 10 applicants from our institute in Berlin, butonly one colleague should apply. Thus, we decided to not distribute the information any further. Although I think next year or the next training program the information will be disseminated further and there will be more applicants. I have also a question, now the course is free of charge, do you plan to do it like that in the future and how it will be funded?

LL: I am making some calculation on the costs and it will be considered in the roadmap for sustainability, to decide how to proceed in the future.

IN: I have a comment for the fact sheet on prioritisation of HI from the Robert Koch Institute colleague, about prioritise data providers in HIS, which is essential for public health action, and how feasible do you see a new exercise to go forward to learn about priority setting, for example in this current pandemic experience we are dealing with.

AH: I think with digital possibilities this is quite possible and also it I very important for the current necessity. Under the current situation HI will be prioritised toward the need of public health, which is based on COVID-19 so the resources are indeed focused on questions about infectious epidemiology and also the HI is centered at this problem. Every country is dealing with COVID-19 in its own way, has its own responsibilities on the health of the population. Wheather it is feasible, it is a difficult question, but we would be

needed prioritisation more than ever because if we could combine and prioritise across MSs we could actually gain more insight into this disease.

SS: maybe I can add, setting up structures to prioritising HI is something that really would need some time. It is good to have the results of our survey at hand so we could use to structuring how we prioritise HI, so maybe in the future when there is a second pandemic we will already have a system to work with.

IV: I have a question for Robert Koch Institute also. The Delphi study is very useful to deal with HI, and my question is: you have a low response rate in the second round, because in the first round you have 19 and the second round you have 6 responses so what are the representativeness of these results? Is there a problem for the final report?

AH: Yes, the decline in the response from the first to second round was very drastic. Although those results do not necessarily have to be representative, because the Delphi methodology is a way to open new questions. In this case the Delphi policy is not defined to find solutions but to extract questions which could lead to later solutions. We are happy with the results. Of course bigger response means more inputs, not only in terms of representability, still we can use those results for the design of upcoming surveys in order to extract ways to deal with that. So the tool, the policy Delphi does not necessarily have to be representative

SS: And once the analysis is finalised the plan is to discuss the results with the InfAct partners. We were thinking about a slot in the next Steering Committee but as the next one is next year, we will probably set up a meeting with experts and discuss our findings to search for recommendations to be approved for InfAct partners

RCh: I have a question about sustainability, for the priority setting exercise and also for the course, priority changes over time and also the contents of the course have to be updated over time, so are these factors included in the fact sheet that it is not just to be done at one point in time but will be updated over time.

SS: For the priority setting strategies, next step is the list of good practice approaches and recommendations and the idea is to work with those outcomes on a national and EU level so once you work with those results you are going to set up your prioritisation strategie. It is an procedure that does not need to be updated per se, only the content will need updating. At the moment there is no plan to repeat the Delphi process but to have insights that can be translated into policy and practice.

RCh: What I meant was not the Delphi but the prioritising exercise, which should be done on a regular basis

SS: Yes, it would be up to the countries on how to proceed. What we can offer is a list of different approaches and a ranking by experts what is desirable, and if there is something highly desirable you have to look at the feasibility It is good to have a system for prioritisation, because just a few countries have a good systematic approach to it.

AP: I would like to invite the NE to give some advice on the feasibility and added value of the fact sheets and the presentations that have been presented today

IJB: I think itis really important the work that have been done. There have been many practical issues and important topics to discuss between countries and when it comes to creating courses, is important to check if there are similar courses given elsewhere. At Norwegian universities they offer also a training course that it's organised to the Nordic research network, they're looking for participants from different countries. Have you had any interaction with other courses that have been established?

