INFACT
Joint Action on Health Information

Deliverable 4.4 : Reports on key holders and relevant EU partners meetings

Report of the Technical Dialogues.

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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/m 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) The Distributed Infrastructure on Population Health (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, the need for stronger EU-MSs coordination and collaboration was also highlighted 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

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I. Introduction

The Technical Dialogues (TD), formerly called Policy Dialogues with 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 (NE) and InfAct counterparts.

II. Aim

To achieve technical support from National Experts on the integration of InfAct outcomes into national/EU Health Information Systems (HIS). This aim pointed out at generating awareness and acceptance in decision-makers on innovative actions to improve EU health information systems 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 (FS). FS were provided in two rounds in June 2019 and July 2020 summarising relevant outcomes from WP5, WP6, WP7, WP8, WP9 and WP10. Later, 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 (NN):

- 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 health information systems.

IV. Results

A. Minutes of the First Technical Dialogues

The First Technical Dialogues were held in Madrid on the 16 of October of 2019, with contributions from national experts of 15 EU/EEA countries

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

Brief overview of InfAct project. Main goals and work packages description. Aim and objectives of Technical Dialogues: the TD are focused on the translation of InfAct outcomes, international EU policies and future sustainability. TD are composed by NE nominated by the countries collaborating in the Joint Action (JA) and InfAct counterparts. NE should assess the added value, the feasibility and support to translate InfAct results into practice: translation into national health systems and EU health systems to perform a better EU health *Information for Action*.

2. Panel 1: Innovation for Health Information and Interoperability for Public Health Policies

Fact sheet (FS) Burden of Disease (Romana Haneef, WP9, Santé Publique France

Burden of disease (BoD) is a "*systematic, scientific* effort to quantify the *comparative* magnitude of *health loss* due to diseases, injuries, and risk factors by age, sex, and geographies for specific points in time"

- Why BoD initiative was taken? Its main goal is to establish a sustainable health information system, which helps to improve the public health policy and healthcare. This project highlights or emphasizes the potential role of BoD measures, which could provide some actionable health information to improve the population health across the MSs.

Two workshops with 40 participants from 25 MSs and 16 experts were held in Paris (Workshop 1 Concept and methodologies of BoD across MSs and workshop 2 Use of BoD estimates in public health policy and practice)

- What are the main results?
    - ✓ the need for methodological trainings to strengthen skills in calculating and in interpreting the BoD estimates across the MSs.
    - ✓ the encouragement of more collaborations across MSs to share or exchange good practices on BoD.
    - ✓ the importance of the implications of BoD data to guide health policies across MSs.

What is next?

There are 2 initiatives to provide guidance, technical support and recommendations to MSs for BoD

- ✓ BoD Steering group within InfAct: whose aims are to develop BoD expertise and capability, to undertake national BoD studies and to promote Europe wide BoD analysis and to explore how the BoD approach can be integrated into a sustainable EU-HIS.
- ✓ COST Action- European Burden of Disease Network: provides networking opportunities for researchers and innovators in order to strengthen Europe's capacity to address scientific, technological and societal challenges (27 MSs for four years).

A third workshop will take place in Paris with the following objectives

- ✓ To interpret BoD estimates in comparison to the Global Burden of Disease (GBD) that develops the Institute of Health Metrics and Evaluation (IHME)/University of Washington), and to highlight the differences by taking into account various factors (technical, public health changes, etc.)
- ✓ To comment on country health profiles from 28 MSs developed using GBD metrics in the background document (BoD report) by participating MSs.
- ✓ To develop a rational/best approach to conduct a BoD study in a given MSs as an InfAct BoD Toolkit.

Comments and questions

Inger J Bakken (IJB) from Norway: Norway provides annual data to the GBD initiative from the IHME/University of Washington, is this initiative of BoD related to GBD?

RH: Not really, because the idea is that MSs should build their national BoD study. Of course, we are giving the option that either they can follow the methodology which has been developed as an standard of the IHME or they can follow the methodology of BoD which is adopted by 4 EU-MS.

Isaura Vieira (IV) from Portugal: Portugal is not included there. We use a little information from BoD to decide about the financing of drugs, because we use health technology assessment methods to decide on the financial of drugs. There are some developments on BoD in the universities but not in the national health systems, so is something to work on.

RH: I think the idea described in InfAct or in the WP9 is how to integrate these BoD approaches in the routine public health activities and not only with research purposes.

Thomas Ziese (TZ) from Germany: I personally attended the workshop on BoD and it is an excellent example of a European experience exchange for starting networks that also involve international stakeholders like IHME. It is a good example on how a health information system could work.

Fact sheet Use of non-health databases for health surveillance (Pablo Fernández-Navarro, WP9, ISCIII, Spain)

In the WP9, Innovation in health information for public health policy development, our aim is to strengthen the efficiency of the HI system for public health policy and research through new ways of using health and non-health data sources, and composite health indicators.

One of the lines of innovation comes from the combination of health information with environmental health determinants for surveillance, epidemiological monitoring and for risk studies in health. The integration is a challenge because the heterogeneity in the availability and formats of data, requires specific expertise and the statistical models and data management are complex.

An easy-to-use java/web interactive application tool ("En-risk" app) was created for this integration. "En-risk" merges environmental and health data for a quick preliminary screening of the association between environment and health. In the case-study, for environmental data En-risk" uses a database for EU countries European Pollutant Release and Transfer Register (E-PRTR), which is free and available in the web and contains the annual list of industrial facilities by economic activities and industrial sector and for each facility it has information of type of activity, geographical location and emissions per pollutant. For health data it uses mortality and population data at the municipal level and the exposure to industrial pollution is defined by the distance to the source. The analysis is carried out in R using spatial regression models.

This easy-to-use java/web interactive application tool does not require advanced statistical knowledge but the interpretation of the results clearly needs public health expertise. It merges the information of The E-PRTR and municipal mortality or morbidity data. Performs exploratory spatial analysis of the association between them by type of industrial facility (9 sectors) using distance as proxy of exposure. Optional information as socioeconomic data might be included as well.

The application directly calculates

- ✓ The expected number of deaths in each spatial unit. *The Reference are the rates by age group and sex for the whole country*.
- ✓ The distance from the municipal centroids (shapefile) to the location of all the industrial facilities included in the E-PRTR.
- ✓ Classifies municipalities as exposed or not exposed to industrial pollution, according with the distance predefined by the user.
- ✓ Performs the spatial statistical analyses.

The main output is a table or forest plot of relative risk of mortality due to exposure to industrial pollution by industrial sector and disease analyzed (both, for men and women).

Recommendations for use

- "En-risk" performs an initial screening:
    - Suggests the presence/absence of an excess risk of the studied disease linked to residential proximity to industrial pollution
    - Should be followed by ad-hoc studies to deepen into this information.
- The interpretation of the results clearly needs public health expertise.

"En-risk" is currently being piloted in Portugal for several types of cancer and hopefully it will be tested also in France.

Comments and questions

IJB: Is it possible to display differences with this tool between municipalities without including the exposure?

PF: At the moment is focused on environmental exposure with the E-PRTR database so the exposure of the municipality is unknown.

Henk Hilderink (HH) from the Netherlands: You can look at different exposures at the same time but can you also correct for other factors as smoking?

PF: You can, as far as you have such information at the spatial unit. For example, if you are working with lung cancer mortality and morbidity it can be controlled by tobacco or other risk factors.

Rana Charafeddine (RCh) from Belgium: We have all the time questions about environmental justice, pollutions levels vary according to income or education, so I was wondering if it is also possible to stratify for those factors

PF: It is possible but is challenging. For the moment the only variable of stratification that we have is sex, but if you want additional analysis you have the databases to perform such analysis.

Fact sheet Assessing and piloting interoperability (Enrique Bernal-Delgado, WP10, IACS, Spain)

WP10 aims at:

- Mapping out and assessing cross-national inspirational experiences on data reuse for both public health research and monitoring initiatives.
- Piloting interoperability in a number of topics relevant to public health research, using a variety of data sources from a number of locations (i.e., countries).

Data collected in real life exchange requires interoperability.

In the mapping stage 59 inspirational experiences were collected through Health Navigator, CORDIS and Bridge Health. The formal mapping has focussed on the type of studies that were conducted within the project or within the initiative (health status, determinants of health, health system performance) and its insights on outcomes, effectiveness and efficiency of the systems. Right now, in depth interviews are being carried out focusing on the four interoperability issues developed in the European Interoperability Framework (legal, organizational, semantic and technical interoperability).

In the piloting stage of the empirical case studies, it touches ground on specific cases to learn about the difficulties of deploying this kind of approach in the reality. What is going to be developed it is a federated not a centralized infrastructure. The idea is to keep data at home and only "moving" the scripts and the software. Then, data are collected, curated, maintained in a proper way, accomplishing the legal requirements in the country and then you are just in charge of using the code that allows you to do any kind of analysis (unlike to what happens with a centralized infrastructure). Three case studies are being piloted; among them, there is a case study on acute care of stroke patients. It identifies the pathways of care, which is a linking exercise to be run at home with a syntax that has been provided before. Previous to the analysis, the semantic interoperability must be checked (ischemic vs hemorrhagic stroke) to harmonize current taxonomies. The analysis is carried out in R and the codes represent: 1) a linking of the different data sources: at home, the emergency data source, in hospital data source, and the administrative data source for the follow-up of the patients, and 2) the analytical script, linked with the data model and the semantics that is the same for every hub. The outputs are presented in two hubs. In summary, it is a mapping and assessment exercise of inspirational experiences with 59 in-depth interviews to know about the interoperability issues and then the development of empirical studies.

Plenary discussion of Fact sheets Panel 1 (Moderator Alicia Padrón, WP4, ISCIII; Spain)

AP: Introduces the discussion on 3 guiding questions

- What is the usefulness of these innovative outcomes for HIS?
- How feasible is to integrate such outcomes into National/European HIS?
- What is the added value for National/European HIS?

TZ: The basic idea is not to collect everything in one place but to find ways to interconnect and analyze them. While more data is available the data protection regulations are stricter so it should be decentralized.

Mika Gissler (MG) from Finland: It is important for InfAct to ensure that the databases can be recycled with ethical considerations. General data protection regulations are misinterpreted many times so lawyers need to be pushed to ensure its use for research and public health purposes; if not, it will not be possible to combine many different data.

IV: Do you like to share the models, for instance the model on pollution to be replicated elsewhere?

EB: You are right. In the case of the model of pollution he has the linkage between big data sources and national mortality. After sharing the model you can run the model in Portugal and replicate it in other countries. The key point is the agreement on the data model to be semantically interoperable.

IV: So, what you pretend is like to develop some guidelines in order to further develop these kind of exchanges of information? I think it is very useful, avoids duplication, enhances cooperation and you can work in several things at the same time. I am thinking, of course, on its added value. On the scale of feasibility I think it is more difficult, because there are several challenges on the concepts and also, about the property of the programs. How can we get agreements on that, because the programs are developed and are property of the investigator. How it should be paid, or not?

