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InfAct: FIRST ASSEMBLY OF MEMBERS (AoM).

(March 12th, 2019. Madrid. Spain).

MINUTES

1. **Welcome by Dr.Isabel Noguer (IN), Leader of Work Package 4. Instituto de Salud Carlos III (ISCIII). Ministry of Science, Innovation and Universities. Spain.**

IN introduced the work package (WP) 4 (Integration in National Policies and Sustainability) of the Joint Action Information for Action (InfAct). IN informed that InfAct gathers 28 countries and 40 institutions with the aim to improve, and provide innovative advances for health information systems (HIS). She stated that the present Assembly of members (AoM) counted with the participation of 19 countries and 29 representatives from ministries of health and research from The European Union (EU) Member States (MS) and EU Economic Area (EEA). She introduced Raquel Yotti as Director of the ISCIII and Prof Neville Calleja, as chairman of the AoM.

2. **Welcome by Dr. Raquel Yotti (RY), General Director of ISCIII. Ministry of Science, Innovation and Universities. Spain.**

RY gave a background review of the mission of ISCIII as the institution that promotes health research and innovation, provides scientific and technical support for the national health system and gives general advice for policymaking.

RY also stressed the importance of the sustainability of health systems and underscored the relevance that has research and innovation to accomplish this task. RY also highlighted the critical role that has a solid health information system (HIS) to improve the performance of health systems. Finally, Dr Yotti welcomed MS representatives and invited them to discuss the main subjects that could facilitate the sustainability of HIS across the EU.

3. **Professor Neville Calleja (NC). Chair of the AoM. Director of the Department for Policy in Health, Health Information and Research, Ministry of Health. Malta.**

NC gave an overview of InfAct, as a project that embodies 20 years of methodological experience on health information in Europe, and that should be sustainable in the future.

NC, based on his experience as health information producer and policy maker, stated that the demands of health information coming from ministries of health (MoH) are progressively

getting very complex and more specific. He remarked that the challenges, upcoming for health information producers, are to research and develop new methods to better answer policy makers demands and to assess the MS needs. As health ministries need evidence to deliver better health and wellbeing to the population, the health information producers strive to provide relevant health information for policy makers. Thus, building a sustainable infrastructure could improve health information (HI) for a better evidence-based and health policy making.

NC explained that the purpose of the meeting was to discuss the needs of MS to make InfAct sustainable and adapted to the needs of the countries. NC also summarized the Terms of Reference (ToR) and operating procedures for this AoM (*Annex 1*). NC said that this AoM is a forum of dialog for MS, which also had the attendance of international observers (DG Santé, and WHO, among others). He also highlighted that the objectives of the AoM were: to provide guidance to optimally shape the future HI infrastructure according to the national needs and to advocate for its sustainability. Thereby, this infrastructure will be designed to fit the needs of the countries. Finally, through the time fame of the project, the AoM is expected to have 3 meetings (two meetings in 2019 and one meeting in 2020).

4. **Introduction to InfAct. Dr. Herman Van Oyen (HVO), Coordinator of InfAct. Director of Epidemiology and Public health, Sciensano. Belgium.**

HVO, asked representatives to reflect about the need of building a sustainable research infrastructure: How efficient are health systems in our own country? How are such systems compared to other European countries? As InfAct, expects to improve the structure of HIS across Europe, those questions could be appropriately answered. HVO outlined the gaps between and within MS in terms of health status but also in measuring population health and presented the goals of InfAct to strengthen EU and national HIS: (1) establishing a sustainable research infrastructure (RI) which will support population health and health system performance assessment, (2) strengthening European HI and knowledge bases and HI research capacities, to reduce HI inequalities and (3) supporting HI interoperability and innovative HI tools and data sources. He then focused on the conceptual framework of InfAct based on 3 pillars: (1) political support focusing on the development of a business case and a road map for the implementation of the RI, and the integration of HI into regional and (inter)national policies (2) capacity building based on assessing HIS through peer review, developing a flagship training to reduce HI inequalities, identifying relevant HI networks and prioritization strategies and (3) HI tools focusing on improving the quality of data, the development of new ways of using existing data sources to derive indicators, the use of new technologies for HI, and the interoperability of health data instruments and sources.

InfAct is working on assessing the current status of HIS, strengthening HI capacity, assessing and piloting interoperability for public health policy, providing innovation in HI for public health policy development, providing optimum tools and methods for HI support, developing a proof of concept for a sustainable structure and finally facilitating the integration into national policies and sustainability. The project is organised in 10 WP whose main tasks are listed below:

- WP4: Organisation of the Assembly of Members with representatives from Ministries of Health (MoH) and Ministries of Research (MoR), fostering Technical Dialogues between technical national experts and WP leaders and the elaboration of the Sustainability Plan.
- WP5: Assessment of HIS through peer-review assessment, cataloguing of networks and projects and prioritization of health information.
- WP6: To design a roadmap for capacity building and a flagship training programme.
- WP7: Elaborate the application for the ESFRI roadmap, connection of MS health information networks, connection with pan-European research networks, development of a business case and a roadmap and the creation of a web-based platform.
- WP8: Health monitoring data, collection methods and indicators. Elaborate guidelines on accessibility, availability, and reporting in HI.
- WP9: Sharing inspiring examples from MS on emerging indicators and data sources to target priority public health actions and health care strategies, enlarging the set of morbidity indicators available across the EU.
- WP10: Mapping and analysing (inter)national inspirational case studies on public health interoperability, developing practical empirical work through case studies and its piloting.

The expected InfAct´s outcome is to build an EU RI that will allow MS and the EU to improve health performance through: an advanced scientific knowledge, increased capacity building and research targeting, improved interoperability and innovation in health information, a more robust data collection and a better-informed decision making for research and policy that will enhance its sustainability.

Comment: Philip Roux from DG Santé highlighted the timeline defined for the project and remarked that the main purpose of the meeting is to make policy makers take the right decisions regarding HI and to define strategies to work together in achieving the goals proposed for the project in a timely manner.

5. **The current EU HIS: challenges and needs. Linda Abboud (LA), Coordination of InfAct. Project Researcher. Sciensano, Belgium.**

LA addresses the question from the representative of the French MoH about the meaning of HI for InfAct. LA defined it as all the data, evidence and knowledge on health and health system performance at individual and population level to facilitate research promotion, prevention, care and support policy making. Additionally, a HIS could be defined as a complex, multi layered system, aimed at producing health intelligence. The steps relevant for population health monitoring from data collection to knowledge translation and policy making were underpinned by research and ended up in evidence for decision making as the most important output of the HIS.

Health and health care, are major policy areas that draw intense political and societal attention because of the increasing concerns to respond to the needs of the citizens, a higher

notion of social justice and equity in Europe and therefore higher expenditures in national health. As a consequence, high-performing equitable health systems need to be guided by health information. Such health systems require up-to-date data and high-quality data, innovative and relevant research and good practices.

Regarding the EU health information sphere, the key players are international organisations, such as WHO and OECD as well as the European Commission, and also numerous individual and independent projects working on health information that are not included in the network of such key players.

The current situation of health information shows that there have been some successful projects that have incorporated their outputs into Eurostat and the Joint Research Centre (JRC), but in general, when funding finishes, the project is discontinued and then all the data is dispersed or this knowledge is stored but not used, and the networks of experts fall apart.

There is a lot of fragmentation, knowledge is dispersed and data are incomplete and difficult to access. HI activities are project based, therefore there is no long term planning; which produces duplication that causes a waste of resources. In addition, there are inequalities in terms of quality and research capacities across European countries. So there is a need for a HI infrastructure to bring all this together and to solve these challenges.

This problem has been discussed since 1998 and finally in 2013 the Council conclusion was "*to cooperate with a view to establishing a sustainable and integrated EU Health Information System, with the potential of a comprehensive health information research infrastructure consortium (ERIC) as a tool*". Thus, the need for an infrastructure at European level was clearly identified and started with the BRIDGE project in 2015 and continued with InfAct in 2018.

6. **The concept of the Health Information Research Infrastructures: rational, goals and added value. Petronille Bogaert (PB). Coordination of InfAct. Project Researcher Sciensano. Belgium.**

PB explained the concept of a RI as an integrated structure that is capable of connecting networks in HI and overcoming fragmentation to enable top-level research for better evidence and more intelligence to support evidence informed policy making with the overarching aim to improve public health (population health and health care system). The main goals of a research infrastructure are: (i) to make available and share quality data, information and tools, (ii) to strengthen scientific knowledge, promoting scientific cooperation and integration, (iii) to support expertise development, methodological innovation and the use of HI to inform policy. The scope of this infrastructure is to fill the gap in population health and healthcare systems.

A RI that has one coordinating hub (central office with a web based platform that delivers services) with different hubs connected around this central hub. There are 2 types of networks in this infrastructure: (i) a *domain specific network* is a group of collaborating researchers on a common health topic or method, and (ii) a *national network* that is a consortium of relevant national actors and stakeholders.

This infrastructure is organised in 4 main services: 1) One stop-shop for EU HI research: The idea is to have a place where anyone can find the HI that are looking for, not only data but also guidelines, tools and reports, 2) innovative research in HI: to support new methodologies and provide computing, interoperability and tool services but also ethical and legal support, 3) Capacity building in HI. As tackling inequalities in Europe is a crucial issue, this infrastructure will have an overview of professional training programs for public health specialists, statisticians and epidemiologists, and 4) Decision making based on evidence based research, focuses on engaging with policymakers and providing them the tools they need for a better prioritisation and translation into policies. The added value for research is to have EU comparative data (fair HI, data quality checks, large cohorts for research, enhanced data access flow, structured scientific exchange, produce quicker results and ensured ethical and legal compliance) and to build a collaborative network (organise and connect public health expertise and systems, create synergies between projects and health information activities, better access to existing knowledge and expertise). On the other hand, the added values for society is to have quality information on evidence based decisions for policy and decision makers, enhanced monitoring of health risks and health related problems to improve health and wellbeing, to optimize funds allocation for financers and to help administrators by providing an overview of international data collection so that duplication is reduced (*Annex 2 Policy paper*).