LL: The first task of the WP was to develop a mapping exercise to identify available courses across Europe. This was done in 2019, so probably in between new courses have been created. The availability of courses is unequally distributed in Europe so offering this course is a way to tackle these inequalities. If you could send us some information, I would appreciate

IJB: I have just send the link of the Nordic course to the chat (https://hrr.w.uib.no/register-based-epidemiology/)

IV: I think the work is very important, and it is important to have a better use of HI in Europe but the work is not yet finished so for me. I think there is an added value in better understanding health information. Now is difficult to talk about feasibility until we have the results, because we do not have the results of Delphi and the training course so we cannot assess the possibilities to integrate them into the national HIS.

RCh: I also have a comment on feasibility, the course has high feasibility value because the resource is here, and it can be used by all countries so there is no problem with that. For the priority setting exercise I think it is very important to have these criteria further developed but in terms of feasibility, of course you know there is a very big leap between having these criteria and approach and being used in a country. You need to have a system that is acceptable on that, you need to have the willingness to work with this exercise, so there is a lot of resources. There is a big step from having this resources available and being used in a country. So I cannot really say how feasible it is and how applicable can be in Belgium or in other country.

SS: The idea was to generate knowledge and to offer countries to make use of it. But at the end it is the decision of the country

RCh: I agree, the resource is here but the willingness to do is unknown and it will depend on each country

AP: Yes, that is the reason of having 2 discussion boards: one at technical level, which are this Technical Dialogues with NE and one at political level, which is the Assembly of Members with representatives of Ministries of health and Research. We would provide your technical insights and recommendations for the next Assembly of Members that will take place on October the 27th.

IN: I agree that there is a long way into having things available and use them in a given country. I think with this pandemic national experts have been highlighted by providing information and expertise to the decision makers. Maybe this pandemic is a platform to

develop innovative ways to tackle help problem by reinforcing the role of TE, what do you think about

RCh: I agree, you are right, we are much more visible now and we can use this to be more proactive in things that you want to implement. But there is a system that needs to be available and now everything is focused on the COVID-19, we need to be able to transpose this to other things as well

AP: I will make a summary of the session, a Pan European health information system prioritisation is missing and the RKI has develop some guidelines and recommendations to the countries that will depend on the willingness at the national level.

A flagship training program has raised a lot of interest, with its modules of data collection, data analysis and interpretation, transfer of data into policy, interoperability and GDPR. It was mentioned that online course will be very important in the future and the next iterations of this course should be more widely disseminated.

Finally, it was highlighted the importance of HES, which are not being carried out at the moment due to COVID-19 but everybody agrees in their importance.

5. Panel 4: Proof of concept of the Distributed Infrastructure on Population Health (DiPOH)

Booklet Distributed Infrastructure on Population Health (DIPoH) (Herman Van Oyen, InfAct Coordination, Sciensano, Belgium)

The Distributed Infrastructure on Population Health (DIPoH) connect networks and stakeholders to enable top level research, to identify sources, access sources, assess quality of source and reuse aimed at policy change, practice change and technology change, whose ultimate goal is to improve health and other outcomes.

3 most important **DOMAINS** to understand population health and health systems: What are the drivers of the dynamics of health of populations, what makes one population healthier than others and what is the impact of health systems in this.

Health systems comprises close to 10% of GDP in most countries and in some countries even more. Better understanding as to what comprises a health system, its goals, and the underlying structure and factors that drive its performance in relation to health outcomes is therefore essential.

This infrastructure is unique Covers the population as a whole (healthy and non healthy), because (i) focus on non communicable chronic diseases, (ii) comprehensive view on health data: population health (administrative data, vital statistics, health surveys, longitudinal studies) and health care (e-health records, hospitalisations), (iii) facilitates secondary use of routine data sources, (iv) Includes individual and aggregated level data,

(v) does not include experimental research, and (vi) boost national population health research.

DIPoH objectives include:

- Support the development of large-scale, integrated and sustainable data services for population health and health services research
- Catalogue information and knowledge generated by a critical and growing mass of European researchers and their international networks
- Strengthen the synergy in the EU by facilitating comparative research, efforts at data linkage, pan-European (re)use of data, methods, results and better involvement of national experts

At the end the goal is to ensure that research is findable, accessible, interoperable and reusable and create ever-stronger research networks.