EB: Absolutely, we are developing everything in open source, meaning that you do not have to pay anything. This is a Federation that means that everyone is contributing, not just with data but also with their expertise. If you are good in another thing, you can be the central hub of that particular analysis or for that particular research topic or surveillance topic. Being a federation, the governance is more difficult, because there are many people making decisions and putting the interest on the table at the same time, but once you have the governance clear enough then is much better in terms of mutual learning, mutual increasing of capacity and mutual contribution.

AP: I would like to add that all the arrangements about the organization and the access to collaboration between MSs is the essence of the InfAct project. We are going to discuss with diverse representatives of the ministries of health and research next month in the AoM, their political interest and commitment on integrating all these outcomes, that we are presenting today, in their health information systems and policies.

IJB: It is good idea to share syntax and not data. Several research projects from Scandinavian countries are being developed in smaller scale. You can look into research projects that have been doing exactly this, and publishing results based on meta-analysis of data collected in different countries but using the same syntax.

EB: I am in contact with Finland and we are exploring this. The point is that this is flexible enough to include either data collected by partners in each country, or with actual hubs in each country or in a federation of countries. In Nordic countries there are a lot of synergies to make possible what we are developing so the key point here is about making a decision and have a clear governance of the exchange of information.

IJB: I come from a public health institute for fertility and health, where we looked into influence exposure in the mother and the outcome in the child, and the results from our data are consistent. We tried to publish it in the New England, but we got the review back and they said the study was too small, so, what we are doing now is to combine data from Canada and Australia where researchers in both countries are using the same syntax, and the results are similar so now, we have a much stronger study and we would be able to publish it now. That is very similar to what you are describing.

RCh: My question is related to sustainability. Few years from now, we will need to update de data, or the methods. Also, there will new themes and new concepts that have to be dealt with. So my question is how this infrastructure accounts for sustainability ten years from now, once this Joint Action will be done?

EB: In parallel, InfAct is running for the ESFRI roadmap to have a proper infrastructure. In political governance terms you could be about to have a formal infrastructure set up, but in technical terms you need to have the data model and if you have a federated infrastructure, this is more likely to happen because with a centralized one it is much more difficult because the data scheme is fixed by design. So, if you want to do anything else, you have to change the schema which is very costly and very inefficient; sustainability is put at stake in these case, so these two elements have to be taken into account: 1) the way you collect the data and 2) the way you build the data models to get the longitudinal aspect into account.

AP: In terms of sustainability, we lead WP4 that is in charge of sustainability of the infrastructure. This is one part of achieving the sustainability, to discuss the feasibility of including all the outcomes that InfAct has produced into heath systems and policies and it is for you to discuss the added value, the feasibility and the possibilities for integration and also to advise the representatives from your ministries of health and research, so in the next AoM the sustainability plan can be discussed. They should consider on which outcomes of InfAct they want to compromise, to provide them long-term sustainability and to include them in their national HIS and policies.

RH: Our Ministry of Health has established a health hub, which includes 16 different data sources. France will have different health data hubs that are linked together as a federated infrastructure, so that would be very useful for the researchers if replicated in different MSs.

RCh: This would imply that the data are comparable and most of the time this is not the case between different countries. An exception is the European health interview survey that is more or less comparable, but at least it tried to be from the beginning. If now we tried to do data hubs and later we are looking at data comparability, this is something that we need to think about.

EB: I see advantages and disadvantages. One of the advantages is that a hub includes all the security procedures, you have all the data properly anonymized and adequately linked (facilitate accomplishment of GDPR). Of course, if you start the other way around as you have a data model, and you want to join with your data set or your data hub, and your data does not fit, these data model will have problems and you will need an interface for interoperability which entails it. It is less efficient at the end.

AP: There are other WP that will present outcomes on harmonization and interpretation and are related to recommended guidelines on how to improve the procedures of data collection and quality assurance for all MS.

HH: Reading the FS I have some questions about the case studies. Why these were chosen, especially number 2 [Health resilience]: to come up with a new composite indicator that might be discussed very heavily and that might not reflect the value of this WP? How will the results of these case studies be brought forward actually with future sustainability?

EB: The selection was very much trying to cope with a number of cases, it is not random. The question was about having a short demonstration of feasibility on one hand, and on the other hand, we wanted to have something related to surveillance, which is the case of health resilience. There is no other reason in the end so it is not random but it is trying to cover different domains and types of data. We are able to have cross sections or longitudinal data. In two of them we have cross sections of data that are refreshed quite slowly. With the stroke case, data are refreshed quickly and ensures longitudinallyty. This kind of framework is behind these decisions. They are looking at healthcare performance assessment of different domains of health status, health determinants and health care performance. It is possible to include 3 more cases.

Plenary discussion FS 2

PF: I am thinking that our future work with Portugal or France, could be a good example in the ecological context. We have problems, for example, with Portugal because mortality data cannot be move outside of the country, so we must work there and there would be other challenges in the rest of the countries.

EB: This is a good example. Any kind of question that you can imagine, because the problem is making decisions about the data model, so you may end up saying now this is not feasible, but once you have a clear thought about what is the problem you want to solve. This is a

typical question of research: you might want to do this but you have no data or you have no access to data.

RH: We need to contribute to the study, which Pablo presented, and we are still in contact trying to convince our environmental department so they can share the data and to apply the tool the same way as you did. Hopefully, by the end of this year we may get some consensus from our department. We would definitely like to have a case study with your project.

PF: The approach we have made is trying to capture different pictures in Europe, for example with Portugal. You do not have to share your health data, the health data you introduce here must be interoperable within your country. If you classify lung cancer, please, use the same code. But the idea is that you can use this application in your computer, and you do not share the information with our institution. We thought a lot of web interfaces but looking at the different pictures we think that the best way is to have your own application in your computer so you do not have problems with data protection. You must not share your health data, but you can use it in your country.

TZ: Looking at the sustainability, you gave the example of linking pollution data with health data, which is a very good idea. But looking from a media perspective, it may happen that you will find lots of associations, some of them could be due to the ecological fallacy or other factors. So, there is a need for putting that information into the right perspective. Do you have any ideas on how to cope with this?

PF: Pollution changes and industrial release substances are risk factors for health, but the degree of harm it depends on the context of your country, the distance, etc. It is not the same an industry in France than in Spain. But the idea is that, you, as a public health researcher, introduce different periods of time and use this application in order to assess the association taking into account that as the industrial sector make changes, for example, they do not release arsenic, you do not expect that the association between industrial pollution and health is constant over time. The idea is that you give data in a temporal context taking this information into account.

MG: I have been participating in Peristat for 20 years and we are going just to collect statistical information and aggregated information and finally hopefully sometimes we can use anonymous data on each delivery in each new-born in order to make better analyses and better science. Even with aggregated data we have been able to publish 30 or 40 different articles, even in Lancet. So we can do good things with aggregated data but it should not limit our vision in the future how to solve different problems and there, InfAct could make a big impact in the future.

PF: All the results of these analyses are population based, so we cannot go further, we cannot apply to a specific municipality, exposed or not exposed, some population based relative risk. Please, take care with these preliminary results. I remember a study where we found association between chemistry industry and pleural cancer. The only environmental risk factor is *asbestos,* so why we find such association if the chemical industry is not releasing the principal risk factor for that cancer anymore? This is the ecological fallacy, you can find a lot of risks that are not associated. You are the person

that is going to decide if this relative risk is reliable or not. This is a quick primary analysis, and you will decide based on the variables you use.

HH: It is important to find a balance. On one hand you can only analyze what has been quantified and, as we know, only 30% of all disease burden can be explained by 20 to 30 risk factors. We do not know which ones cause the remaining 70%. The other point is that you are looking at one point in time, while the risk factor might be an accumulation over time. People might have moved or might be exposed in a different situation, like at workplace. So there are all kinds of things that you might have to take into account before you make any conclusion.

IV: I think it is a combination of two things but you said that it should be analyzed by experts before making any assumptions. But at the same time it is a really good tool and I think it has an important added value. For example, we have worries at Portugal and even in Spain about the solar radiation and melanoma. There are several studies that relate these things, and now we are working on notifying populations at risk when the solar radiation is too high. These kind of studies could work on this area. You can develop some policies in order to protect people from some kind of risks that you know because you made the analyses. It has an added value: the health public institutions should work on that in order to minimize the complications of those risks. I have speak about solar radiation because we are notifying people “do not get out to the street between these hours because it is more hazardous” and people are assimilating this information and are protecting themselves from this kind of risks. I do not know if with pollution companies is similar, because if you turn this information public, maybe all people would get out of the towns and those municipalities.

PF: One of the databases in Europe is the solar radiation. Now we are working in airports because it is very easy, you can put an estimation of solar radiation in these models and go on. This is a good idea to reflect in the discussion. I had the opportunity to see the context of the solar radiation and industrial pollution in the same model. The results showed that it is a confounder in some associations, but it is not a big confounder, at least for Spain, I do not know in Portugal or in a country with higher or lower solar radiation. One question we discussed a lot it is if the models should be only focused on the environmental variables you select and do not consider other important variables you included. Imagine you need to contrast that tobacco is associated with lung cancer, taking into account the industrial pollution. If you do not take into account that tobacco is associated with lung cancer, something is wrong. This could be a change in the final application we are designing, to assess all the relative risk associated with all the variables that you decide to include. Someone in this meeting asked about interactions. It is easy to implement an interaction term and see that if we stratify, we identify different relative risks. The problem is: imagine a spatial model with two random effects, some fixed effect like the environment, and you have an small territory (for example, our country has 2098 spatial areas), but if your country has even smaller territories, you do not have enough data to contrast them correctly. We prefer not to include interaction terms, but it could be a possibility. It is not a technical problem if you want it. I think in that case we are driven to research instead of giving a preliminary tool to give some information for some action research.

RH: I think we have known so much about the different risk factors, that maybe the added value would be to minimize these risks and find out how to include them into the policy actions and how to convince the policy makers to minimize these factors. And I have a question: did you communicate these preliminary results as recommendations to the ministry for public health prevention? Did you do something or would there be any chance to improve the practices of pollutant industries?

PF: Working with these ecological analyses, only allows us to put in the public agenda the possible existence of a problem, and make researchers of public health policies to take new ways to assess it. It is a screening tool that would answer preliminary questions: We must pay attention to industrial pollution or not? And leave the interpretation of the results to public health experts and let them decide whether to include them in the agenda of public health policies.

EB: There was not a comment about feasibility of this distributed structure. I am curious about your opinion about whether you consider that it is safer for your countries to hold data at home, which is the basis for this research infrastructure. I would like to hear your thoughts about both things: do you think this approach is more feasible because at the end we have to compare options? Is more feasible that the usual way of transferring data out? And related to that, whether you feel more comfortable, you feel more trust with the researchers if you keep your data at home and you only move codes, scripts and syntaxes?

Ivan Ivanovic (II) from Serbia: Serbia is not a MSs so maybe we will be interested to hear something not from the inside but from the outside of the EU. I think that it is not such a big question to answer. I agree with keeping data in place. We have to understand that it is not easy, for the different countries, to make and get resources in capacity for the same or equal analysis and equal use of that data. That is why it is very important to have these common standards and technology, and if we have basic standard tools for the Federation, every country can make a deeper analysis and research. The biggest problem of all that project is actually the sustainability because if you exclude those who have to make an effort to gather the results of the projects you will not have sustainability. Maybe the solution could be some kind of recommendation: not to exclude hubs or institutions of the system but just to strengthen them or to make them some kind of focal points in the countries because in that case the federation will have a sense.