In summary, the proposed RI plans to tackle the challenges of HIS

Problem	Expected solutions
Fragmentation	Connecting stakeholders and information, efficient use (reuse) of data
Inequalities	Capacity building, knowledge translation
Project based	Sustainable infrastructure, knowledge depot, return of investment

Comments and questions:

Bertrand Schwartz, French MoR Representative.

Some HI are already there, and has been checked for quality. Quality must be checked before collecting data. You must give figures at some level.

What is the action of the proposed infrastructure? What are we supposed to do? Is it to work on quality? What is the overall purpose of the infrastructure apart from connecting data?

HVO illustrated the answer with an example of two levels on which you can think about data. The first issue is to ask a simple question to yourself: What do you know in France about diabetes? That is a simple question and I can tell you it is a very hard answer to find. First of all because there is no clear definition about what people do about diabetes, if the main treatment is getting people on diet and exercise, this kind of information is currently not integrated because we are focused on what it is done in terms of pharmacological treatment.

On one level, there is simple data that should be there. Burden of disease (BoD) is a very old indicator that was promoted by WHO and the World Bank and it is about combining years lost by early death and by bad health. Right now only very few EU countries are currently able to do this calculation, because they understand the mathematical modelling behind it and used it for establishing policy priorities. Thus, this is basic data that should be there and that is collected through the national bureau of statistics. At another level you can think about genomics because previous research have identified traits that are potentially linked with cancer but at the moment there is no clue on how to act medically when people have these traits. In addition, there is no knowledge about the causal link in people that have both cancer and these traits. Therefore, the question is how to introduce this knowledge about genomic and big data not only into clinical research but also at population level. In conclusion, it is not only about collecting data but to be able to use what is already there and to know which standards are necessary to do so. For a comprehensive health information infrastructure, it is important to bring researchers, epidemiologists, social scientists, health economists, and different professionals that are working in different projects to facilitate the exchange of knowledge and methods. Many things are established but they are fragmented. For example, if you ask about a particular health problem, depending on the data source you use (WHO, Eurostat, OECD) you obtain different answers.

7. **Case study Euro-Peristat: research networks in public health. Marie Delnord (MD), Euro-Peristat and Sciensano. Belgium.**

MD informed about maternal and newborn health in Europe (importance as a burden of morbidity and mortality, differences on mortality between and within countries, the crucial need of new technologies and limiting the iatrogenic effects) and why it is a priority for surveillance and research. Euro-Peristat project is an EU-funded initiative starting in 1999 with the aim of monitoring perinatal health in the EU and it is based on valid and reliable routinely collected indicators. In this network, 31 European countries are participating. It uses population-based data during pregnancy, delivery and postpartum. Its data sources are vital statistics, medical birth registries, and hospital discharge data.

Monitoring maternal and newborn health in Europe is important because EU countries face common challenges: average increase of maternal age at delivery and higher prevalence of obesity among others. Moreover, the approaches to perinatal health differ greatly across Europe, many country level indicators are not comparable and key indicators are not available in the international databases (preterm birth rate, maternal smoking, etc).

In Euro-Peristat there are core indicators that are essential for each country to monitor perinatal health: newborn health (fetal, neonatal and infant mortality rates, birth weight distribution, distribution of gestational age), maternal health (maternal mortality), population and risk factors (multiple birth rate, distribution of maternal age, distribution of parity), health services and its provision (mode of delivery). Furthermore, there are 20 indicators that are recommended to monitor the percentage of women that smoked during pregnancy, distribution of mothers' educational level, distribution of parents' occupational classification, distribution of mothers' country of birth or distribution of mothers' pregnancy

or body mass index (BMI). Translation from knowledge to action needs good research and evidence to sustain interventions and policies, which could improve maternal and neonatal health. Research outcomes need to be communicated in appropriate way through different channels (in Euro-Peristat such channels are Perinatal Health Reports, data on indicators that are available in internet and scientific conferences). In addition, publications in peer-reviewed journals add validity to all Euro-Peristat products and its results are used to inform clinical guidelines, policy briefs and to improve the quality of perinatal health monitoring. There is also a potential to generate revenue streams by leveraging data and expertise. Euro-Peristat data aid in the investigation on the population determinants of maternal and child health and the indicators are used to generate hypotheses about the reasons for differences in health, to identify high and low performers and to set benchmarks for policy. For example in the Netherlands the analysis of poor mortality rankings ended up in an assessment of quality of care and further reorganisation of antenatal care that had positive outcomes in maternal health. There is also a platform to develop better methods for cross-country data collection/analysis and to collaborate with other EU research projects. The impact of Euro-Peristat has been observed in promoting best practices among national professional societies through the development of the European Board & College of Obstetrics and Gynaecology (EBCOG) standards of care, on raising visibility of maternal and child health inequalities and to advocate for better outcomes by The European Foundation for the Care of Newborn Infants (EFCNI), standards of care for preterm births and fostering international organisations consultation to update reporting criteria, for neonatal and infant mortality data.

Building a European research infrastructure might have a strong added value for the Euro-Peristat network because research at EU level provides strength in numbers by increasing the capacity to detect population determinants with a small but cumulative impact on health. In addition, it is an opportunity to boost research by extending hypotheses to the social and environmental determinants of health for solution-oriented research.

In her concluding remarks, MD pointed out Euro-Peristat's vision for a sustainable perinatal health reporting. They support the idea of creating a European RI to facilitate participation in European research projects across domains, with regular collection of Euro-Peristat indicators and a pluridisciplinary network of experts who would meet regularly to analyse and interpret data.

8. **Improving health information and health information systems through InfAct: what's in it for MS. Dr. Enrique Bernal-Delgado (EB), Senior Health Services Researcher. Institute for Health Sciences in Aragon (IACS). Spain**

EB started his presentation with a set of research questions that could be relevant for public health professionals

- Would it be possible to predict the attributable fractions of risk after a public health intervention, and to report them as quick as possible?

- Could I know the economic burden of a disease?
- Could I discover care pathways of chronic patients and to see whether different pathways are responsible for different outcomes?
- Can I access to open source data models and analytics to respond similar questions on public health research?
- Can I get advice on how to reuse existing datasets in public health research?
- Is there any training program that could help me to develop my capacities to conduct public health research reusing existing datasets?

These are questions that public health specialists are asking themselves to produce relevant and meaningful information for policy decision makers. Public health research is oriented to public decisions, and it is addressed to answer relevant questions to promote evidence-based decision-making.

InfAct is working on several case studies to demonstrate the added value of research for better health for the MS. The idea is to answer these questions and to assess if a potential ERIC provides the researchers an added value to respond to those questions. For example, when it comes to the economic burden of disease: could we know the cost of outpatient care in patients with dementia? InfAct in France has conducted a linkage exercise about individual episodes of dementia in different settings and tracked them down for a year. Then they allocated the costs derived from those patients and compared France with other European or OECD countries using the purchasing parity power. They assessed that the cost of dementia was much higher in France.

Another question for these case studies are: Would it be possible to predict the attributable fractions of risk after a public health intervention, and report it as quick as possible? This question is related to adding different data sources for predicting events on the basis of machine learning algorithms. When you add information, you refine your prediction of the attributable fraction of such events.

A third important question. Can we know how care pathways work and how they impact patients´ health? In the case study that we present, data sources from 6 different countries were mapped and compared. There were a variety of data sources and, as different institutions have different pathways of care, we could see that outcomes were different depending on the pathway of care.

The ERIC services are aimed to answer these kind of research questions. The interoperable data model (IODM) that we are proposing is focused on the following aspects: advice on the definition of entities and attributes to build the indicator and confounders, available semantic and syntactic repertoires, available metadata from other projects or HIS and to deal with legal and ethical provisions to access raw data. There will be Extraction Transformation and Load (ETL) scripts to extract events and an IODM for data quality assessment. It will include also a self-contained analytical pipeline for the rapid cycle and a training for full application of such analytical pipeline.

InfAct also aims at capacity building. It will try to answer the following questions: What are our knowledge gaps? What are our needs? What we want to know? Are our HIS good enough to get the most out of the research supported by the ERIC? Am I prepared to design and conduct research reusing existing data collected and maintained elsewhere and to produce relevant policy-oriented research outcomes? Do I have the computing capacity to do so? InfAct hopes to pave the way for capacity building by carrying out activities such as developing a prioritization exercise along with MS to understand how to link the research agenda with the policy making needs, performing a formal assessment to understand HIS current status and how they could size up to others in Europe; thus, to get the most out of the research supported by the ERIC, maintaining existing datasets from past and ongoing European projects of interest for the research and policy making communities and mapping out existing training programs on the reuse of routine health data to foster better research.

Questions & Answers

Jerome Weinbach from the French MoH. You are supporting an ERIC. Are there any options in terms of the legal status of your activities? What kind of services do you want to provide at the EU level? How are you including existing opportunities that are supported by EC (ELIXIR, etc.)? Do you plan to design the RI from scratch or to use the existing infrastructure?

HVO: There is a missing link in the puzzle if you look at the health domain. We´ll try to use what is already there. There are activities dealing with clinical and experimental design; although there are no activities on population health. We will work with key research existing communities. We need to think big and do little to accomplish a lot, because currently we are doing a lot and none of our investments gives a return of investments.

Aziz Naji Belgian MoR. This task entangles a lot of difficulties, because data is collected in different ways and it is not harmonized so we need to put it together to add another layer of analysis. It means creating a RI to safely store data that could be useful not only for ourselves because that is the issue with an ERIC. I do not think that this is already an infrastructure in itself, but a process. How would you go step by step towards a full grown infrastructure such as the one you described?

EB: The environment of networks working in Europe doing research are very likely based on a centralized infrastructure data and it is necessary to move forward. It must have flexibility and provide remote access to basic data to all users. Data could be in a cloud and to access to metadata and data with detailed granularity so if you wanted to get further information it would be necessary to provide the protocol and the purpose of such data. So it should be flexible not everything for everybody, centralized, or partly decentralized and maybe shielded. We are not starting from scratch but starting from the needs.