DIPoH structure is constituted by

- **National Nodes** (NN) units within MSs representing national network,
- **Research Networks** (RN) and their research communities,
- A **Central office and** governance structure,
- A **Health Information (HI) portal** as gateway to data, services and tools on population health

Regarding DIPoH services, 4 main services are provided in a stepwise approach, which can be seen in the figure 5.

Figure 5. DiPoH services.

Our proposal for DIPoH through the European Strategy Forum on Research Infrastructures (ESFRI) Roadmap application was submitted in September 2020. Some Ministries of Health and Science, organisations and networks expressed their interest in joining the development of DIPoH (12 Memorandum of Understandings, 10 letters of political support, 3 expressions of financial commitment and 8 letters of intent).

Fact sheet Connecting health information system's stakeholders through national nodes (Petronille Bogaert, InfAct Coordination/WP7, Sciensano, Belgium)

In many EU MSs and associated countries, health information activities are scattered over several institutes. Regular coordination and communication among these institutes is often missing. This leads to duplication of activities, limited interoperability and linkage of data between institutes, inhibited exchange of data and lost opportunities for research or policy support.

The aim of the National Nodes (NN) is to bring together the regional/national health information stakeholders to: share expertise on regional/national level, share ongoing activities on regional/national level, update on initiatives, meetings and expert groups at EU level, provide overview of national data sources through web based platform, and provide coordinated overview of national and international health information related initiatives and activities.

InfAct reaches out to all InfAct partner countries to support them in the process of the development of the national node. To do this, InfAct initiated a national node survey to investigate the current status regarding any meetings that brought together health information stakeholders or partners at a national/regional level. More specifically, the survey collected information on how these meetings are organised, which national

stakeholders are included, and what topics are discussed in these meetings in case such a meeting had already taken place. Based on the collected experiences, InfAct developed a stepwise approach to set up a national node. The stepwise approach provides European countries with guidelines on how to set up, define, and organise a national node. Being aware that responsibilities, organisations and procedures are different in each country, the stepwise approach provided room for adjustments based on the specific situation within each country taking flexibility into account.

InfAct keeps a record on the current status of the national node in the partner countries. Countries have presented their national nodes during the General Assembly meetings and subsequent national node meetings. Opportunities for best practice exchanges and support have been organised through these regular meetings. 19 countries have provided regular updates to InfAct on their national node: 12 countries have a national node based on an existing group and 7 countries initiated first meetings in the framework of InfAct. Various stakeholders of national health information systems have shown enthusiasm in this endeavour.

Example of NN: case study Finland.

Key stakeholders for health information: Finnish Institute for Health and Welfare (THL), Statistics Finland, National Social Security Institution (KELA), Researcher groups in different Universities.

No formal National Node but several joint activities of key stakeholders

- TULANET: A ***collaboration forum*** of governmental research organizations
- ***Meetings*** with the heads of THL, Statistics Finland and KELA in routine meetings related to use of data for both statistical and research purposes
- New ***legislation*** 'the Act on Secondary Use of Health and Social Data (552/2019)' will further facilitate information exchange

FinData will be operational in 2020 and will ensure a one-stop shop for the secondary use of social and health data. FinData grants data permits when data are requested from multiple registers and provides the data in a secure IT-environment for data users. The goals are: (i) enable effective and safe processing and access to data, (ii) enhance data protection and security, (iii) eliminate administrative burden and (iv) improve register data quality. There are two types of uses of health and social data, the primary use for patients and also the national registers and the secondary use for scientific research, statistics, innovation, teaching and knowledge-based management, among others. There are many different data sources that are incorporated in Findata as disease registers (THL), prescriptions (KELA), causes of death (Finland Statistics), population data (Population Register Center), occupational illness (Finish Institute of Occupational Health) and benefits and incomes (Finish Centre for Pensions).