MG: In Finland we have used the wiper and data shield and different kind of technical solutions in order to increase the use of the Finnish register data and earlier this year there was an IT company who made a review of these shared systems and they were not very happy on their Data Protection (DP) issues (which were mostly technical ones). So, there is a way forward in order that we can trust this system. We have to make sure that both the research community is happy with the system, the lawyers, and also the people who are in charge of these registers. The lawyers are the main problem, because their interpretations are sometimes very difficult. In one case, we wanted a US researcher to contact our system and then the university had to sign that they will not contact the persons whose data were in the register. (Although they could not know their identities because the data was anonymous) and also they had to sign that they will not take a copy of the data. Finally, the university did not sign the contract and the researcher had to come to Finland to analyze

the data. There is always solutions, but we have to make sure that we have a clear vision about what can be done.

TZ: At the moment we are discussing the perspective of research but InfAct has another dimension, which is public health. There should be also an essential unit who provides the corporate information of relevant indicators. The target groups are not only the researchers but also politicians and decision-makers. They do not want to deal with data and data hubs. They need some results and some priority information and this kind of aggregated information does not necessarily has to stay at home. It could be centralized if they are not sensitive to data protection regulation.

IJB: It is very important to carefully consider which institutions are doing the analysis in the countries because there is a lot of strain on governmental organizations. They are not getting any increased resources, so which groups are going to do the analysis in the individual countries and how is this to be financed.

AP: That is foreseen in the sustainability package that we are leading. In the Assembly of Members (AoM), that we are organizing, they come high political level representatives, one from the Ministry of Health and one from the Ministry of research. They have all together one vote for each MSs (both ministries) so they must talk between them and decide, because each country has different settings, priorities, organization, and in general different internal issues. It is the country, with the representatives of the all organizations involved that must decide about its internal arrangement. For example, Ministry of Health and Ministry of Research could have different interests, and they must come together to a decision to represent their country.

RCh: I agree with the previous remark. For instance, in Belgium and in many other countries, we sent our data outside from our Health Interview Survey (HIS) to the European Health Interview Survey (EHIS), and for the survey of income and living conditions. Many universities and researchers request this centralized data. This kind of data are very important for researchers, for policy makers and for people who works in administration. That is why the tool that you are talking about it is very interesting. For the HIS in Belgium we have our data, that can be shared, but also we have a specific tool online and we know that the ministers and everybody in the administration use it, this is what they are interested in. It is not either-or, it is in a way a little bit of both.

EB: It links with what Thomas said about what we have to report for decision-making to the decision makers. They might not be interested in the raw data because they have not the capacity to do research, but they can benefit from the outputs. What I need to take from your idea, would be a user designing in this distributed infrastructure, a way to report indicators out of the research in order that it would be of use for decision-making.

II: Maybe we can try to put this question in a reverse way. What institution actually is going to put together the outcomes? None at European level because this is a pretty practical question and I know that most of the data that we are providing for the EU are going through the national statistical offices and through them to the Eurostat.

EB: Actually there is a part of one of the work packages in InfAct, which is not here represented today (WP7), that is thinking of the governance of this potential infrastructure, and how to link the central hub of a federation with the actual partners in that Federation that might be statistical offices in a country or any other, let say, a research group and network as European stat.

II: Eurostat prefers to deal with the national statistical offices, so most of the data we are providing is from our National Statistical Office. We are in charge of that at the internal level, but they insist to exchange data with the national statistical officers.

EB: The question is the opposite. To do research that at some point in time I will translate into some indicators, which is a bit different. I take your point but the idea would be: a national statistics office, plus data collectors of the health care system, plus whoever else, want to join this Federation applying these data models, yes/no? And then what they get back from that?

II: With some different analytical tools it is questionable the idea of comparing some health systems and some other health indicators, and on the other side when we asked Eurostat what is the source of data that they were analysing, it was some kind of business secret. It has a very big influence on our health systems because they are ranking some countries and we do not want to have the situation of not knowing who is responsible for performing the analysis.

IN: Regarding the infrastructure and the future in terms of sustainability, we are thinking at two levels: one level is, WP7, which is the sustainability in terms of infrastructure and another one, the sustainability in terms of including innovative indicators in the EU and national HIS. To this end, we do not need an infrastructure. This is another way of getting sustainability and this is the reason why we are here: to assess whether this initiatives and new indicators are feasible and useful at EU and country level.

HH: For the research objectives actually I am not too much worried. We also have a very open data policy, and of course, you are more comfortable if you have a something to say about how the data is being used as well, but I am more worried about what kind of mandate do we think InfAct has regarding policy recommendations or where does it ends? For example, priority setting might be one of the outcomes. What does it mean for policies? How far do we want to go or not? And who is the authority for doing that? How far is the mandate going?

AP: The mandate of InfAct is going to be decided in the AoM. The MSs representatives are going to decide, in their own country, what to do and what it should be included in their national policies to give them sustainability, and be incorporated and accepted into the Sustainability Plan. Such plan is going to be developed with all the information that we presented to you, with the outputs that you are providing and with your recommendations to the representatives of your own country. The MSs representatives of the AoM should sign the Sustainability Plan after the feedback provided by you, the national experts, about InfAct innovative outcomes.

HH: Then we have to think about how to make the results more policy-relevant, how to translate them into messages that policymakers do understand.

IN: We have selected one way: an expert national representative of the Ministry of Health and Ministry of Research from each MSs, to inform health and research authorities about the fact of including these new initiatives of managing different databases. We think this is the best way, an expert informing health authorities and research authorities. There are other ways, but we have selected this one, when we wrote the proposal for the Joint Action.

Stefan Mathis-Edenhofer (SME) from Austria: In Austria the policymakers, especially local policymakers, are very critical with the data and also with anomalies that derive from data analysis. I think that the data should stay in Austria and also that the interpretation should be performed by our researchers that have the knowledge of the context that our policymakers have (they have their own observations and their own works for data and data definitions). It is very important to adapt to these individual contexts of the policymakers. I think is better to share the models and the techniques about how to calculate the indicators, this is a big chance. For example, in our institution we have the discussion over some departments: many departments calculate indicators, some of them are very close, and we now try to communicate between the departments their different procedures. We have a big database with the data in a raw form. We extract data for spatial purposes, we make a data model, and then we make indicators on different regional levels, about different subjects. For this process it would be interesting for us to provide us information about how can this be done, how the style of coding looks like, tell us how to calculate its error, how to use Python, how to use PowerPoint and Excel, and how to make it sustainable? And also would be interesting exchanging information about statistical methods: confidence intervals, on the use of bootstrapping, how do we calculate the indicators... This knowledge is important in our house to share and this could also be the chance to communicate it between countries and centralize this knowledge and based on that knowledge to develop tools and access to data.

PF: For example, in relation with the confidence intervals, when we think about our results, of industrial pollution, we do not just want to obtain the relative risk. Imagine that you are the expert and you see the excess of mortality… What is the confidence interval for a decision-maker? In these statistical models there are some approaches that established thresholds of probability, to make the results reliable. This kind of approaches can be used to depurate all the results to give only one clear message. We can work on the output in order to merge all this information and to make it useful, not only for research but for policy. I really agree with you that we must take care of all things (statistical models, code language...).

RH: The other task of WP9 is different from BoD. In that study we created a genetic algorithm using machine-learning techniques, and we estimated the incidence of diabetes for the next two years using the individual data. For the next step we would like to share it with other MSs, so they could apply and see in their databases how it works. So, the idea is that we can collaborate among different MSs and see how these different methods are developed to share with each other.

AP: An example of the added value for the national health system and policies, it is to have the chance of sharing the knowledge about indicators and how to harmonize them. This very afternoon, WP5 will present a FS with the aim to develop a guideline of good practices about collecting information, harmonize it, its access and its availability in order to present them to the political decision makers and also to the researchers.

WP9 Burden of disease

HH: I would like to clarify a little bit more the information about National Burden of Disease studies because there are many more approaches on BoD and those can be very partial for different diseases. The focus here is about National BoD studies. Moreover, that focus also gives a better position to all the other burden of disease activities. And the second point is that I think we should strengthened more, the capacity building within the MSs making use of the experience from the GBD that was mentioned before. My question is: How are the methodological trainings going to be worked out? Do you already have an idea about that? Because that is a huge effort if you want to have that capacity building being built in many MSs that are not listed yet as being active on BoD.

RH: In InfAct project we just highlight that the MSs are what their current capacities are. At the end of the third workshop we will provide a toolkit with the minimum requirements that a MSs should have to meet to initiate the BoD study (what sources they would need and why they want to do this BoD study). We will try our best that MSs could initiate the study by themselves and of course with the backing of the COST action. This action and the collaboration with the BoD steering group committee, could provide some technical support, in terms of assistance, moreover in this toolkit we would have some case studies like four case studies from Netherlands, Belgium, Germany and Scotland, which are based on their national BoD studies. We asked these MSs to provide a narrative overview describing their experience so other countries could use that experience in planning their own study. If they would need further assistance, of course we will try to organize more trainings in future. At the moment, we hope that the third BoD workshop will take into account all the steps, needed as minimum requirements to develop a BoD study. There are 18 MSs who do not have any experience so I should clarify that the survey participants were from the National Institutes of Public Health and they declared that BoD approaches are not part of their routine activities. There might be some other research institutes who should apply.

II: In 2000 there was a European BoD project. Because of some conflict of interest, this project actually was only made available to the researchers (universities). When the project finished they lost their interest. On the other side, in the Institute of Public Health of Serbia, where the data were collected, we are capable of doing some research. Unfortunately we were excluded from the project so we missed the training on methodology and other capacities. The idea is actually that you cannot split between the institutions that collaborate and the ones that have access to data, to the methodology and other assets. They have to work together.

RH: Certainly, I think in BoD the collaboration is the most important point either collaborating between MSs or within where different research groups.

II: Which institution is going to be responsible for that the project?

IN: I am personally convinced about the importance and the usefulness of the BoD in establishing Public Health priorities. I think there is a big consensus across countries. We have an excellent opportunity regarding BoD in Europe. Our American friends have a lot of experience in BoD. We have two opportunities: we can use the American experience, so we can include calculations for disability, software and different models that have already designed for BoD and risk factors or we can provide our own experience. I think the measure of disability is not the same in the United States with their different health system than in Europe with our health systems. InfAct is bringing an excellent opportunity for EU cooperation in terms of BoD.

RH: I think the Public Health Institute should have the governance for initiating the BoD study, this should be their priority as well. And second, of course, there should be a collaboration with the Ministry of Health (MoH) because public health Institutes do not use to have sufficient strength or power to work on that. Also IHME has developed this methodology, so we need to keep a standard or a baseline and then the MSs might be able to modify it or adopt it according to what would be the best for the country.