PB: We should not answer all questions today. We are in the application process and when you have the ESFRI application you are provided with the resources to develop this platform. What we have to do today is to show the way forward and how we are going to do this over time.

NC: The details of the technical issues about the platform will be defined after ESFRI application. What we have to do today is to know what we want this RI to produce.

Patrizia Theurer, Representative from the Austrian MoH. Recommended to think about flexibility. It would be interesting to have 2 levels of participation because for instance Austria is just starting to link many data now and is not participating in the projects you have mentioned.

Lieven de Raedt. Representative from the Belgian MoH. Expert group on Health systems performance assessment (HSPA) started their discussions with the conceptual and normative framework. What is performance of a health system? They answer it first and then continued with the next steps of the project. I think here the conceptual and normative debate is missing.

NC: I am participating in the HIS assessment. It is giving us very rich information about local context specific landscape in Europe. We found weaknesses in which we perceived previously as strong information system and strengths in those that we previously perceived as weak information systems. So, at the end of the session we may have some answers to this question.

HVO: contextual framework can be driven by many elements. It is important to define first what the subject of study is: Air quality? Health system? So conceptual framework depends on the subject and when you work in a multidisciplinary group you allow different visions come together in a conceptual framework.

EB: Normative framework also depends on the subject and it is project specific. We cannot define it now because this project is unspecific at this point of time.

Ricardo Proença. Representative from the Portuguese MoR. My question is about the future scope of the RI. I saw that one of the main objectives was to set up data collection networks at the European level and data standardization. The question is: if we have a health research project that produces a dataset and that is considered relevant, is the RI that you propose open to register that data?

HVO: Yes this is one of the main aims of this research infrastructure

Philip Roux: I think it is the outcome what is more important to think of. Two elements of reflection: 1) the scientific advice mechanism we have in the Commission (SAM). We expect the same here. The politicians ask questions and we expect the technical experts to give answers and 2) to identify financing mechanisms and institutions apart from the ESFRI application.

9. **The importance of research for policy making: the health system performance example. Dr. Josep Figueras (JA), Director of the European Observatory of Health Systems and Policies. WHO Europe.**

JF started his presentation with the argument that the policy side is messy beyond belief so putting energies in knowledge translation is urgently needed. This does not mean that InfAct is not necessary, quite the opposite, without the quality, validity and comparability of data, there is no point in translating that data and deliver it to policy makers. We need information and research for policy impact. The idea is to be aware of the uses and misuses of Health Systems Performance Assessment (HSPA). There is no doubt that more HSPA is needed because MS need to demonstrate transparency and impact of the health systems, particularly in time of crises. We want to learn from best practices. Moreover, in this times people don´t want to be in the Health System only as patients, they want to be more proactive.

When interpreting HSPA for policies a number of questions arise: What we want to measure? What is the domain? What is health system performance? It depends on who and how is being measured.

Several years ago WHO defined objectives of the health systems: Level of Health is the 50% of the performance, with both responsiveness and financial protection account for 25% each one. In turn, responsiveness is divided in equal parts by level and equity. However, what ministries of finance care about is Sustainability and Cost containment and three potential scenarios might appear: contain costs and increase efficiency, contain costs and decrease efficiency and contain costs and decrease health.

There are key questions on policy interpretation of HSPA: 1) What do we want to measure? It is related to the phenomenon and domain under assessment and to the framework to be used, 2) Are these the right indicators? Are we measuring them well? The indicators should measure the domain under assessment, have good data quality and a comprehensive methodological approach (risk adjustment, composite indicators, roles of values and trade-offs and absolute and relative levels of performance); it is important to be aware of methodological complexities. 3) What the differences mean? How to interpret the data, who is accountable for this results? For example diabetes is a good indicator for effectiveness of primary health care avoidable admissions, it could be used for some insight into performance and country comparative position, as a starting point for further discussions on quality improvement and it is a good reflection of the overall quality of primary health care, 4) What can we do about? It could be oriented to different policy interventions at primary health care, hospitals, governance or access and to policy levers (public reporting, incentives, regulatory tools, consumer choice). At this point, it's necessary to be aware of perverse incentives, interpretational interests to resist change and complexity in changing clinical and policy behavior.

To sum up, there are some lessons for policy: (i) Need data valuable for HSPA comparisons, (ii) variety of data sources, (iii) data is easier to be used for describing population health or health systems, (iv) measurement challenges (methodological comparability, conceptual clarity, consensus, common and good indicators), (v) ensure health systems contextualization, (vi) embed with health systems governance, (vii) link with levers of policy improvement and (viii) knowledge brokering across contexts and from evidence to policy.

10. Group discussion

Individual presentation of representatives, stakeholders and international observers. (*Annex 3 List of attendance*)

Explanation of discussion guide and distribution of groups as presented below

Group	Countries	Facilitator
1	Norway(1), Croatia(1), Belgium(2), Spain(1)	Neville Calleja.
2	Finland(1), Czech republic(1), France(2), Portugal(1)	Enrique Bernal Delgado.
3	Bosnia & Herzegovina(1), Estonia(1), Austria(1), the Netherlands(2)	Herman Van Oyen.
4	Lithuania(1), Luxembourg(2), Ireland(1), Italy(1)	Petronille Bogaert.
5	Serbia(2), United Kingdom(2), Malta(1), Belgium(1)	Alicia Padron Monedero.

All groups were asked to answer two questions:

1) Why or why not an EU health information research infrastructure (RI)? Identify strengths, weaknesses, opportunities and threats (SWOT analysis)

- *What are strengths of having an EU health information RI?*
- *What are weaknesses of having an EU health information RI?*
- *What are opportunities and added benefits for setting up and EU health information RI?*
- *What are barriers or threats for setting up an EU health information RI?*

2) How can an EU health information research infrastructure (RI) respond to your needs?

- *What are your 3 most important needs for health policy?*
- *How can research accommodate your national needs?*
- *How can European research collaboration support these needs?*

Answer from AoM to the **question 1):**

- Nobody questioned the need for a health infrastructure supporting HIS, thinking that "the more countries to follow this initiative, the better in terms of EU-added value and public health utility".

- What it is not clear is the need of a research infrastructure because this kind of infrastructure has to deal with very different needs: Health management, Health policies and Research purposes. Each one with different vision, timeline, objectives, professional profiles and horizons.

- Most participants are not sure whether an ESFRI roadmap or an ERIC are the best way of building up or financing it. They suggested that InfAct should look for other options.

- The ERICs are financed by Member States (MS); therefore, before going any further discussions about MS commitment, it should be clear who will pay and how much. This question is one of the most important issues.

InfAct is not the only project looking for an ERIC. MS could be unsure about in which initiative they should put their limited budget assigned to international research purposes.

- It is assumed that going to an ERIC means that not all MS will join the initiative. This means we will not gather HIS from all countries, so that could put in risk the EU benefit and InfAct outcomes.

- MS stress international organisations (WHO, OECD) difficulties in accessing an ERIC since its administrative framework is quite complex and inflexible for them. How does InfAct expect OECD and WHO to be part of this ESFRI roadmap or ERIC?

- There is a lack of clarity in the proposals. There is a need of a well-structured written business plan including: services offer, funding scheme and funding resources, MS participating, timeline and articulation with current initiatives and stakeholders in the field of health data (DG-Santé, DG RTD, DG Connect, DG ECO).

Answer from AoM to the **question 2):**

- Providing evidence based for political decision is the most pressing need. Policy makers need urgent and performant response. For researchers a response could take years. Therefore, a concern is how InfAct is going to deal with different timelines and needs.

- This project and the future infrastructure should enhance data quality, data availability, common procedures and standardization in data collection, data linking and universal access to EU comparable data.

- Providing a network of experts, with credibility, bringing MS inputs.

- Much diversity for data collection, purposes and utilities has been exposed today, but MS need to clearly identify the domain of this project. We heard in your presentations, that you want to keep to different options, which is understandable on one side, but on the other side it is difficult to sell a project if you don't tell clearly what you really are going to do and which domains are you planning to address.

- The most positive response of this Infrastructure would be to provide available evidence-based information for decision-making process. Providing in a timely manner innovative, quality and comparable data and public health policies across Europe, would be an expected outcome.

- There is a need of linking researchers, policy-makers and patients.

- Common health care indicators and health population data for prevention activities would also be an asset.

- Besides the link between the public and the private sector should be engaged in collaborating and focusing on research questions related to efficiency and effectiveness

- For the future, we need a very clear proposal where decision makers could see benefit and progress for our future health challenges.

In summary

- All counties welcome a unique infrastructure gathering research, best evidence to inform policies and health information systems for health management.

- MS needs clarity on what kind of infrastructure and outcomes are going to be provided.

- MS needs one stop-shop to provide in a timely manner quality and comparable data for decision-making.

- There is a need of linking research and health management in order to increase evidence based health policy.

- Funding such an infrastructure remains a concern, since for being useful in terms of EU-HIS most countries should be involved and providing national data in a standardized manner.

- A research Infrastructure does not need many countries involved, but it is not able to gather in one stop-shop research results and health information for health management and policies

11. **ESFRI Roadmap. Gonzalo Arévalo (GA). Deputy Director for International Research Programmes and Institutional Relations. Carlos III Institute of Health. Ministry of Science, Innovation and Universities. Spain.**

Research infrastructures are facilities, resources and services that are used by the research communities primarily to conduct research and foster innovation_at EU and Associated Countries level. The objectives of the EU approach of a RI are: to address collectively the complexity and cost of the design and development of new world class RI, to open access to the research infrastructures existing in the individual MS to all European researchers, to avoid duplication of efforts rationalise their use, to trigger the exchange of best practice, develop interoperability of facilities and resources, develop the training of the next generation of researchers, to connect national research communities and increase the overall quality of the research and innovation and to help pooling resources so that the Union can also develop and operate research infrastructures globally. ESFRI is a strategic instrument to develop the scientific integration of Europe and to strengthen its international outreach. The ESFRI roles are: (i) to jointly reflect on the development of strategic policies for pan-European Research Infrastructures (RIs), (ii) to prepare a European Roadmap (with regular updates as different areas mature), (iii) to act as an incubator for concrete RI projects with pan-European interest. It is important to note that ESFRI it is not a decision making body to boost Europe's competitiveness.