How to access data sets? For individual data the direct identifying data will be removed and for statistical data it will be granted free use for the purposes specified in the Act. The secondary use of data will benefit the entire population as it is intended for public health purposes.

Summarising, at national level DIPoH will pool existing resources, enhance and support secondary use of existing resources and reinforce knowledge based to achieve better population health across the EU.

Panel 4 Discussion (Moderated by Rodrigo Sarmiento, WP4, ISCIII, Spain)

RCh: Regarding NN, do you mean every country will decide NN's structure and activity to be developed?

PB: The NN functionally is more or less the same within countries. I propose different stakeholders, for example the Ministry of Health, the public health institute, the statistical office, they are brought together to discuss issues that are happening at national level, so I provided the example of "Findata" because there is a room for development of this health data, so what happened at these meetings is that they are now organising more frequent meetings and more actors were asked to be involved into the process of developing the health data hub.

HT: In Finland the process is a bit different because we have the legal basis for the secondary use of the data, which automatically frames the different actors to find the common ways to do things, there is close cooperation of the people working on health data. We have still challenges for the organisation but now is established and functioning

IN: We would like to know your views about the DIPoH, which is one of the main results of this JA so I invite the National experts to give their views about this big proposal

IV: I try to answer the question, I think this DIPoH infrastructure on population health has an important added valuable and it is an important initiative, but for me it is not quite clear who is going to manage this infrastructure (InfAct or an independent management organisation). Other concern is the financial aspect of this project because as I saw in the presentation it is a one stop shop to facilitate exchange and access to the data, so how it will be funded? I see there is a proposal to fund it through ESFRI. Those are my main concern. But I considered that DIPoH is a proposal with an important added valuable and we all need this EU Health Information Infrastructure.

HVO: Our proposal is for the next coming 10 years and as we saw in the example shown by Findata and as far as I understood that they have a budget of 10 to 20 million euros, so it is never the purpose of the infrastructure to take over but is to build on other initiatives that other people have been doing either at national or using the work that is being doing by other research infrastructures. DIPoH will be built on the current financing structures that research networks are already using and will be focused on research that has to be done. So we have foreseen a budget of 5 million euros for all the different phases. One of

the advantages is that there is work already developed within InfAct, as working with different research infrastructures within the European health data platform, so it is time to build further on and develop our services.

IV: And how is going to be managed this infrastructure?

PB: InfAct finishes at the end of May so in the near future we will continue with InfAct through the NN and as we mentioned we applied for the ESFRI application and the countries that actually signed, which means in the near future when we have the evaluation from the Commission and DIPoH gets in the roadmap, it will have finances to continue their activities on building an infrastructure for population health. As Herman explained we have an specific use case on COVID-19 through new funding, when we already kick-start the Research Infrastructure, which we called PHIRI and this will start the 1st of November and we will build these catalogues with the perspective of COVID 19, where countries will be reached out too and we provided finances to the countries to be able to do that and to fill in the catalogues and to describe what kind of resources are available at the country with regards to COVID-19 databases, public databases. We will also catalogue capacity building exercises our colleagues from Portugal will be looking the different training that are available for COVID-19, so the activities will continue there. In addition, we will continue building on the NN, for country-specific support of the MSs. So as you can see PHIRI will pick up all of the things we' are doing within InfAct and will be further developed.

PB: I actually have a question for the participants, I was keen on knowing, for the people that are not involved in the project, have you heard about InfAct, about a NN being set up in your country? Have you heard about a meeting carried out with different stakeholders being carried out in your country? Or if you haven't heard about, do you think it is good to organise a meeting with this NN?