TZ: BoD is probably an instrument for priority setting in addition to what we are doing. And has already started a network, which is producing outcomes and publications. I think both aspects could be more emphasized in the fact sheet (FS), just to make it more prominent. I think it is a kind of success story so far within InfAct.

HH: I tried to emphasize capacity building because something as important as the results is also the process of understanding your data and improving your data. And then IHME is also very interesting because they perform the process in a centralized way but also knowing from the National data sources how good or how bad sometimes the quality is, and how to improve the data collection as well. BoD but also the other projects help a lot to have a comprehensive analysis to make comparisons between countries and also for benchmarking so you can assess how your country is doing.

TZ: We need also to consider non-EU databases. This term of big data coming from social media is getting more and more important in public health research. How to integrate health data which could be derived from social media?

PF: We have a colleague that used social media information to detect increasing risk or increasing worries about cardiovascular diseases by Google consultations. The curve of this social media reflected exactly a health problem. We have information to work, we have good data and good indicators.

IJB: *Googling* on influenza is more precise than health recorded data.

RH: My personal perception is that to make decisions based on that these data, might not be very interesting or useful; because sometimes people just tweets or just posts something because they are in a group. It may not reflect the current situation or the ground reality of a problem.

SME: There are very different basic understandings regarding data from social media. There are big companies that dedicate a lot of energy to analyze the data and to use it for

commercial interests. So they have totally different priorities and I think these differences between the objectives of these companies and the objectives of public health have also to be clearly put out. We should be cautious with these techniques. Great Britain gave data to Oxford analytics and afterwards they feared about what happened to this data.

IN: Social media inputs are already included in a systematic way in the risk assessment that is periodically generated by ECDC. We can do it for NCD, why not? We have no FS regarding the link between social media and health system performance or NCD, but we can decide its inclusion.

FS9 BoD

IN: Do you think, as national expert, that we would be ready to incorporate BoD tools within our national health systems? Will it be difficult? Do we have enough resources? We can further develop national BoD studies in order to compare results within Europe?

TZ: I am a bit sceptical whether we really have enough resources within InfAct for the time being. You might think that if you provide a kind of technical infrastructure, and tools, then the demand that this is going to develop will help it to become a permanent structure but probably not in the exploring pilot phase we are now in.

IJB: In Norway there is a group working with BoD projects, it is about eight or ten people and it is funded through the government budget. I do not think this would be possible without this funding, which is quite large. There are permanent positions and they are funded through the government budget.

HH: I think the variation in Europe between countries is too high to have this kind of harmonized goal for BoD results being included in HIS. In the Netherlands, we recognize how important it is to have BoD estimates and especially if you translate them to the allocation of the underlying determinants of health. We do it every four years, so we have to analyze a lot. To understand your data is very important but I think the resources are not enough to get all countries at the same level. I would focus much more on collaboration on capacity building.

IV: I think that at this time there are not enough resources at the national level. If you focus on the National Institutes of Public Health they do not have enough resources to start on this work by themselves and I think their main goal should be the capacity building and the development before trying to have all the results and to be able to harmonize them. It will be very difficult to implement the BoD calculations by the National Public Health Institutes. I also would like to ask you if you thought about, introducing this group, not only to the national entities but also to universities and research institutes that work at the national level but that are not the National Public Health Institutes. This working collaboration could help to improve the capacity building because there are researchers that are working right now on these aspects.

RH: We just look at the National Public Health Institutes. Maybe it is a good idea that we contact again to the National representative and try to see if there are some local research

institutes working on that. This would help to improve the collaborations within the country. I agree with all of you, that it is a huge work that needs a lot of resources and of course if some MSs do not have the capacity to develop the task, then the collaborations among each other and sharing best practices or tools will help a lot. The first need is to initiate this approach at the national level and then later on we should think about the integration into the EU-HIS

Giovanni Nicoletti (GN) from Italy: As a part of this Joint Action we have the problem that this project is big but clearly not big enough to include every interesting thing that could be done within the chapter of health information. There is a sort of self-selection based clearly on the partners and the countries that are actually part of the Joint Action. I think the scope of the Joint Action is more an addition, not an alternative to provide success stories and examples of good practice. It aims also to create an infrastructure, but the work might be a bit confusing in order to allow a number of these initiatives to be facilitated. I think that the main goal is to create or improve the conditions, in particular about access to data, interoperability etc, which could allow researchers, and policy oriented research to have an easier way forward, (not to ask 100 permissions to have access or to search for a potential cooperating colleague) and also to make the European or multilateral cooperation less complicated than it is now. I think that they (AoM) and the remaining part of the project should try to focus on how to address these potential facilitating factors and convince MSs to invest in these options rather than on individual projects. Without good research and research networks, we cannot do anything. It is important that these researchers will have their task facilitated in the future through our proposals.

AP: I would like to finish with a small overview of your comments. About the usefulness of these innovative outcomes and their added value, I would like to stress some remarkable comments: (i) the more we are the stronger we are about the information we would be gathering; (ii) the information should be useful for guiding political public health decisions; (iii) the process of understanding and improving this information will require our work, resources and commitment but will be an added value for us all; and, (iv) although we do not have yet an harmonized register of data, with the work we are all doing in these projects we are collecting knowledge on that way. Another very interesting aspect it is that we are going to exchange useful tools to work with them. On the other hand there is a question about the feasibility to integrate the outcomes at the national and international level and the need of resources to do so. One thing that has been said is the difficulty to achieve at national level the collaboration between different institutions like the Health and the Research Institutions. InfAct through the AoM could facilitate this goal by bringing people from the national and the research institutes together. Another interesting aim of InfAct is the policy-oriented research for policy making.

3. Panel 2: Status of Health Information and Tools for Health Information Support

Fact sheet Two-round Delphi of methods for prioritizing health information at national level (Thomas Ziese, WP5, Robert Koch Institute, Germany)

WP5 aims to outline the current state of health information collection among EU-MS and associated countries with 3 tasks

- Task 5.1 examines the state of HIS by mapping and assessing current HIS.
- Task 5.2 examines health information sources by cataloguing international health information, collecting networks, projects and indicators/datasets.
- Task 5.3 examines health information priorities by cataloguing prioritization of health information in MSs and at the same time tackling health information inequalities.

Defining the state of health data collection across EU-MS is a first step towards tackling inequalities in health data across European MSs. Development of standards tackling inequalities in data sets across countries is also important.

In the literature we found no EU-wide reviews of methods used for health information prioritization; Task 5.3 seeks to fill this research gap through a Delphi Survey. This Delphi Survey seeks to fill this gap by providing a collection of ranked approaches for prioritization of HI at the national level. Following literature review of methods used for prioritization of HI at the national level, we developed 19 open-ended questions to collect information about the existence of structured health information prioritization in participating countries, and methodologies applied for prioritization of HI. Respondents were also asked to provide information about informal processes for prioritization of HI. The Delphi questionnaire was distributed within the InfAct project to respondents working in National Public Health Institutes, National Statistics Offices, stakeholders producing national health reports, or national organizations developing health targets, and health policy. First-round responses will be used to develop closed questions. In the second-round, about HI prioritization, respondents will rank methods, processes and criteria based on their own expert opinion.

- ✓ The first round Delphi Survey asks representatives from EU-MSs about how information is prioritized in their country, and how stakeholders are involved in health information prioritization. Respondents are also asked to share details about development and application of criteria used to prioritize HI, including linkage of criteria to international regulation and frameworks. Finally, respondents are asked to evaluate the contribution to health system functioning of the current method used to prioritize HI and to suggest points for improvement.
- ✓ In the second round, respondents will rank the collected the methods, processes and criteria collected in the first round according to degree of “desirability“, “feasibility“, “importance“, and “confidence“, based on their own expert opinion.

Sustainability of the task is achieved through dissemination of results, laying the foundation for a framework, which could be scaled to the European level, and documentation of prioritization processes across MSs to tackle inequalities in health data. Visibility of prioritization processes and overcoming HI inequalities is essential for agenda keeping through public health policy action, and agenda setting through identification of emerging public health issues.

Comments and questions

HH: To my understanding a Delphi process also always looks for consensus. Is that also the purpose here? I would say that if you have very different kind of practices that might work out in different countries, then consensus might not be the main objective.

TZ: One of the more common aims of a Delphi is to identify good practice models and we avoided this term "best practice", we just said "good practice" because you have to adapt it to the political system in which you have different actors on different regions. The aim is more to get an overview about what has worked in the past in different systems.

Fact sheet: Questionnaire for MSs regarding health data collection methods and procedures (Alicia Padrón, on behalf of WP8, ISCIII, Spain)

WP8 aims to summarize existing health data collection methods in EU by:

i) reviewing and identifying standardized data collection methods and related quality assurance procedures

ii) elaborating common procedures and guidelines for accessibility and availability of health information (HI) both for individual-based data and for health indicators

WP 8.1 developed an ad hoc questionnaire to identify projects/studies, which collect health data for population health monitoring (HM)/public health surveillance and health system performance assessment (HSPA) at national or regional level

- The questionnaire was addressed to epidemiologists, researchers that have played leading roles in EU projects, health data managers working in national health and research institutions, and universities.
- In the pilot phase, the questionnaire was shared with EU and associated countries' representatives who participated in the InfAct WP8 meeting held in Brussels in February 2019.
- The final version was distributed to all InfAct participants asking them to share the questionnaire with their colleagues (snowball recruitment).

The questionnaire is composed of four sections: (i) source of information/data sources/ project/study background information, (ii) quality assurance procedures in data collection,

(iii) availability, and (iv) accessibility. In addition, socio-demographic characteristics of the respondents were also collected. Overall, the questionnaire was composed of 29 multiple choice or open-ended questions.

Preliminary results with a total of 219 responses:

i) In the pilot phase, 26 questionnaires were completed from 11 countries (Belgium, Czech Republic, Estonia, Finland, France, Italy, Latvia, Slovenia, Spain, The Netherlands, and United Kingdom).

ii) 10 projects/studies were representative at the national level, 10 at the regional level and 6 at both national and regional levels.

iii) 8 projects/studies were shared with European Research Networks (ECHO1, EHIS2, ECHIM3, EHES4...), while three were under development (EHES, ECHIM).

iv) 13 projects/studies had public description of dataset purpose and content (metadata). Of these, only one project used metadata reporting standards, in particular DDI-Data Documentation Initiative.

In Summary, the aim of this questionnaire is to generate the knowledge on standardized health data collection methods and procedures for health monitoring and HSPA. It will also facilitate the identification at the national or sub-national level of the data collected through standardized procedures, but that are not included in the international databases of research networks that we all know (WHO, Eurostat, OECD). These results will facilitate the work of researchers looking for standardized methods and procedures for collecting, processing and sharing health data; and also for policy makers in accessing comparable and reusable HI. The sustainability is ensured because it will be created a guidance for good practices in health data collection and their availability and accessibility for research purposes and policy making. Moreover, the guidelines of good practices will meet metadata standards that could guarantee the interoperability of different HIS. This is the key of the implementation of a sustainable evidence-based research infrastructure for also policy guiding.