Since 2006 ESFRI established an updated European Roadmap for Research Infrastructures (new and major upgrades, pan-European interest) for the following years. ESFRI stimulates the implementation of these facilities, and updates the roadmap as needed. ESFRI is a self-regulated body, which operates openly and on a consensus basis. ESFRI Delegates are senior science-policy officials or equivalents, who represent ministers responsible for research in their country.

ESFRI Projects: are RIs in their Preparation phase, which have been selected for the excellence of their scientific case and for their maturity, according to a sound expectation that the Project will enter the Implementation Phase within the ten-year term.

ESFRI Landmark: are RIs that were implemented, or reached an advanced Implementation Phase, under the Roadmap. The Landmarks can be already delivering science services and granting user access, or can be in advanced stage of construction with a clear schedule for the start of the Operation Phase.

The European Research Infrastructure Consortium (ERIC), is a legal instrument, based in the EU Regulation 723/2009, to provide a legal framework for Pan-European Research Infrastructures. ERIC is a body with its own legal personality, recognized by all EU MS. Memberships of ERIC are countries not organisations. ERIC contributes to execute EU research Activities, offers scientific and/or technological value added at EU Level, facilitates and promote the mobility of researchers and knowledge through the ERA, disseminates and optimizes the use of the results and outcomes of the research and innovation activities.

In order to get the ERIC Status, there is a process for its application and it is re-evaluated every five years

Questions:

Q: How often is opened for application? How many projects have applied already that have not been admitted to ESFRI roadmap?

GA: ESFRI is opened every two years. The amount of applications are considerable but I don't have the exact figure of the number of projects rejected

Richard Blundell, MoH Malta. The last ESFRI was launched in 2018, now the next one will be 2020-2021. The process is different to become an ERIC because the application is not cyclical so you can apply at any time. For the ESFRI there is a minimum requirement of having 3 MS committed to the ESFRI.

Jerome Weinbach. ERIC is a legal status that do not provide any funds, what is the joint action doing with the 2021-2027 process? How relevant would be to obtain a call regarding research infrastructure for public health data?

Comment from Aziz Naji There in an infrastructure pillar in the new program. They are not providing funds for routine operations but they might fund projects of developing or outreaching to new MS. There is another pillar for health that is project-based development that could be funded.

Philip Roux: Although an ERIC does not provide any funds, you should have a legal status to receive funds and the InfAct project should follow this route.

Q: Sandra García. An ESFRI roadmap does not uniquely lead you to an ERIC. Could you elaborate more the other options?

GA: The ERIC is not mandatory is the gold standard but other options are being financed by external sources, grants, contracts with enterprises, etc..

Giovanni Nicoletti. ESFRI application is a sort of softer way of taking time but regretfully not for us, because there is a national decision that might be official when the application will be opened. There is a national roadmap, and an application to the national roadmap. Those who do not pass the application are not allowed to support the applications from other countries.

MC: This came up with the discussions and is definitely a threat to all the countries.

12. **Health Information Research Infrastructure-The ESFRI roadmap application. Dr. Herman Van Oyen (HVO), Coordinator of InfAct. Director of epidemiology and public health, Sciensano. Belgium.**

HVO explained the ESFRI lifecycle approach and their phases: design, preparatory, implementation and operational.

Why applying for an ESFRI

- Stepwise and structured process to set up a European Research Infrastructure Consortium (ERIC) on Health Information.
- Stamp of scientific excellence, its Pan-European relevance, and the socio-economic impact.
- Opportunities for European funding.
- Engagement of MS and collaboration of research institutions at operational level.

Steps within InfAct: connecting National Networks in MSs, engaging Domain Specific Networks and their research communities, situating of the RI in the HI landscape, setting up web based platform, fine-tuning the services to be provided and develop a model for their implementation, interact with relevant stakeholders in HI field and submission of the ESFRI application

Timeline: the project is in the design phase and it will apply for ESFRI roadmap in 2021.

Stakeholders in health information research infrastructure field (existing infrastructures, international organisations and potential research communities have been already identified).

13. Programme and objectives for the next Two Assembly of members. Dr. Isabel Noguer (IN), Leader of Work Package 4. ISCIII. Ministry of Science, Innovation and Universities. Spain.

IN presented the aim of WP4 which is Sustainability for EU HIS supporting country knowledge and capacities, health research and policy making. It has three tasks: 1) support integration of JA health information activities in MS through an AoM, 2) technical dialogues and 3) sustainability plan. The second AoM meeting will be held on November 13th 2019 in Brussels and the third one in October 27th 2020 in Madrid. The AoM objectives are for the representatives to: (i) act as liaison with Research, National Health System, and National Public Health authorities, (ii) give feedback/policy guidance to InfAct partners regarding potential translation of outcomes into national systems, (iii) assess the ESFRI roadmap or structural alternatives for InfAct long term activities, and (iv) support the potential integration of InfAct main outcomes in EU-HIS and policies.

For the schedule of the second meeting, it is expected to have a progress of the JA and to present fact-sheets with main findings from each work package, a report from technical dialogues and the Memorandum of Understanding (MoU) on the way forward (ESFRI and ERIC). Finally, for the third meeting, apart from reports of progress of the JA, the sustainability plan will be presented for review and approval.

NC: The proposed agenda is not rigid and would be adjusted according to what have been discussed.

14. View from the European Commission. Dr. Philip Roux (PR), Head of Unit "County knowledge and Scientific Committees" DG Santé. European Commission.

PR mentioned, that DG Santé is funded through taxes so, eventually, the European citizens money is funding InfAct. Thus, DG Santé´s main interest is that such money is well and usefully spent. He raised 5 points to take into account about the meeting

First, it is important to keep in mind that not taking any decision is already taking a decision; and representatives should take responsibility on that. It is in the representatives hands to have a tool to steer national policies on health. Before launching InfAct there were long discussions about the different options to address HIS and their challenges. Is important to overcome the discussions and start acting to tackle the rising health problems and challenges across Europe.

Second, a business plan is indeed needed, it was discussed before and the elements of such plan already exist.

Third, it is important to consider the vision of DG Santé about the purpose and the expected impact of InfAct that should be (i) reducing health inequalities between and within MS, (ii) translate research faster into actions, because very often the research results are not used, and (iii) adding better services to citizens at a reasonable cost for ensuring sustainable health systems. PR said that the AoM representatives encourage the EC-DGs to work together, he

agrees but he also would like to encourage AoM representatives to cross-sectorial work between Research and Public Health at the national level and DG Santé will do the same at the European Commission level because the most important goal is the health of the citizens.

Fourth, it is necessary to take advantage of the opportunities offered by new technologies to improve the way of collecting and disseminating data and to explore brand new technologies such as artificial intelligence. Health data should travel with the citizens when they travel across Europe and it is necessary to work together at least in the interoperability of the systems within and between the countries.

Finally, the process should go fast, and going faster means progressing by doing. It would be desirable to put energy in starting fast and while working, to analyze what is needed and how to make it better.

Annex 1: Terms of Reference (ToR) and operating procedures for the AoM.

Assembly of Members
Terms of Reference & Operating Procedure

Joint Action on Health Information (InfAct) Project Number 801553

Introduction

Political Relevance of InfAct:

To make the most of health spending and investments at EU and Member State level, health policy and decision making must be based on robust evidence in the form of high quality and timely data on population health and health systems and thorough research outcomes.

Following the recommendations by the Council of the European Union[1], the Commission and it's member states were invited to cooperate with a view to establishing a sustainable and integrated EU health information system. More specifically, the Council Conclusions urged to explore the potential of a comprehensive European health information research infrastructure as a tool.

This gave rise to the BRIDGE Health project[2] which concluded that the creation of a European Research Infrastructure Consortium (ERIC) to collect, process, analyse, report, and communicate health information could facilitate the governance of health information activities in the EU in a way that best supports evidence-based health policies and investments.

The Joint Action (JA) on Health Information (hereinafter referred to as InfAct) builds on previous work and further develops collaborative action to set up a sustainable infrastructure for EU health information. InfAct started in March 2018 and will run for 3 years, bringing together 40 institutions from 28 EU-countries (EU-Member States and associated countries).

[1] http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/140004.pdf
[2] http://www.bridge-health.eu/

The major expected outcome of InfAct is a sustainable solid infrastructure on EU Health Information to improve the availability of comparable, robust and policy-relevant population health data and health system performance information. Through country collaboration, InfAct streamlines health information activities, reduces the data collection burden and facilitates and supports country knowledge, health research and policymaking.

InfAct is focused on: (1) providing tools and methods for HI support through innovation for public health policy development and research, and (2) integrating population health and health care information systems in a sustainable EU research infrastructure. It will contribute to reduce HI inequalities by strengthening country capacities and enhancing HI priority setting, methodologies and practices. More information can be found on our website www.inf-act.eu

Assembly of Member (AoM):

InfAct will also bring together health information players around Europe in an Assembly of Members (AoM). Representatives from Ministries of Research and Health from EU and associated countries are invited to participate in this AoM. The AoM will decide on a strategic vision for a sustainable infrastructure for EU health information. Major decisions on the way forward will be taken through a Memorandum of Understanding (MoU). The AoM will serve as a communication channel between InfAct and the ministerial representatives.

AoM's participants will be able to exchange ideas among MS government representatives and inform each other about national developments and political viewpoints of their MS regarding the creation of a future sustainable HI research infrastructure in the form of, for instance, an ERIC (European Research Infrastructure Consortium). Furthermore, this committee will develop a shared vision about possible levels of commitment, ways of governance and types of organisational involvement of MS for such a research infrastructure. The AoM can set

the basis for a permanent structure in a future EU health information infrastructure.