IV: Speaking to myself, I have heard about this node in Portugal. I am not sure if my institution is participating in this NN. I have information of a group working on COVID-19 but not about NN associated with InfAct project

OJB: In Norway, the platform for health analysis is under establishment and now there are some estimates right now from couples of months ago. Applicants that need data, they send their application through this central agency and to the individual registries and I think is something that is going to be similar to FinData. This system is established so you can say that is the NN in a given country but it is not necessary, since we already have this platform where all researcher apply for all needed data at the same time.

PB: Every country is different, so is up to the country to see whether they like to set up this NN, so is up to you to evaluate if it can be placed there. But in many countries there are a lot of different players that interact with the health data hub it is a good idea to place this NN.

Mika Gissler (MG): Most likely the Finnish NN will not be Findata but Findata will be assisting well, it is very helpful because there will be international data users, we have

FIndata but most likely the legislation is quite strict so no new tasks can be allocated to them so the Finnish NN will have a role to fulfil.

IJB: How do you proceed to establish a NN?

HVO: That is something that needs to be considered in each country because each country has different researchers, it depends on how they interact with their Ministries, some countries are centralised and other de-centralised, etc. It is very important that a research network take the initiative to set up the NN in the country, that is why we asked the InfAct partners to take the initiative. One important aspect is that in InfAct we developed a peer reviewed evaluation of the health systems adapting to WHO tool for health system assessment and, and the countries that intervened in the assessment were matched with other 2 countries it gave them the opportunity to learn from each other and it helped InfAct to give some recommendations on good practices about what has been done in the countries.
So, there are several ways to set up the NN, depending on the structure and other aspects related to any specific country, but InfAct has made a Report with recommendations that should be adapted to the specifics of the country.

PB: To add to this comment, the HI portal is being constructed right now and when it is operational in 2 months we reach out the NN to ask them to actually share their information on different data sources that are available in the country and in PHIRI we will strengthen that and we will reach out to all of these NN again to organise these meetings but also to describe the NN in more detail, stating who will be the contact point in the country so it will facilitate the information exchange between and within countries.

Giovanni Nicoletti (GN): Congratulations to the colleagues for the huge qualified work done here, now we actually see a very comprehensive and well-designed model for future steps of the HI Infrastructure DIPoH. My only concern is that I do not see too much European institutions for the future with us, I hope this is just a temporary situation and we will see someone from either DG Research or DG Sante or any European Commission units, because I think that all the work that has been produced in InfAct is working quite well within the network of researchers, but I do not see any real EU-institution frame on this.
We are starting to build this at national level and I think that this is a very important point and we are creating an excellent networking relationship among public health organisations at the national and European level, but we have not been successful it is to find this architecture frame at the institutional European level. I think that with the impact of COVID-19 it is more than necessary to do it, because we observed some problems in the ability to react from the European institutions in the last months, so a lot of improvement is needed on the issue of the data on communicable and non-communicable diseases. I think is key for the future. We only see the MSs and the researchers working together but I do not see too much Europe in this initiative. I think that this group should to continue to work cooperating in this line. This my overall personal perspective, this is the only weak point on the project as 90% of the objectives have been achieved. I think it is not our fault, only partially, but it is an aspect that we

need to overcome in the future. Thank you for the excellent work and it was more that we expected.

PB: COVID-19 has shown that when stakes are high and challenges are big everyone has to focus more on national perspective, but at the same time by exchanging between countries we managed to learn from each other. At the beginning we were not planning to do anything on COVID-19 but our partners reached out telling us that we need to interact more between countries because there are some questions that cannot be answered by international organisations. And then we strengthened exchange and we saw the added value of having a quick response to the questions from other countries. We hope that with PHIRI we will be trying to regain the attention of the European institutions to go forward with our project, for example we have discussions with the ECDC for a specific use case to coupling health data that will be producing and cataloguing through this infrastructure with ECDC surveillance data. We are getting also support from DG RTD and our policy officer is raising awareness of the work we are doing with DIPoH. COVID-19 showed that HI is a really hot topic so it's an opportunity we have to seize and have an infrastructure on health information in place that helps us to improve the data collection and analysis during upcoming crisis but also at regular basis.