Plenary discussion Fact sheets Panel 2 (Moderator: Rodrigo Sarmiento, WP4, ISCIII, Spain)

RS: We are changing the focus right now, previously we have discussed data analysis and interoperability, and now these InfAct outcomes are more related to data collection and standardization. The main discussion will focus also in the same questions than before: Which is the usefulness of these outcomes? How feasible is to integrate them? And, what is the added value for national and EU-HIS? Who would like to comment on these outcomes?

MG: That both of these are very important parts of this Joint Action and we have the experience that it has been very difficult to publish anything related, for example, the

prioritization of healthcare system. We did an exercise, almost 20 years ago, and none of the scientific journals accepted the paper, because they consider that it was not important, it was not public health and it was not informatics. Finally, our report was published in WHO papers. It is there, it is great literature but it is difficult to find. Therefore, it is also good to try that this system will improve the HIS nationally, and to get ideas and inspiration from other countries. It is very easy to achieve that in Norway and Finland, with the personal identification number we just implemented. Although we know that politically or for other reasons in some countries, it is not possible. Therefore, we must find different ways, to make the data linkage without unique identification numbers.

IJB: I think that to have an overview of how health data is collected through European countries is very interesting for many reasons. If you are going to publish a paper on your own you usually spend a lot of time describing the data sources, but a work like this could be used as a reference. Also for teaching, we are teaching courses on epidemiology and registry based epidemiology with students from different countries and to have an overview of data sources through Europe is certainly something that would be of interest. Moreover, it is interesting also to better understand your own system by comparing it to the ones in other countries.

RCh: About usefulness, I was wondering how the results of the study would be available to all people in different countries, and for people who make decisions and priorities.

TZ: One way of creating visibility is just the publication in scientific journals, and on different websites. First, we started by doing a classical literature research which did not delivered very much information. Then we did a broader one using just Google to look at the great literature, and most of the information was in not commonly used languages. So I think if you properly put it on different websites that would make it available and visible. I think that being visible would be a kind of soft recommendation. Hopefully, we identified some ways of making priorities in a sound and plausible way, because the way data gets into action is complicated, and not very well investigated. This can only be a small step toward that goal. Still I think it is helpful to have some tools about how it has been done before. I think we have to keep in mind that making health priorities and making health policies it should not be completely data-driven. Science must point out at the most important problems. But then more problems can be tacked, and who is going to select them? This is the policy part and I think it makes sense to deliver instruments for society to discuss this in a transparent way. It is the idea of making it available.

AP: Also the WP5 will support the sustainability objective by making it visible through the AoM. The representatives of the MoH and MoR will have all the information about what has been made in prioritization, so they could decide whether to include it in the Sustainability Plan that is going to be made with their consensus.

HH: I think it is very important to have much more research being done and to know how priority setting is taking place. But I would also like to focus, not only on the results, as you were saying, but also on the process of how to involve people from the beginning for the priority setting. That might allow also some diversity, there is not one set of priorities or criteria that can be used to reflect all what people value most in society because that

differs. We did it in the Netherlands, we had four different perspectives on health, and people value things differently. And as soon as you try to put that together in only one set of priorities people will not accept the results either. Having the process you have mentioned is something very important and not only the results. That is something that should emphasized.

RH: I understood from your presentation that the idea is to identify good practices for prioritizing the HIS among different MSs. At one point you mentioned that you will rank them. Are there different priorities in different MSs for HIS? How would you take into account that?

TZ: One way of dealing with it would be the way you present it. You could do it in a kind of top 10, listed from 1 to 10, or you can present it as a basket of different solutions, because different problems or topics need different solutions. A basket of possible solutions could provide us some advices.

IV: About the data collection methods I do not know if I quite understand. What you pretend is to create information about health databases that they are not known internationally or to developed the good practice of how to collect information? I think both are very important. I think the first one maybe easier than the second one, but I think that both are useful. As the colleague just said it is very important to know what kind of databases exists around and if they are good databases, if they use good methods of collecting or not, and also I think it is important to promote the good practices for collecting databases.

AP: We are including the guideline of good practice of collection methods because the information is fragmented. The data they have collected is not the one that is included in the international databases (OECD, WHO and Eurostat). They are working on other databases at the national or the regional level that are not integrated in the international networks that we all know. The aim is to assess the quality of the data collection, the method of data collection, where it comes from, and also if they follow the standardized procedures for the accessibility and availability, following some standardized guidelines. The final aim it is to elaborate guidelines of good practices for the health data collection to facilitate the availability and accessibility for research and policy making, assuring that they have good quality.

IN: I am wondering what has been the criteria for considering a best practice among the persons you have contacted for the questionnaire.

TZ: It was based on the mapping we had. I think there are some activities trying to get a mapping of the public health and health research activities in Europe but these are never ending projects. So we looked at the networks we already have, for example IANPHI, to identify the contact persons. Another important source were InfAct beneficiaries/stakeholders, because they have an idea of what is the whole exercise about. If you are not familiar with this whole task, it is very difficult to understand.

RH: You mentioned that some data sources are not part of the EU databases, EU networks, so they are part of the national health databases I guess.

AP: I meant that they are not included in the international databases that we all know (OECD, WHO and Eurostat). Some are developed just at the national level and others at the regional level. Now, they (WP8) are in the process of elaborating the report.

GN: This morning we were focusing on some potential outputs of this future European information system, while in this afternoon we are looking more to the methods and to the possible engine that is behind. And once again, in my personal view, these kinds of things are more related to the concept of infrastructure and to the potential hardware of this future structure. We should spend more time to discuss on the potential development of these issues while outputs of the systems are so many that it is difficult. The second point is that I am involved in other fields to do this kind of exercises at national level and they are extremely difficult, not just for methodological reasons, as others have mentioned. It is difficult to replicate the same outcome among different groups of stakeholders, with different interests. It is not clear how they do their priorities for the future, it is a balance of what is feasible, what is acceptable by the countries, what is politically recommended… There is also a sort of indicators for priority making in Eurostat. And as AP was mentioning, we are even in a more difficult situation because we are dealing with topics that still they do not have in their agenda. Moreover, the European regulation, which is accepted by every MS, makes prioritizing a little more difficult. They prioritize not necessarily in a very rational and organized way. What is good for Eurostat planning is usually mid long term, it is not just for the next year but they have some development plans. It should be a characteristic of any future job to consider the long-term planning. About the final comment to TZ, I quite agree that having the results published on a journal will improve a lot the standardization, but I was wondering if your ambition is to register the method or to promote the final results of your survey? I mean, the list of priorities, or the need of having this kind of consensus making something like a Delphi in each country or in each group, to make priorities? Because I think there is much more evidence to support a method than the final outputs of your study because your final results will be very interesting but I am not sure if they would be incorporated as such by other countries.

TZ: There are different methods of selecting indicators by a bunch of criteria: availability, comprehensiveness, validity, so there are quite a lot of criteria around, we are not lacking those. What we are lacking is the process of how is it done. From our experience, each expert group which wants to focus on a problem starts to re-develop those criteria again and over again. It will be helpful to have some procedures, which have the advantage of being proven to work in the past. It is the feasibility of the processes, which we would like to add. We want to open the door for possibilities to identify priorities.

RS: We will move to discuss more in detail the sustainability and the feasibility of these two FS that we have discussed. We want to hear your insights on this. Would you think that, if you propose these FS to policymakers they will agree, or what will be the barriers or the pitfalls that they will argue?

II: I want to make an overview not from the inside but from the outside. What is the institution at the European level that will have the data and do the analysis? What are they going to do with that? The countries that are already examples of best practices are going to be much better after that? Or there is going to be some kind of the action among those

countries that is not so good? Because we are talking here about total different health systems, some of them come from socialist republics, for example Serbia, some of them are totally different, some of them are collecting data mandatory by the law, and some of them are buying data and paying for it. There are very different situations. On the other hand, they also have very different resources for HIS. I am coming from a country, which, I do not want to say how many euros we are spending for the health services annually per person, because it is very low. In that case it is not easy to give the priority to HIS, if you are struggling about buying drugs or equipment or heating in hospitals. I will say that the HIS is not the priority. Maybe this is something that we should recommend, to become more equal and not to become more unequal.

TZ: One of the tasks of WP5 included tackling inequalities in health data with the Delphi survey. It will be helpful for MSs to look at the criteria to decide, among the data sources they have, which they would like to be more developed, and which data sources are there just for traditional reasons. I think it is quite difficult within the country to argue because sometimes there is a data source well established but not very useful, although there are people depending on that. To give an overview about the data sources or the criteria to identify which data sources are needed may help to keep the focus right. If resources are limited, we have to focus. To improve this kind of focus prioritization is a key. It may be helpful to see how other countries have done it because not everything that is measured is important and not everything that is important is measured. You have to change the balance sometimes and to know the criteria, which worked well in other places, may help MSs to reduce this gap of health information inequalities.

IV: About the feasibility, I think the main question is how to convince the national authorities that this is important because the policymakers want to look for information in a summarized way. They do not want to know about methodologies and criteria, but they want to know that this information is reliable, so we should focus on that. When we improve criteria methodologies and when we know the quality of data sources we can have more reliable information. It is more feasible, to present them that they are going to take decisions on information that is more reliable with more confidence because it is based on scientific criteria, on harmonized guidelines. It is important to present this kind of information. A long time ago I was dealing with politics that were decision makers and most of the time they do not have time and they are not very interested on the methods and how do we get the information but they are very interested in knowing that they take decisions based on the most reliable information.

RCh: I think that a project like the prioritization project is more important for researchers than for policy makers. And especially researchers who work supporting policies like researchers in health administration. It helps us to demystify this process of where all the resources are going and how priorities are being put in place. This is really something that we really need, because we have a lot of data but we do not know really what would interest policy makers and what is the best way and approach for this information to reach to them so they can use it in their decision-making.

HH: I agree but also we should understand that setting priorities does not depend only on the information and the data, it depends on many other factors Taking that into account,

we should also focus on policymakers but understanding that maybe the primary target group is research. We must give them more tools, to prioritize. Just an example: in the Netherlands we give the rankings of certain diseases according to the disease burden, according to the cost of illness, according to its occurrence… but also in terms of loss of quality of life. And then it is up to policy makers to decide which of those criteria they find most relevant.

SME: I think that stakeholders do not think about which data they prefer, but they think on terms of health problems. We could give the message to the stakeholder that there is a connection. If you want to solve health problems you also have to solve data problems. It could also be highlighted that it is important to make data more reusable. For example, many data are routinely collected but you cannot use it because of one small thing or one field that is not necessary is missing and this hinders completely the analysis. Thus, it is important, this sensibility to make data that are systematically collected reusable on a later stage.

IJB: I would like to know more from WP8 about details regarding data collection. In Norway there are 100 health registries and many other registries as well that are irrelevant for policymaking. My guess is that you do not intend to list all registries in every country. What will be the output of WP8? When you have this questionnaire regarding data collection to each MS, how will you present your results?

AP: The aims of the survey are: To assess the quality of the information that has been collected, the source of data information, to assess also the degree of quality of each source, and with all that information to make a guidance of good practices of collecting and assessing the quality of the information. Moreover, they are aiming to assess the availability and accessibility of the information. They are going to establish if they fit the standards and to make recommendations for them like the standards of the data documentation initiative (DDI). According to that, they are going to establish recommendations for the quality assessment of the data collection and its availability.