AoM will also act by monitoring InfAct's activities, provide guidance for better coordination at national level for health data production and reporting and facilitate the integration of InfAct's tools, outputs and outcomes in national health systems and public health and research policies.

Specific Objectives:

1) To give feedback/policy guidance to InfAct's partners on results and its translation into national HIS.
2) To sustain InfAct's long-term activities, identifying national and domain specific networks to be considered for inclusion in the European Infrastructure.
3) To assess the roadmap of the proposed HIREP-ERIC or structural alternatives for InfAct's long term activities.
4) To support the EU institutional integration of InfAct's main outcomes in EU-Health Information Systems (HIS) and policies.
5) To contribute to the international health agenda on HI and chronic diseases.

Outcomes of the AoM:

1) Terms of Reference for the AoM approved. March 2019 (M13). Deliverable 4.1.
2) Reviewed outcomes and InfAct long-term projection from InfAct WP. March 2019, October 2019, October 2020 (M13, 20, 32) Milestone 15.
3) Reports of AoM integrating MS and participants view and proposals: April 2019, November 2019, November 2020 (M14, 21, 33) Deliverable 4.2.
4) InfAct-Sustainability Plan October 2020 (M32) Deliverable 4.5.
5) MoU on the way forward through the application into the European Strategy Forum on Research Infrastructure (ESFRI) roadmap.

Composition and Rules of Procedure

Membership:

AoM will be composed of the following representatives:

- **MS representatives**:
  - Each MS shall nominate two senior level representative (one from MH, one from MR) and their alternates, which will be addressed by a letter.

International Observers to be considered by MS representatives:

- **Representatives of International Organisations**:
  - One representative from the Organisation for Economic Co-operation and Development (OECD).
  - One representative from WHO Europe:
- **Representatives of the European Commission Services and of ECDC:**
  - One representative from the European Commission Directorate-General for Health and Food Safety (DG SANTE)
  - One representative from European Commission Directorate-General Research (DG RTD)
  - One representative from the European Commission Directorate-General of Eurostat (EUROSTAT).
  - One representative from the Joint Research Centre (JRC)
  - One representative from the European Centre for Disease Prevention and Control (ECDC).
- **Representatives of European and International Associations**
  - One representative from the European Public Health Association (EUPHA).
  - One representative from the Association of Schools of Public Health in the European Region (ASPHER).
  - One representative form the International Association of National Public Health Institutes (IANPHI)

Secretariat and Chair of the Assembly of Members:

- The InfAct WP4 (Integration in National Policies and Sustainability) leader and co-leader (ISCIII and SPF) will support the AoM **Secretariat**.
- One representative from InfAct (Prof Neville Calleja) shall be the **Chair** of the AoM.

AoM Rules of procedure:

- The Secretariat will distribute relevant documents according to the work plan of InfAct. These documents will be deliverables and milestones presented by InfAct WP leaders. AoM will provide feedback and comments within the following fifteen working days.
- In addition to the annual meetings, routine communications will be done by email and audioconferences.
- AoM shall deliberate by consensus.
- In case of different positions, MS´ Representatives from MH and MR will be the only members with voting rights.
- In the event of a voting procedure, the outcome shall be decided by a majority of two thirds of the AoMs´ present at the meeting. Each country shall have one vote (according to competences assigned at national level). Abstentions shall not prevent the adoption of deliberations by consensus.
- Members shall comply with the obligations of professional secrecy laid down by Article 339 TFEU (Treaty of the Functioning of the European Union) and its implementing rules, as well as with the Commission´s rules of security regarding the protection of EU classified information, laid down in the Annex to Commission Decision 2001/844/EC, ECSC, Euratom of 29 November 2001 amending its internal Rules of procedure.

Meetings of the AoM:

The AoM will meet three times during the Joint Action time frame: March 12th 2019, October 2019 and October 2020 (months 13, 20 and 32).

- Additional audio/video conferences could be convened if required.

Agenda:

- The Secretariat shall draw up the agenda in closed collaboration with InfAct coordinator.
- The Secretariat shall send the invitation to the meeting and the draft agenda together with relevant documents no later than thirty calendar days before the date of each AoM's meeting.
- In duly justified cases, time limit for sending relevant documentation mentioned above may be reduced to ten calendar days before the date of the meeting.
- Members of the AoM can propose items for the agenda up to five weeks before the AoM meeting.

Admission of third parties:

- The Chair may invite, on ad hoc basis, experts from outside the AoM with specific competence in a subject on the agenda.

Minutes of the meetings:

- A summary of the main conclusions will be formulated by the Secretariat at the end of each meeting.
- AoM summary minutes shall be drafted by the Secretariat and sent to the members in months 14, 21 and 33.
- Members will be requested to send their written comments to the Secretariat within two weeks after the draft minutes have been sent.
- The summary minutes shall not mention the individual position of the Members during the AoM discussions, unless specifically asked for.
- The Secretariat of the AoM shall publish relevant information of the AoM decisions either by including it in InfAct's deliverables, as reports or by presenting conclusions in relevant international fora (e.g. EUPHA).

- The Secretariat shall inform the AoM of the distribution of the minutes (InfAct Governance and relevant international forum (e.g. EUPHA)).
- A list of members attending each meeting will be annexed to the minutes.
- the Minutes and all AoM will be publicly available through the InfAct website

Correspondence:

- Correspondence relating to the AoM shall be addressed to the Secretariat (provide email), for the attention of the Chair.
- Correspondence for AoM Representatives shall be sent to the e-mail address or addresses they provide for that purpose.

Access to documents:

- Requests for access to AoM's documents shall be handled in accordance with Regulation (EC) No 1049/20015. It is for the Commission to take a decision on requests for access to those documents pursuant to its Rules of Procedure as amended by Decision 2001/937/EC, ECSC, Euratom. If the request is addressed to a MS, that MS shall apply Article 5 of Regulation (EC) No 1049/2001.

Protection of personal data:

- All collecting, processing and publishing of personal data for the purposes of these rules of procedure shall be in accordance with the General Data Protection Regulation (GDPR) (EU) 2016/679 approved by the EU Parliament on 14 April 2016.

Meeting expenses:

- AoM representatives shall not be remunerated by InfAct for their participation.

- For the first and the third meetings (the ones hosted in Madrid); a budget is allocated to cover travel and accommodation expenses of the EU/EEA-AoM representatives.
- For two of the three meetings (the ones hosted in Madrid), accommodation management will be facilitated by the Secretariat.

Table 1: List of beneficiaries.

Applicant No	Applicant organisation name	Acronym	Country
1 (Coordinator)	Sciensano	Sciensano	Belgium
2	Gesundheit Österreich Gmbh	GÖG	Austria
3	Ministry of Civil Affairs	MCA	Bosnia and Herzegovina
4	Hrvatski Zavod Za Javno Zdravstvo	CIPH	Croatia
5	Ministry of Health of the Republic of Cyprus	MoHCy	Cyprus
6	Ustav Zdravotnickych Informaci a Statistiky Ceske Republiky	UZIS	Czech Republic
7	Ministry of Social Affairs	MoSA	Estonia
8	Terveyden ja hyvinvoinnin laitos	THL	Finland
9	Agence Nationale de Santé publique	SPF	France
10	Robert Koch Institut	RKI	Germany
11	Ethnikos Organismos Parochis Ypiresion Ygias	EOPYY	Greece
12	Department of Health	DOH	Ireland
13	Istituto Superiore di Sanità	ISS	Italy
14	Centre for Disease Prevention and Control of Latvia	CDPC	Latvia
15	Higienos Institutas	HI	Lithuania
16	Ministère de la Santé	MOHLUX	Luxembourg
17	Ministry of Health	MFH	Malta
18	Universitatea de Stat de Mecicina si Farmacie Nicolae Testemitanu Din Republica Moldova	SMPHU	Moldova
19	Rijksinstituut voor Volksgezondheid en Milieu	RIVM	Netherlands
20	Helsedirektorate	HD	Norway
21	Ministry of Health of the Republic of Poland	MZ	Poland
22	Ministerio da Saude – Republica Portuguesa	MS	Portugal

23	Institutul National de Sanatate Publica	INSP	Romania
24	Institut za Javno Zdravlje Srbije 'Milan Jovanovic-Batut'	IPHS	Serbia
25	Nacionalni Institut za Javno Zdravje	NIJZ	Slovenia
26	Instituto de Salud Carlos III	ISCIII	Spain
27	Folkhalsomyndigheten	FoHM	Sweden
28	Welsh Assembly Government	WG	United Kingdom

Table 2: Collaborative Stakeholders.

City & Country	Institution	Contact person (First name and last name)
Albania	Ministry of Health	Romeo Zegali
Austria	Ministry of Labour, Social Affairs, Health and Consumer Protection	Patrizia Theurer
Belgium	Belgian Consortium on Health Information (IBRI)	Lieven De Raedt
Bulgaria	Ministerstvo Na Zdraveopazvaneto (Ministry of Health)	Nayden Chivarov
Denmark	Direktør, Statens Institut for Folkesundhed	Morten Grønbæk
Germany	Federal Environment Agency	Marike Kolossa-Gehring
Iceland	Directorate of Health	Gudrún Gudfinnsdóttir
Slovakia	National Health Information Centre	Jan Cap
Switzerland	Swiss Tropical and Public Health Institute	Nicole Probst, Michael Käser
United Kingdom	Analytical Section Head Population, Geography & International Statistics NHS Digital	Robyn Wilson
International	The Organisation for Economic Co-operation and Development (OECD)	Ian Brownwood Gaetan Lafortune
International	World Health Organisation (WHO) Europe	Claudia Stein
International	European Observatory on Health Systems and Policies	Josep Figueras
International	International Association of Public Health Institutes (IANPHI) Secretariat	IANPHI President

Annex 2: Policy Paper.