V. Implications and limitations

Main Implications of this second TD are the need of integrating views, and recommendations from all participating national technical experts. They are considered the link with health and research authorities in order to achieve approval, acceptance and practical integration in national health policies and future reforms of the organisational and functional framework of the HIS and research access to national and EU-data.
The format of TD, as platform for discussing InfAct outcomes with national experts gather the same limitations of a Delphi consultation. Most participation and involvement from countries would have been welcome, to enrich discussions and providing new views, but in terms of objective-achievement an extended participation is not necessary in this kind of expert meetings.
We are satisfied by the contributions from the participating experts and these conclusions and views will be driving next InfAct steps.

VI. Conclusions and recommendations

Several issues were raised on the adaptability and transferability of the proposals into national and European health information systems.

1) There was a consensus about the ***added value*** of the already advanced proposal in terms of promoting Member States (MSs) mutual learning and cooperation. In addition, InfAct outcomes were considered relevant for defining priorities and for decision makers.

2) The integration and access to different data sources, with an adequate level of quality, accuracy and robustness were considered important goals.

3) There was a concern about issues related to the application of measures from the European General Data Protection Regulation (GDPR) that could affect interoperability for public health policies, which must be tackled at national and EU level. Moreover, there are differences in the interpretation and implementation of the GDPR in different countries. To address and overcome these differences, WP10 provided options to perform data linkage, sharing, management and reporting respecting GDPR regulation. In any case, anonymization of data was considered an important concern, for this reason an EU-consensus guidelines were encouraged.

4) NTE (National Technical Experts) asked for more specific results to properly discuss feasibility, which is a relevant issue regarding different country functional and organisational approaches.

5) With the aim of translating these results into policies, NTE highlighted the need of involvement of national data providers.

6) Regarding capacity building experiences, NTE provide insights in the framework of a stronger MSs involvement and coordination among them in terms of curricula for public health training within Europe and a flexible approach to integrate new evidence and learning from country experiences.

7) DIPoH was considered a proposal with an important added value. The need of an EU health information infrastructure was highlighted, but its feasibility was a concern due to the financial future sustainability and country political commitment. Although it was detailed that DIPoH will be built on the current financing structures that research networks are already using. Additional governance and financing options were presented in the ESFRI roadmap.

8) The set-up of National Nodes on Health Information was considered important for the Health Information Infrastructure, and it was considered positive that they were flexible to be adapted to the specificities of each countries. There was agreement on the added value of the national networking, but it was highlighted that the EU institutions should also participate and support it. Moreover, It was also highlighted the need of stronger EU-MSs coordination and collaboration to achieve and sustain main InfAct outcomes, since main steps to move forward to a DIPoH and NN counterparts in some countries are not functionally established.

References

[1] Haneef R, Delnord M, Vernay M, et al. Innovative use of data sources: a cross-sectional study of data linkage and artificial intelligence practices across European countries. *Archives of Public Health*. 2020;78(1):55.

[2] Data Protection and Artificial Intelligence: https://edps.europa.eu/data-protection/our-work/subjects/artificial-intelligence_en, accesed September 2020

[3] EPRS. How the General Data Protection Regulation changes the rules for scientific research: https://www.europarl.europa.eu/RegData/etudes/STUD/2019/634447/EPRS_STU(2019)634447_EN.pdf., 2019, accesed September 2020.

[4] Haneef R., et al. "Use of artificial intelligence for public health surveillance: a case study to develop a machine-learning algorithm to predict the incidence of Diabetes Mellitus", (manuscript under peer review)

Escuela Nacional de Sanidad, Instituto de Salud Carlos III| Avenida Monforte de Lemos No. 5 | Madrid | España| e-mail: InfActSpain@isciii.es| Website: www.inf-act.eu |Twitter: @JA_InfAct