II: You mentioned that in Norway you have many registries. Are you talking about the geographical distribution or some topic distribution?

IJB: It is divided between central health registries, and medical quality registries. The medical quality registries typically cover a certain topic like cerebral paralysis, back operations, or myocardial infarction. For many different diseases or procedures there is a singular quality registry, which collects data. Both registries altogether are more than 100.

II: Some countries have problems to gather data at the national level because they have decentralized registries and it is not so easy to get national data.

RCh: Here we are talking about only surveys or also administrative data collection? Are we talking about Hospital data and insurance data? We use it a lot for health research but I do not know if you would produce standard guidelines for the processing of this kind of data? These are very different from one country to another.

AP: The survey is collecting this information of HI and public health surveillance and also about HSP assessment. All those databases analysed in the survey are going to be included in the report and it is expected that in the guidelines, they will make their quality assessment, not only about health monitoring but also about HSPA.

IN: So far we have different HI collected from different institutions (Eurostat, WHO and so on) and this information is usually provided by countries, but regarding the analysis, the communication and the transmission of this information, in most of the countries, they are not analysed and interpreted by public health professionals. My question is, what kind of involvement have you identified from the national public health staff and researchers to use and compare countries? We have spoken about priorities and data collection methods. I think we are using the same data (I mean mortality, morbidity, different questionnaires for the general population and so on) and sources, but there is a lack of possibilities to compare data. We need to compare countries, we need to use the same collection methods. So to what extent do we have comparable methods to properly interpret European data? I think this issue is really important and we have our European data managed by other institution where, maybe, the people linked to the public health and epidemiology are not the majority. Maybe the majority is linked to mathematical models, statisticians… In different European meetings I have identified some kind of interpretations rather linked to mathematical models and statistical models than to a public health and epidemiological interpretation.

II: Maybe the solution could be the establishment of the Institute of Public Health of the EU, which will be something like Eurostat, or a new department in Eurostat, but dealing with the public health data.

TZ: A NCD ECDC. I think the WP, which is led by RIVM is looking at the questions you have been posing. I think there have been a lot of efforts in Eurostat, looking at the comparability of data sources either exposed or ex ante. I think the most experienced now is the ECHI list, which is about ten years old, and needs to be refreshed. The most important aspects are: Is the data available? What do you want to look at? What is the best data source, the most comparable one? This is a key group and our colleagues are doing a very valuable work to look at the data sources that are they still existing? Are they in good condition? How would they rate them in terms of comparability? This is within WP5 too and there is very much within this work in progress. I think just focusing on prioritization, among the three outcomes of WP5, is too short, you need to get the complete picture.

RCh: Comparability is a very big issue. I work in the Health Interview Survey. I have once compared exactly the same questions asked in the Health Interview Survey and in a survey on income and living conditions (SILC). These same questions provide totally different answers and different prevalences in those surveys. There are many issues to think about when you look for a possible explanation. For example, if the question has been asked at the beginning of one survey or at the end of the other survey it might give different answers. And then there are the obvious considerations: is the mode of data collection different between them? There are many other surveys and it is necessary to compare between what comes from the Health Interview Survey, what comes from the SILC and what comes from

other surveys. So it would be important to have somebody who is looking at it from a very comprehensive point of view.

TZ: I fully agree and that is why I think Eurostat implemented this expert group on public health statistics, which looks at the different areas of public health statistics and they have a permanent working group involved in a task force on EU-HIS, on the European Health Interview Survey. So at least there is an instrument, which is continuously looking at the quality, and continuously improving those issues you just mentioned. Maybe we should think that we will never get a perfect data source but we should focus on the best available data. I think the quality management of the EU-HIS is a very good one, but not perfect.

RS: More insights regarding Isabel questions and concerns? You have more comments about the added value of these two surveys, one from WP5 and the other one from WP8?

IV: About the survey on prioritization, I did not understand what results you are going to present. The results from phase one? The ones from phase two? Or both of them altogether? I think it is an added value to know which countries are using specific methodologies to prioritize, those who are not using them, and the ones that are not thinking about that at all. I think it is important to know that. But I cannot understand what are you going to make public. The final report is going to be the result of all the Delphi panel?

TZ: The final way of presentation is not decided yet, but definitely we want to lose as few information as possible in the final publication. We are thinking about compiling all the information we have and then linking it to the ranking of the experts. Then to have a smaller publication policy briefs, which are the most favourable ones. The main goal is visibility and transparency, so we want to get it published. But keep in mind we do not cover all MSs, this is not a complete mapping, the response does not allow it. We contrast a few examples, which have been ranked, which is very valuable and helpful.

HH: I find very difficult to anticipate already what the added value is without having the results yet. I think that is also the general feeling in the audience because if the results are showing something that also has some robustness or a common ground for all the MSs that are included, of course then you have something that certainly has an added value. If you do not obtain a common ground but a diversity of options between the countries, then you have a different result so it is rather difficult to anticipate on that, to assess its added value. The added value could be very big, I hope so, but we need final results.

AP: We are in the middle term of the InfAct project, so most of the results are in an ongoing process. In the next TD, we will have the final results of WP8, WP5 and the rest of work packages that have not enough outcomes at this moment. You will have all this information on the next TD and it will be presented one month before the next AoM. You will have all this information, so you can advice your country representatives, about the outcomes included in the next AoM and in the Sustainability Plan.

HH. There has to be a lot of thought in what has to be done about the dissemination of results. How to reach out to a bigger audience and how to ensure that it is better embedded in all kind of platforms. This is a good discussion point that should be taken up.

AP: It is unfortunate that the coordination is not here now to provide more detailed feedback about that question, but the WP2 consists on dissemination. InfAct has a webpage that presents all the results. Other congresses and meetings are also the ways of dissemination. If you want more information about it, please check the webpage.

RS: We just wrap up this panel by summarizing some of the comments from both surveys that have been presented. We will not get into detail about what it was discussed here because we have to take all the comments and put them in a minute that we will circulate later on. Just to summarize. InfAct is just running one and a half years ago. Therefore we have no results from all WPs. This TD is focused on getting your insights and assessment about our main results. We have provided initiatives ready to be EU-implemented (linking pollution and cancer or other non-communicable diseases), others in progress (WP5 and 8), and promising results (BoD in Europe). We have also other important initiatives like piloting interoperability, which is finding troubles due to EU and national data protection regulations and the ex-change of databases between and among countries. For the next TD you will have more results and directions provided by these WP. New initiatives and indicators will be presented in terms of composite indicators. We have spoken about quality, comparability, resources and political will. We will provide the recommendations of this TD to the AoM.

B. Minutes of Second Technical Dialogues

The Second Technical Dialogues were held virtually on the 28 and 30 of September of 2020, with contributions from national experts of 14 EU/EEA countries

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

IN: The major expected outcome of InfAct and its TD as well as the main conclusions of the first TD were presented. 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 availability of data generated from different sources is increasing with the possibility to link these data sources with each other. However, linked administrative data can be complex to use and may require advanced expertise and skills in statistical analysis. The main objectives of this study were to describe the current use of data linkage at the individual level and artificial intelligence (AI) in routine public health activities, to identify the related estimated health indicators and health determinants of non-communicable diseases and the obstacles to linking 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 (the use of data linkage and/or AI)[1]. The majority of European countries use data linkage in routine by applying a deterministic method or a combination of two types of linkages (deterministic and 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 infrastructures should be encouraged.

D. Organizational and structural aspects, 6. Ministries of health and research from European countries should provide their support (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 for health surveillance (Romana Haneef, WP9, Santé Publique France)

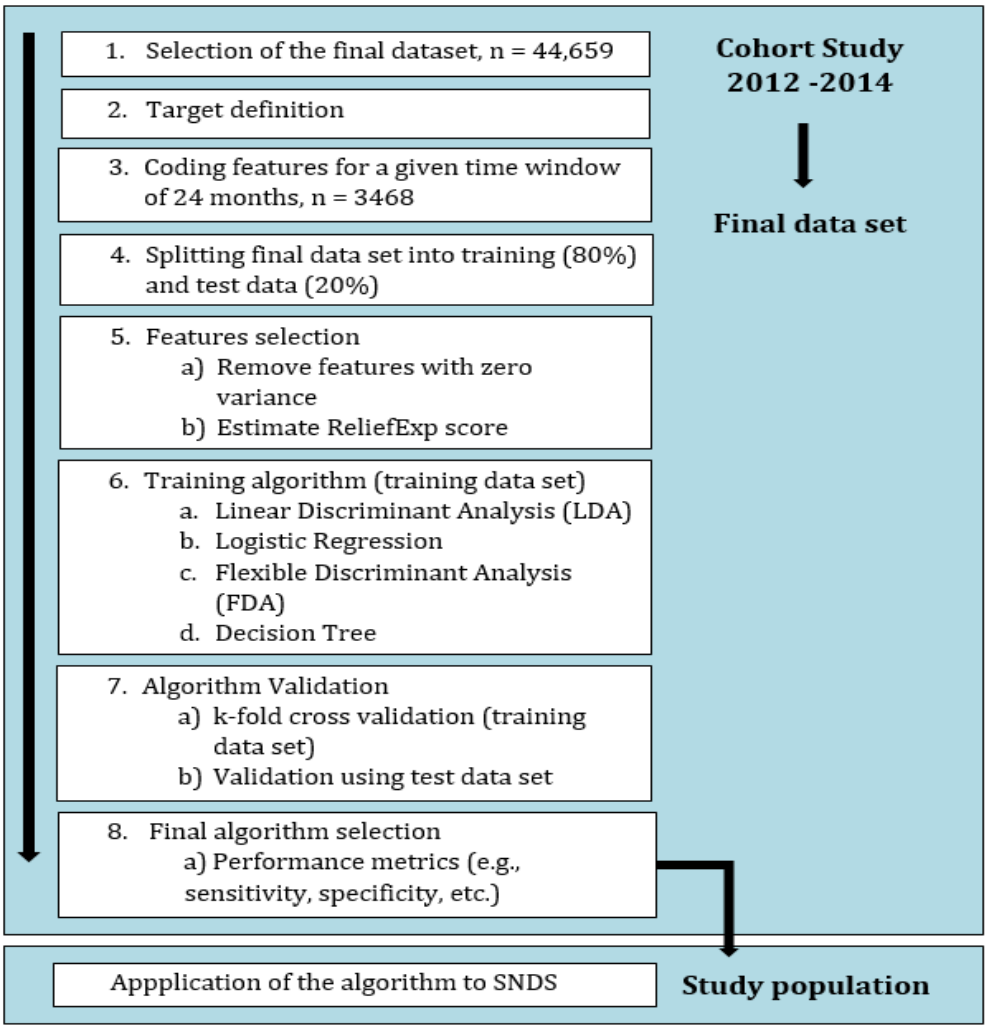
The possibility to link different data sources with each other and the use of artificial intelligence to analyze large datasets are increasing in healthcare. These innovative techniques (data linkage and/or artificial intelligence) have several advantages such as data linkage improves completeness and 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, linked administrative 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 techniques 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]. The 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 3,468 SNDS variables that were coded similarly. Only 23 of those 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 the 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 applying machine learning and 2 studies using 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 makes challenging to analyze 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 comparing various approaches used for innovative use of health information across MSs, and iv) would support to develop the methodological guidelines, which allow to estimate health indicators using linked data and artificial intelligence. Eventually, the evidence produced by using innovative techniques would guide policymaker 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)