Health Information Research Infrastructure: high level summary

Introduction

The right to health is considered one of the most basic human rights and plays a fundamental role in all societies. Moreover, a healthy population is a prerequisite for economic productivity and prosperity. EU countries[3] share the ambition of improving citizens health, tackling health inequalities, providing optimal prevention and universal access to safe, effective and efficient healthcare in a financially sustainable way.

Health systems are one of the most important contributors to population health. However, population ageing, technical innovations in health care, and growing citizen expectations increase financial constraints on health systems. On the other hand, increasing national health expenditures need to be able to meet growing demand.

To make the most of health investments, health policies and decision-making must be based on robust evidence in the form of high quality and timely data and research on population health and health systems. International comparative research, benchmarking and exchange of best practices is indispensable for strengthening the evidence base for national and international decision making on health and health systems

Gap analysis

At present, there are three main challenges to ensure the availability, accessibility and use of high quality health information for policy-making and research.

In the area of population health and health system performance we find a highly fragmented landscape in Europe that needs coordination and strengthening. Much of the evidence and knowledge is **dispersed, incomplete** in important areas and/or **difficult to access**. An example is the limited data on non-communicable diseases, even though they are the main cause of death and poor quality of life and high healthcare costs in the EU[4].

Better health information governance is needed to facilitate data collection and bring together research networks, and ensure that the generated knowledge is robust and accessible.

[3] This includes EU Member States, EFTA and EEA countries.
[4] Elliott H. European Union health information infrastructure and policy. In: Greer SL, Kurzer P, editors. European Union public health policy. New York: Routledge; 2013. p. 36-50.

Under the lead of Eurostat, the European Statistical System provides a solid working base for gathering and providing essential health data[5]. However, beside this core activity by Eurostat and other international institutes and organisations, a wide range of health data collection and research activities are often **funded through ad hoc projects**. This results in important and relevant output, but causes a **lack of research continuity, lost expertise, data collection mechanisms, fading research capacity, and dissolving networks**[6].

Mechanisms are needed to feed the knowledge and know-how generated by these networks and projects into a more permanent structure, to ensure a long-term continuity and more sustainable financing sources.

Large differences can be found in terms of **availability**, **quality,** and **comparability** of health data and information between and within countries. This makes it difficult to learn from each other. Without health information, evidence based policy is difficult to achieve. Moreover, health information tends to be poorest in areas where health itself is poorest. This does not allow to assess the full magnitude of health inequalities across the EU[7], let alone to identify appropriate, targeted action.

Better support and coordinated action are required to reduce health information inequalities across the EU to support countries in better using their health data and improve the quality and comparability of data.

The way forward

The need to establish a sustainable and integrated health information system at EU level has been recognised by individual Member States, as well as, by the European Commission and the Council of the European Union[8]. A previous project called BRIDGE Health[9], has investigated possible solutions and different structures for a comprehensive, integrated and sustainable EU health information system to support research and evidence-based policy for EU countries.

[5] http://ec.europa.eu/eurostat/web/european-statistical-system
[6] M. Verschuuren, et al., Public health indicators for the EU: the joint action for ECHIM (European Community Health Indicators & Monitoring), Archives of Public Health 2013, 71:1-12
[7] http://ec.europa.eu/health/social_determinants/docs/healthinequalitiesineu_2013_en.pdf
[8] Council of the European Union. Council conclusions on the "Reflection process on modern, responsive and sustainable health systems". Brussels, 10 December 2013. [cited 2016 Jun 16]. Available at: http://www.consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/lsa/140004.pdf
[9] BRIDGE Health. Bridge Health: Concept Paper Technical Report BRIDGE Health N° WP1_2016_03 Available at: http://www.bridge-health.eu/sites/default/files/Technical%20Report%20WP1_2016_03_Concept%20Paper_final_V2_0.pdf
Bogaert P, et al. Towards a sustainable EU health information system infrastructure: A consensus driven approach. Health Policy (2018), https://doi.org/10.1016/j.healthpol.2018.10.009

A **Pan-European Research Infrastructure** is found to be the most feasible solution to solve the current limitations. An integrated approach offers the governance and coordination for a sustainable structure that will effectively underpin the entire research lifecycle and provide, expertise, knowledge, and access to linked, reliable and precise health information.

Now, a core set of countries have decided to pursue a comprehensive European **Health Information Research Infrastructure** and to apply for the European Strategy Forum on Research Infrastructures (ESFRI) roadmap. ESFRI contributes to the development of a strategic roadmap by selecting vital new European Research Infrastructures for the next 10-20 years. The ESFRI application is based on expression of political support by at least three Member States, and a wide scale of inter-institutional agreements such as agreements with national public health institutes. Successfully applying for the ESFRI roadmap will provide the Health Information Research Infrastructure with a stamp of **scientific excellence, Pan-European relevance, and socio-economic impact**. This approach will pave the way for a European Research Infrastructure Consortium (ERIC) on health information.

Health Information Research Infrastructure

A Health Information Research Infrastructure will bring together existing research networks and experts in health information and support the developments of new ones in a single web based platform. It will enable health data collection and research to operate as a versatile and integrated system of distributed nodes. These will sustainably work together under one governance structure to overcome inefficiencies and inequalities and ultimately improve the health of European citizens.

The ideas of sustainability, connecting, supporting decision-making and improving health in Europe is taken up in the mission and vision of the future Research Infrastructure (see figure 1).

VISION	MISSION
A sustainable infrastructure for the best health knowledge improving population health and care in Europe	Connecting and advancing comparative health research for well-informed (inter)national decision-making

Figure 1: Vision and mission Health Information Research Infrastructure

The services

The Research Infrastructure will focus on the following four services:

Figure 2: The services of Health Information Research Infrastructure

1. One-stop-shop for EU health information

The Research Infrastructure is a one-stop-shop for population health and health systems research. It pools data, research experts, research networks, guidelines and tools on a single web based platform. It facilitates and supports the development and hosting of virtual and interoperable repository platforms for research. It provides central coordination for EU countries to provide data and exploit economies of scale by facilitating the extension of existing data repositories. The platform provides a forum to foster multilateral research cooperation to form and expand research networks.

2. Capacity training in health research

The Research Infrastructure provides methodological and technical expert support for the development of comparable, standardised and accessible data and indicators for health status and determinants, health services and health systems. It enhances best practice exchange between countries and support mutual learning by focused capacity building through dedicated training programmes and mobility programs. Newly developed methodologies will be taught to enhance the expertise of the health information research workforce across Europe and thus tackle health inequalities.

3. Decision making based on evidence based research

The evidence and knowledge produced by research are not always readily available and may need further analyses, syntheses and translations to inform policymaking. The Research Infrastructure supports researchers and institutions in charge of health and health related research to disseminate, translate and optimise their output to better inform policymakers and citizens.

4. Innovation in health information

The Research Infrastructure supports methodological developments based on expert reviews and validation studies of existing tools and procedures. This includes the development of new and more efficient methods and tools for data collection, quality assessment, use, analysis, translation and reporting. More specifically, the development of new research methodology with respect to the analysis of large data sets and data linkage, priority setting and horizon scanning to inform policy making. The innovative developments facilitated by the Research Infrastructure will strengthen the evidence for health systems reforms, public health interventions and policies.

The users

The Research Infrastructure will serve a wide scale of different users, of which the primary users are researchers in public health and population sciences as well as epidemiologists, statisticians, pharmacist, doctors, data scientists, ethicists, sociologists, project managers etc. The secondary users are policy and decision-makers in national and international organisations both governmental and non-governmental organisations or civil societies, as the outcome of the infrastructure will benefit their work. Other users include:

- The healthcare sector.
- Data providers and developers in various health information domains.
- Students and educational organisations of population health and health services.
- The media and the general population.
- Other European level infrastructures, industry and private sector.

National added value

The Research Infrastructure strengthens the view of the national situation and trends in both population health and health system performance. This, by generating more and better national data and broader evidence to build on. The Research Infrastructure strengthens the development of stronger national health research capacities and more expertise to consult with, as well as, more options to find best practices in other countries. Finally, it contributes to developing stronger national health information systems and strengthen the evidence base that supports well-informed decision-making at all levels. A comprehensive overview of the assets, activities and impact of a Health Information Research Infrastructure can be found in annex I.

Next steps

The ESFRI application is now in the process of development by a core writing group within InfAct and is expected to be submitted by the summer of 2020. Additional political and scientific support for the development of the ESFRI roadmap application is sought. Your expression of interest in supporting our cause is highly requested.

Annex I Overview Health Information Research Infrastructure assets, activities and impact

INPUTS/ASSETS	OUTPUTS/ACTIVITIES	OUTCOMES/IMPACT
What we invest and have available	*What we do and who we reach*	*What is our short-term impact?*
Building blocks for a strong organisation Governance, experience, commitment **Our special assets** Experts, good practices, networks **Experience with project and network development** Senior investigators and project developers **Output and experience from previous research** Good practices, tools, methods, evidence **National nodes for health information** Direct access to national experience	**Provide services to our research networks** Support project development and fundraising Build and expand platform functionalities Support data management and exchange Support cross-national capacity building Support data quality maintenance **Provide services to policy makers and stakeholders** Build a policy portal for health information Assess national health information systems	**More and stronger research networks** **More comparable data for research** **More equal national research capacities** **More effective use of existing data** **More efficient use of research funds** **Improved knowledge transfer** **Better data and indicators for health policies**
Our ambitions and values	*How we work on impact and future strength*	*What is our long-term impact?*
Be a reliable research partner **Work with stakeholders and citizens** **Aim for equity, sustainability, quality, efficiency** **Better health and care is our core business** **We work for the public good** **We believe in European research collaboration**	**Liaise, communicate, teach and advocate** Liaise with stakeholders and decision makers Liaise & coordinate with other ERIC's Collect & distribute information and news Organise our advocacy and communication Organise conferences, meetings and fora **Develop and implement knowledge brokering** Reach out to NGO's, citizens and private parties **Enlarge our conglomerate of distributed research networks** Identify and support new partner networks **Expand our research focus and potential impact** Support knowledge transfer research Foster foresight studies Support cost-effectiveness research Support horizon scanning and priority setting	**A stronger EU health research infrastructure** **Full grasp of population health trends** **Understanding health system dynamics** **Mature national health information systems** **The leads in comparative EU population health research** **Better EU health and well-being** **Efficient European healthcare systems** **Health is wealth: stronger economies**

Annex 3: Evaluation.