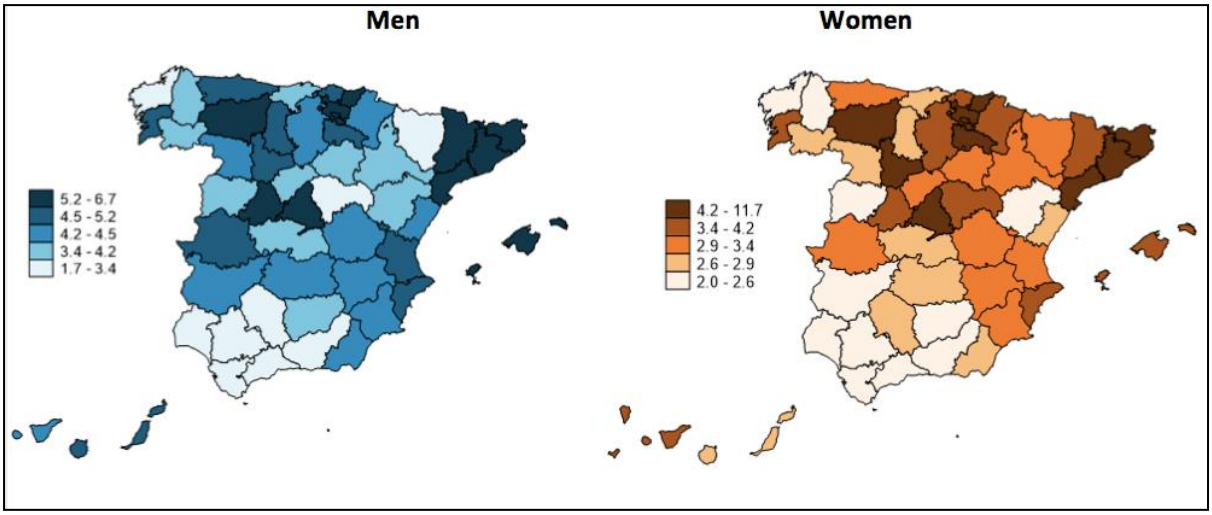
Using data linkage and/or the use of artificial intelligence to estimate and predict health indicators varies across EU-MSs and the estimation of health indicators from linked administrative data is challenging due to several reasons such as variability in data sources and data collection methods, availability of a large number of variables, lack of skills and capacity to link and analyze 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 a study design, iii) selection of 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 developing 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 examining 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 HSP, which is especially important in reducing the impact of COVID19 pandemics on vulnerable populations.

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

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

IJB: Congratulated the speakers and recommend to publish all results, since it makes them more accessible to national correspondents and the 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 they 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 we validated and assessed that the performance was adequate in the cohort study then it could be applied 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 individuals 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: The implementation of GDPR is different in different countries, and of course it was perceived differently, which makes very difficult to be able to link 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, needs 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 making 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 EEA countries).

The survey collected information on data related to 91 projects/studies from 18 EU countries, and the most important results were: i) only 1/3 of the projects share data with EU research networks, ii) less than half of the projects follow meta-data reporting standards for data description, iii) less than 1/3 of the projects evaluate all quality criteria defined by Eurostat and ECHO, and iv) 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 HSPA 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 an information or discussion base for health policy is a key objective of health reporting (‘data for action’).

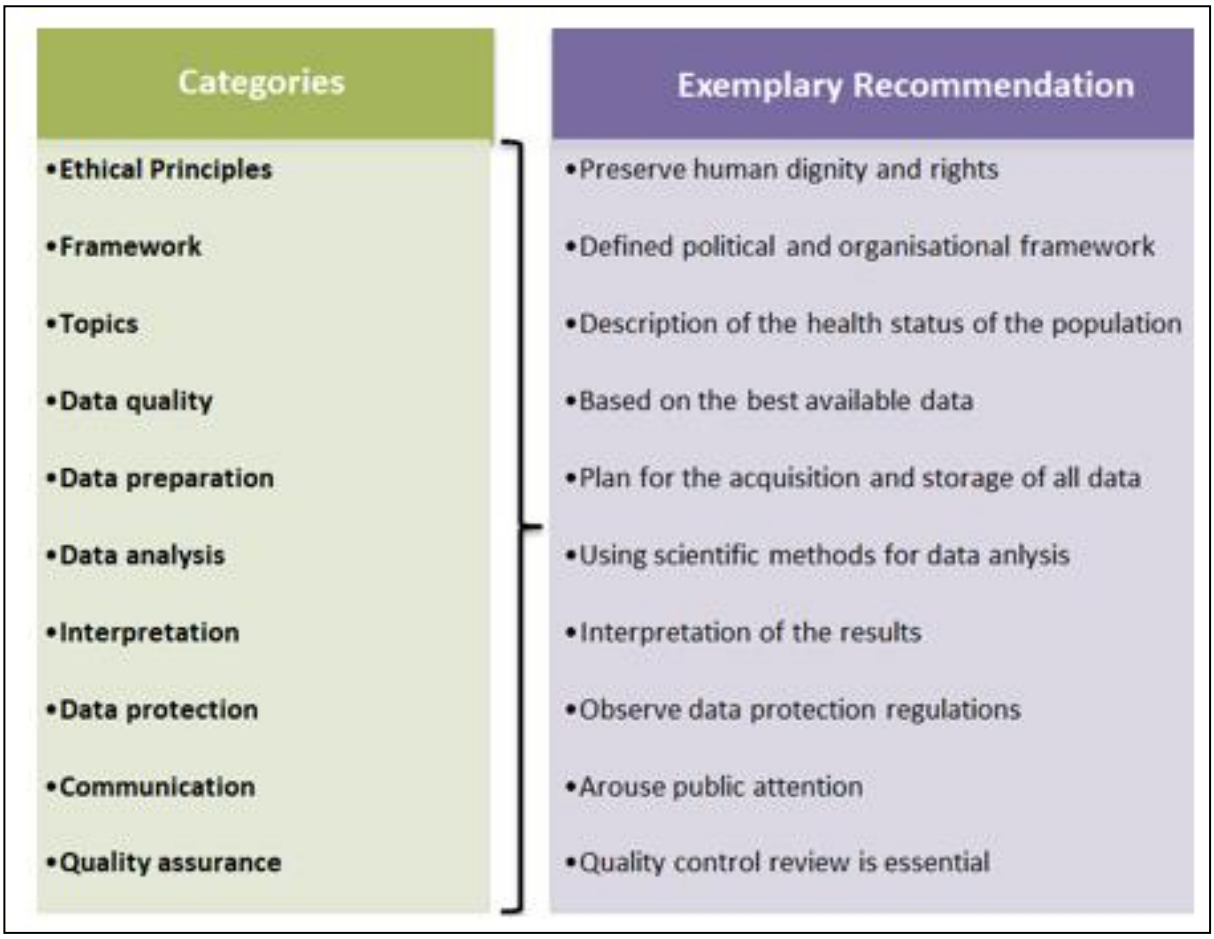
A web-based desk research was conducted among InfAct countries to generate a comprehensive overview of different national health reporting formats and their respective target groups. A guidance document for MSs and regions for health reports was drafted to facilitate making health information adequately 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 with a variety of quality criteria for health reports 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 strengthen 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.
- 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 MSs effort and it was first implemented in 2012. Currently contains 88 indicators. DG Santé 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 on EU and national level, there are no formal updating procedures nor there is 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 it.

Message: *the documentation sheets need to be reviewed regularly (every 3 years) and also to be 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 and developed the idea to change the structure of the shortlist and include a flexible subset to accommodate emerging information needs.

Message: *Content and suitability of the list need to be reviewed regularly (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 EU-MSs/EEA and EU to get more out of ECHI and to 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 MSs. InfAct organised a meeting with DG Santé and ESTAT to discuss progress and possibilities to increase sustainability.

Message: *"Adoption" of the ECHI by EC and MSs/EEA would benefit their HIS.*

In order for the ECHI to be a useful indicator set at the heart of European Health Information, it 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 doc sheets, how to disseminate?
- 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 can go out?
- Who should ideally be responsible for the ECHI? (Role for EC, MSs, 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 a goal to better understand 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 of a work done by a pre-existing project.

We piloted the development of a distributed infrastructure taking into account as pillars the European Interoperability Framework (EIF) and the FAIR principles and we also assessed the feasibility of complying with GDPR and Ethical principles. We also adapted to the organizational specificities of each data hub, assured semantic interoperability across hubs and developed 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				Aragon (ES)

	stroke patients	Insurance data ER data Hospital data	Individual patient Care provider Contacts Time stamps Events	Complete solution Docker with open source Log builder and process mining analysis (1.10)	Marche (IT) Norway (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 HIS 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 2 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: 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 Institute, 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.

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 it is no longer related to single individuals. So, this is a question to all presenters, have you ever thought about 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 it is a very important topic in a way to improve the exchange inside countries and also at the 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 anonymization we have to remember that purely anonymised data means that 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 kept somewhere we are talking about de-anonymised data and GDPR is in mandatory. 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 it is important to have the data that could be link with different kind of databases. For example if you have anonymised data from primary healthcare then we need to make some connection with secondary care, for instance for 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 that it is different anonymization and de-anonymization, when there is a link where we can find information related to that patient. On the other hand, I liked all the interventions and in the overall I think that all these FS 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 them to researchers of several institutes, universities, etc.

Ivan Pristas (IP): I have a brief comment to the discussion, thanks 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 developments. 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 will have to be more involved in not completely anonymised data, either for cross-border sharing or for EU level data linkage purposes. Hopefully, to tackle the barriers of legal interoperability 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? 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. 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 terms of policy-relevant contents.

LL: ECHI is a fundamental pillar for HIS European strategy. Why the European Commission is not so much on it?

MT: It is a really complicated question that we have to discuss with the Commission. I think that there are very dedicated people at DG Santé 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. We

could split it 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 ones 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 these outcomes into national HIS?

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

IJB: I think there are other systems like the BoD and in Norway we have indicators that each municipality can look into (their own data and the 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 the 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 FS on BoD but we did not include it in the agenda as we discussed it last time in the First TD.

RH: Regarding the FS, 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 it 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 for any country to do their own BoD study. These recommendations in terms of strategy, methodology and so on will be shared in the nest BoD workshop.

HT: Linking metadata information is important and it is also important what kind of metadata countries already have it available, published and have the data incorporated in the European catalogue of metadata. 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. Also if we can demonstrate that the indicators 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 could we 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. 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, and we want to preserve privacy. So, in our work we have to fulfil GDPR requirements. Of course we want to do good research and we want to cooperate within countries, but still data protection is an important issue.

IP: In a way I agree with Inger. In traditional health data collection systems, data ownership is not within institutions. GDPR is protecting data privacy. 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 acceptable use of the data, considering data protection, to trace patients without geolocations. That is why it is 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 TD, we are grateful with your participation as EU national experts. Just to remind you that the TDs aim to achieve technical support from National experts on the integration of InfAct outcomes into national/EU HIS

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 important issues (agenda-setting). How health information for national health reporting is prioritized in EU-MSs/EEA 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 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 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 the 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 to 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-MS/EEA countries. The guidance could be further developed into a health information prioritisation strategy at the European level for the establishment of a 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 e-skills).

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 aims to respond to the need of reducing inequities across all MSs and to 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 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 that 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. Face to face component consist 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 Health Information 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 health information.

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 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 health information.

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 (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 health information.

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 Health Information 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 for their use.

3- CAPACITY BUILDING: A sustainable capacity building programme in health information should be stablished, aiming to increase knowledge on availability and the use of standardized Health Information methods and the 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 health information.

5- EUROPEAN FLAGSHIP TRAINING PROGRAM: In this flagship programme, the following thematic areas should be considered as priorities: 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-GDPR).

6- COLLABORATION: Collaboration among European MSs 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 already available academic and non-academic structures specialized on training in 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.

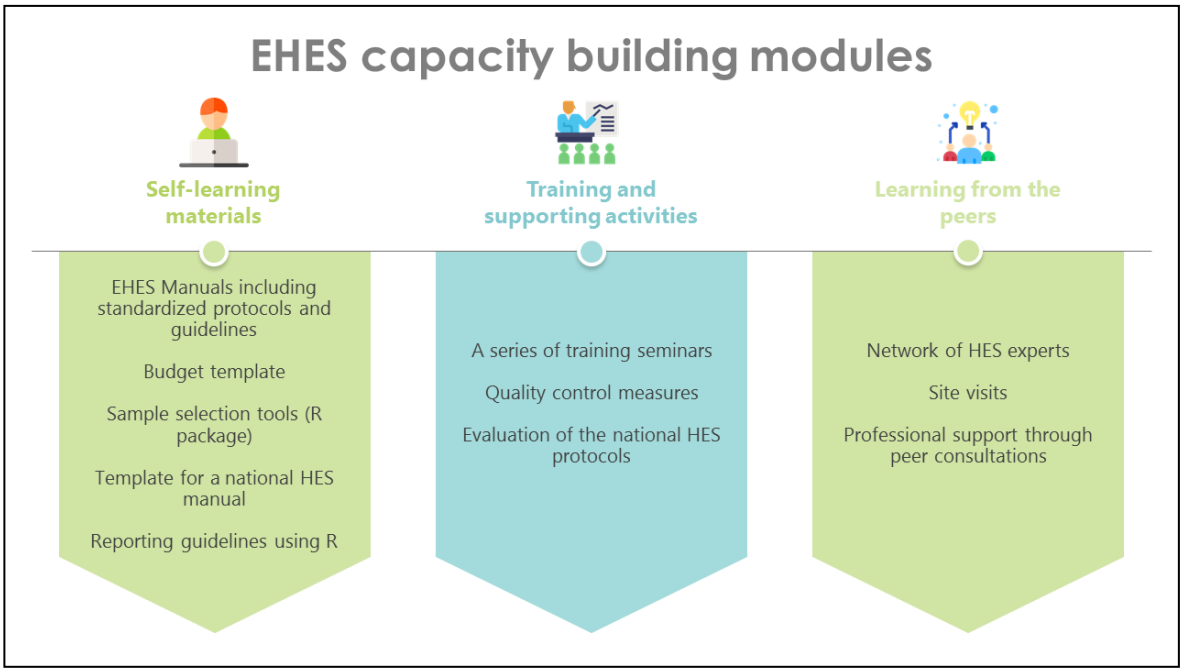
Fact sheet Capacity building under European Health Examination Survey (EHES) (Hanna Tolonen, WP6, THL, Finland)

EHES is a collaboration between organizers of national health examination surveys in Europe (HES). EHES supports 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: i) material for self-learning, ii) training and supporting activities and iii) learn from your peers and are shown in detail in the figure 4.

For cross-country comparisons, knowledge to use standardized protocols is essential. Currently, EHES network exists without a 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.

Figure 4. Capacity building under the EHES



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

AP: We open the discussion panel. Please let us know your 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: 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 people should not come to the examination clinics and we cannot do it at their home visits. I think that Germany is one of the countries that is planning to get started when the 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. Now there is no new date for restarting. It seems to be wise to wait a little longer before planning to start again.

RH: I have a question for Luis. You will also focus on data analysis. Which 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. You can check it at the website

Herman Van Oyen (HVO): This is the pilot course, which is focused on one particular topic. For the next 5 to 10 years additional topics and more technical and methodological issues 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): 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 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, 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 an amazing number 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 there are similar networks in every country. Thus, I think that 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 courses 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 it to online mode.

IJB: Online courses 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 organization, etc. Moreover, 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: Thank you for your suggestion, I think this feedback is very important.

SS: I would like to quickly explain for Germany that we have 10 applicants from our institute in Berlin, but only one colleague was supposed to apply. Thus, we decided not to distribute the information any further. Although I think next year or for 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 calculations on the costs. In the roadmap for sustainability, it will be decided how to proceed in the future.

IN: I have a comment for the FS on prioritization of HI from the Robert Koch Institute colleague. 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 is very important for the current necessity. Under the current situation, HI will be prioritized 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 and has its own responsibilities on the health of the population. Whether it is feasible, it is a difficult question, but we would be needed prioritization more than ever.

SS: Setting up structures to prioritizing HI is something that really would need some time. It is good to have the results of our survey at hand to structure how we prioritize HI. So, maybe in the future when there is a second pandemic we will already have a system to work with.

IV: I have another question for Robert Koch Institute. 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. 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 Delphi policy, does not necessarily have to be representative

SS: Once the analysis is finalized 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 an earlier meeting with experts and discuss our findings to search for recommendations to be approved by 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. Thus, are these factors included in the FS?

SS: For the priority setting strategies, next step is a list of good practice approaches and recommendations. The idea is to work with those outcomes at the national and EU level so

once you work with those results you are going to set up your prioritization strategy. It is a 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 prioritizing 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 about what is desirable. If there is something highly desirable you have to look at the feasibility. It is good to have a system for prioritization, 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 FS and the presentations that have been presented today.

IJB: I think it is really important the work that has been done. There have been many practical issues and important topics to discuss between countries and when it comes to creating courses, it is important to check if there are similar courses given elsewhere. At Norwegian universities they offer also a training course that it is organized by the Nordic research network. They are 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 this lapse 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 more 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. There is an added value in better understanding health information. Now it 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, at this moment, we cannot assess the possibilities to integrate them into the national HIS.

RCh: The course has high feasibility value because the resource is here, and all countries can use it 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 to use them in a country. There is a big step from having these 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 any 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 use it 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 these TD with NE and one at the political level, which is the AoM with representatives of Ministries of health and Research. We will 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 decision makers. Maybe this pandemic is a platform to develop innovative ways to tackle help problems by reinforcing the role of TE

RCh: I agree with you. We are much more visible now and we can use this to be more proactive in things that you want to implement. But now everything is focused on the COVID-19. We need to be able to transpose this to other diseases as well.

AP: I will make a summary of the session, a Pan European health information system prioritization 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) connects networks and stakeholders to enable top level research, to identify sources, access sources, assess quality of source and reuse of data sources. It is aimed at policy change, practice change and technology change. Its ultimate goal is to improve health and other outcomes.

The 3 most important **DOMAINS** to understand population health and health systems are: 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 on this.

Health systems comprise close to 10% of GDP in most countries and in some countries even more. Better understanding of 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) has a comprehensive view on population health data (administrative data, vital statistics, health surveys, longitudinal studies) and health care (e-health records, hospitalizations), iii) facilitates the 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 a 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.

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, organizations 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).

Figure 5. DiPoH services.

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

In many EU-MS/EEA, 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 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 and update on initiatives. Moreover, 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 NN. To do this, InfAct initiated a NN 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. Based on the collected experiences, InfAct developed a stepwise approach to set up a NN. The stepwise approach provides European countries with guidelines on how to set up, define, and organise a NN. 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.

InfAct keeps a record on the current status of the NN in the partner countries. Countries have presented their NN during the General Assembly meetings and subsequent NN 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 NN: 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 HIS have shown enthusiasm in this endeavour.

Example of NN: case study of 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 NN 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) to enable effective and safe processing and access to data, ii) to enhance data protection and security, iii) to eliminate administrative burden and iv) to 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, enhances and supports the secondary use of existing resources and reinforces 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 that every country will decide on its NN's structure and activity to be developed?

PB: The NN functionally is more or less the same within countries. I propose that different stakeholders, for example the Ministry of Health, the public health institute, the statistical office, are brought together to discuss issues that are happening at the national level. I provided the example of "Findata" because there is a room for development of this NN on health data. What happened at these meetings is that they are now organising more frequent meetings and more actors are 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 still have challenges about 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 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 concerns. 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" they have a budget of 10 to 20 million euros; so, it is never the purpose of the infrastructure to take over but it is to build on other initiatives that other people have been doing at the national level, 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 it 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. Thus, 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. Countries actually signed, which means that 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 a new funding, which we called Population Health Information Research Infrastructure (PHIRI) and it will start the 1st of November. We will build these catalogues with the perspective of COVID 19. We will provide finances to the countries to be able to fill in the catalogues and to describe what kind of resources are available at the country with regards to COVID-19 databases. We will also catalogue capacity building exercises. Our colleagues from Portugal will be looking the different trainings 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 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 in your country? Or if you have not heard about, do you think it is good to organise a meeting with this NN?

IV: 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. 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 it is the NN, since we already have this platform where all researchers apply for all needed data at the same time.

PB: Every country is different, so it is up to the country to see whether they like to set up this NN. But in many countries there are a lot of different players that interact with the health data hub, so 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. We have "Findata" but 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 takes 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 the WHO tool for health system assessmen, 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. 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 will be operational in 2 months we will reach out the NN to ask them to actually share their information on different data sources that are available in the country. 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 with us, I hope this is just a temporary situation and we will see someone from either DG Research or DG Santé 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 the national level. 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 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. 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 continue to work cooperating in this line. This is the only weak point on the project as 90% of the objectives have been achieved. I think it is not our fault, but it is an aspect that we need to overcome in the future. Thank you for the excellent work and it was more than 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 needed 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 hot topic; so it is 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 not only during the upcoming crisis but also at regular basis.

V. Implications and limitations

Main Implications of the TD are the need of integrating views, and recommendations from all participating national technical experts. They are considered the link between 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 infrastructure.

The format of TD as platform for discussing InfAct outcomes with NE share the same limitations of a Delphi consultation. A wider participation and involvement from countries would have been welcomed, to enrich discussions and provide new views, but in terms of objective-achievement, an extended participation is not necessary in this kind of expert meetings. We are satisfied with 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 HIS.

1) There was a consensus about the ***added value*** of the 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 the 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 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 countries´ 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 (NN) 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, the need for stronger EU-MSs coordination and collaboration was also highlighted 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.

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