The overall results of the meeting were assessed through an evaluation form that considered 4 categories (Logistics and organisation, contents, communication and conclusions) in a scale of 1 to 5 as is showed below

5: Strongly agree

4: Agree

3: Undecided

2: Disagree

1: Strongly disagree

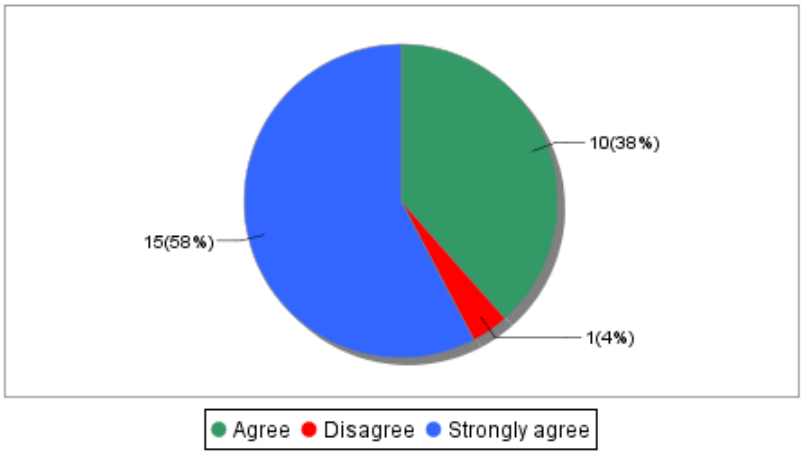
26 filled forms were retrieved, from which 24 were filled from representatives of the ministries of Health and Research accounting for 85% of participation.

In general, the overall evaluation of the Meeting was satisfactory. The main points to consider in future meetings are more time for representatives to engage in discussion groups, presentation on the progress of other work packages of the Joint Action and take into account some logistic improvements for the next meeting.

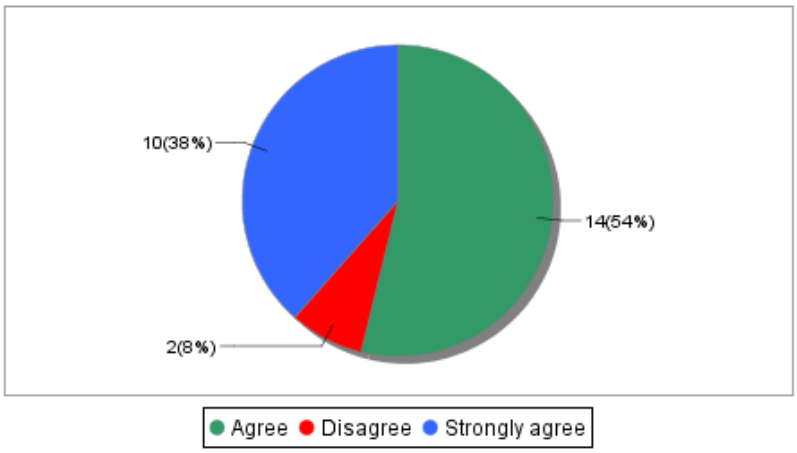
A graphic descriptive summary and specific observations from some participants are presented here.

Part I. Logistics and organisation

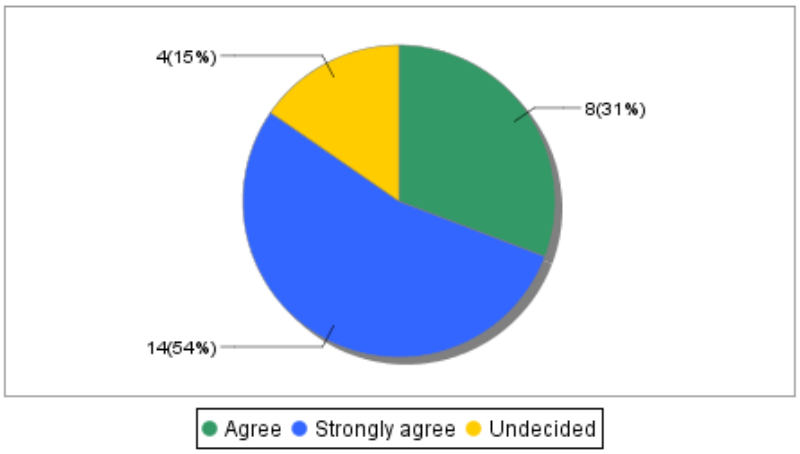
1) The Assembly was well planned and organised



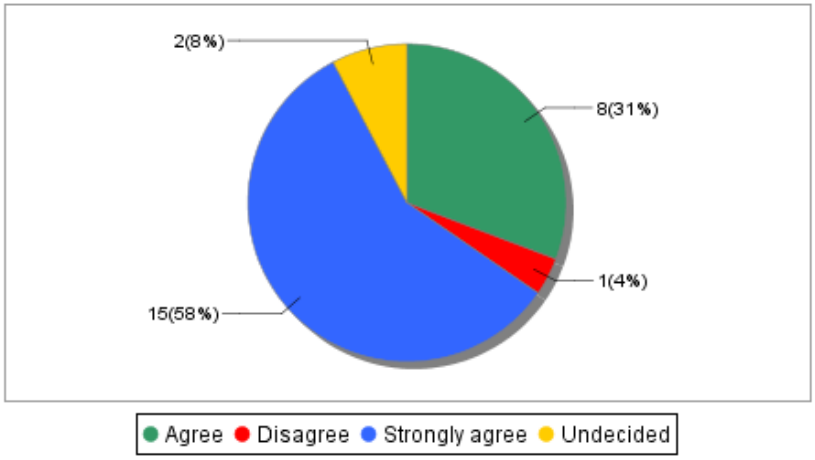
2) The Assembly met my expectations



3) I received all information needed for the Assembly on time



4) The meeting rooms and its facilities were suitable and adapted for work

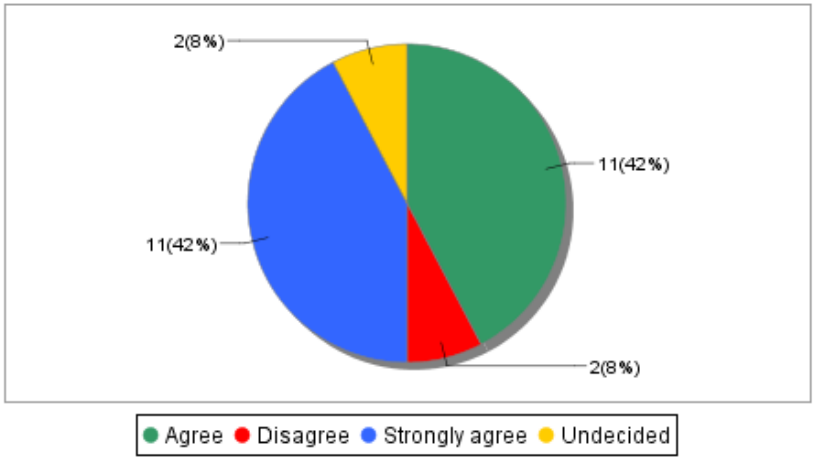


Comments and suggestions:

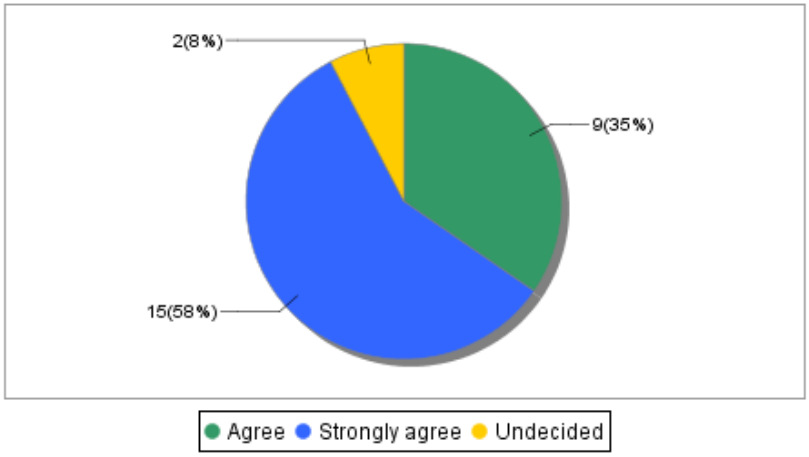
- More time to talk and interact with other among representatives of Member States and also to take advantage of this important group to get more out of it.
- There was a lot of sending information and information arrived rather late.
- To hand in a location map
- To make the presentations available
- To provide more water throughout the day
- Some groups that were located in the Main Meeting Room didn't have a table

Part II. Contents

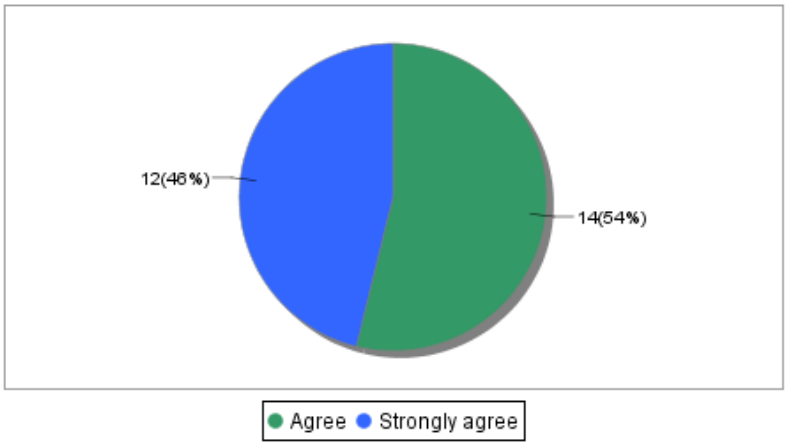
1) The contents of the Assembly corresponded with the objectives of the meeting



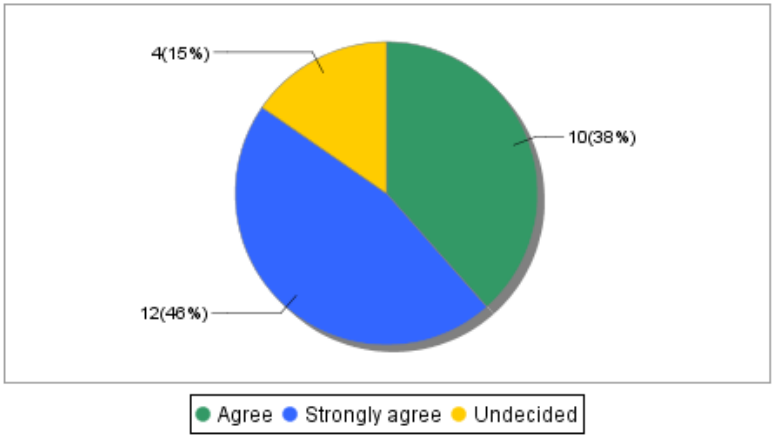
2) Presentations were clear and to the point



3) The time schedule and length of the Assembly were appropriate



4) There was enough time for questions and discussions

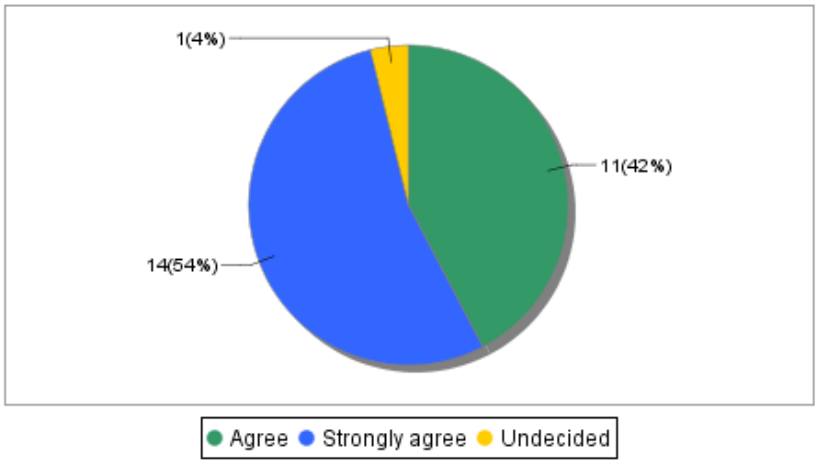


Comments and suggestions

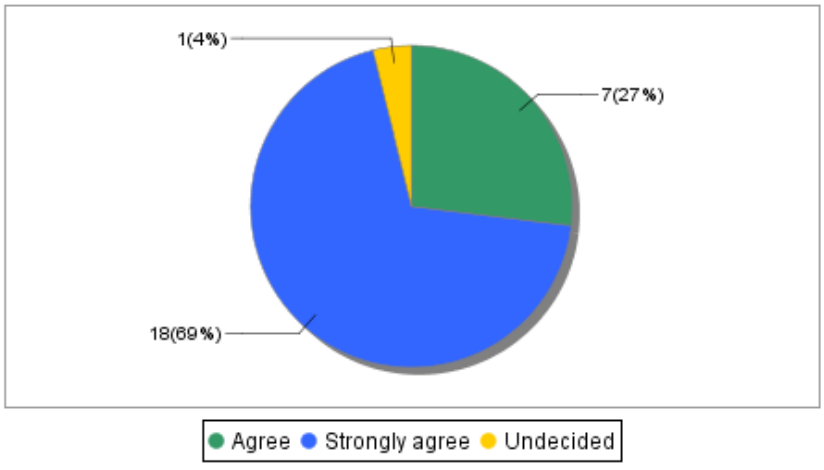
- To include researchers in the meetings
- The agenda did not help in increasing commitment among Member States. More discussion opportunities among Member States is needed.
- To introduce in more detail the activities of the Joint Action

Part III. Communication

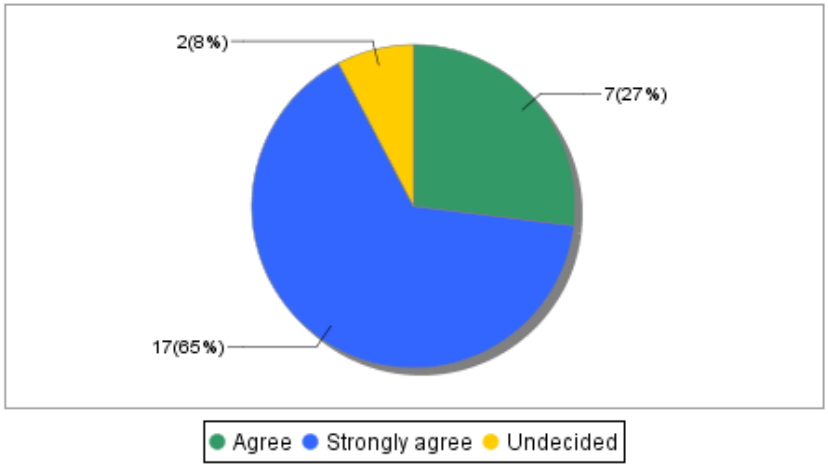
1) All representatives had the opportunity to participate in the discussions



2) I had the possibility to meet and interact with the other representatives.



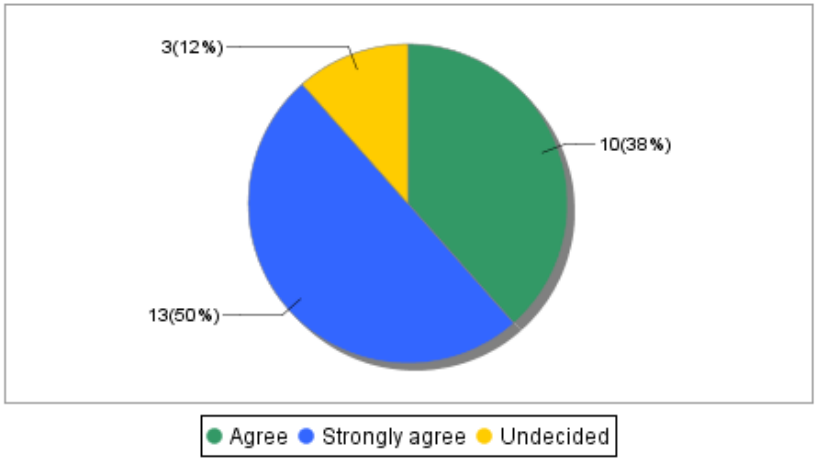
3) I am satisfied with the working atmosphere during the Assembly.



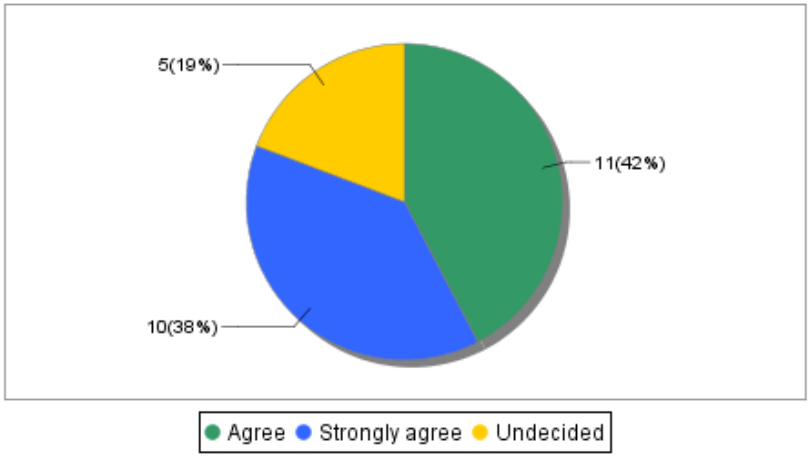
Comments and suggestions: Keep representatives informed of the advances of the project via e-mail, etc

Part IV. Conclusions

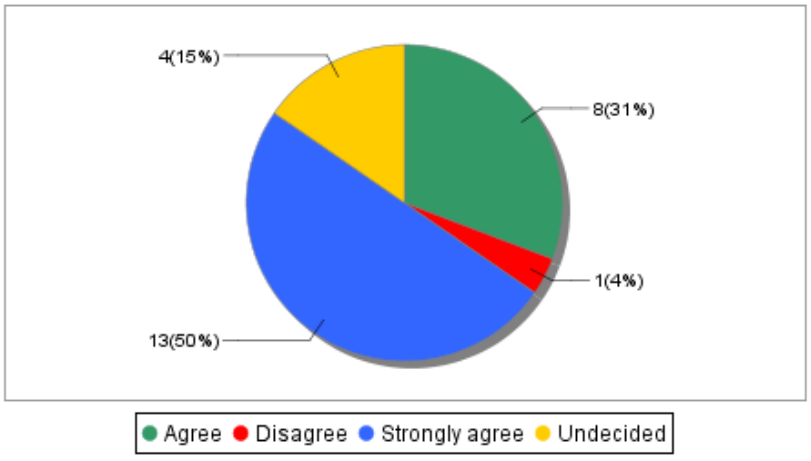
1) My overall assessment of the event is satisfactory



2) The participation in the Assembly was beneficial



3) The meeting stimulated me and increased my motivation to participate in future Assemblies



Suggestions for future improvement

- To motivate counterparts of Ministry of Research
- To organise transport from the hotel to the venue
- More fruits and vegetables for the coffee break
- To spend more time outdoors and assign rooms that are less dark.