

European Health Information Training Programme

Roadmap for Capacity Building Programme for EU MS

W.P6. Task 6.4

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Work Package 6 - Strengthen EU countries Health Information Capacity

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I. Introduction

The European Union has evolved over the years to progressively integrate a wide number of countries, currently 27. Most of these countries were integrated long after the Rome treaty in 1957 with all their differences. While very different, as it says in Europa's lemma "In Vareitate Concordia", these countries are an economic and political union, now under the Lisbon Treaty.

EU Member-States (MS) are historically diverse, have individual histories, and are at different socioeconomic development stages. The idea of unity, bringing all together at the same pace to the highest levels of human development, is ideal for all European citizens to understand well. Giant steps are being made towards the European ideal. Nevertheless, there is still immense work to be done moreover regarding reducing inequities. Now more than ever, with a worldwide facing COVID-19 pandemic, this unity is of great importance in the collection and reporting of health data, in vaccination and its roll-out and in developing the skills of member states' health professionals to understand better the importance of health information. Clearly, the COVID-19 pandemics had a tremendous response from the research community, with significant improvements in developing vaccines as well as in providing evidence about population health interventions.

This 6.4 delivery report is the culminating work of INFACT WP 6, on Health Information in Europe, resulting from previous tasks: task 6.1. - Mapping needs, capacities, and education/training programmes in HI in MS, task 6.2 - Design of a Flagship Capacity Building Programme to improve MS capacities in population health and health system performance and monitoring, task 6.3 - Piloting and evaluation of the European Health Information Training Programme (EHITP) proposal, the independent evaluation report - Evaluation Report of the Sustainable Capacity Building Programme (European Health Information Training Programme - EHITP) - and the INFACT Joint Action will in establishing a Roadmap for Health Information training and Sustainability for Europe.

Overall, the WP9 dealt with capacity-building aspects related to Health Information inequities in Europe. Bringing together two different notions: health - comprising citizens' health and wellbeing, public health, global health, one health, and human development - and Information - slightly reduced to aspects of statistical measurements for monitoring, surveillance, and preparation for action, linking research to policy-making. At the European Union level, these two subjects are polarized, health being prominently a member-state driven responsibility whereas statistical information has more a wider European framework.



Health information is a comprehensive area, including indicator development, data collection, data analysis and inference, information management, and translational research. The management of health information is a critical function within health systems, and therefore an important ability to leverage the resources in healthcare. Health information is often taught in different courses or as modules of information systems, or as part of epidemiology courses. Still, most of the courses focus on one or only some topics.

While being diverse across Europe, health information is facing the challenges posed by modern social and technological advances. A current data-prone society poses both challenges and opportunities that must be faced and seized. Europe as whole needs to excel in using health information to policy making.

It is also clear that knowledge and capacities on health information vary among EU MS. The research carried out previously on InfAct WP6 highlighted the different capacities and varying Health Information needs across European countries (Lapão et al., 2019).

Based on the work carried out on mapping needs and capacities,

- Public health specialists, public health researchers, and epidemiologists are the most common professions using health information systems. Together with statisticians, these professionals are part of the range of people who need additional health information systems training. From a long-term perspective, within 10 years, public health program managers and health professionals (e.g., physicians and nurses) will also need additional training.
- A considerable number of existing training programmes related to health information were also reported both at the academic and professional levels. These training courses are based both at universities and in national institutes of public health.
- It was, therefore, considered necessary to establish a sustainable capacity building programme (European Health Information Training Programme) in health information that focused on the main health information competencies: data analysis and interpretation, especially interoperability of data sources, derivation of European Core Health Indicators (ECHI) indicators, and foresight/scenario analysis; transfer from data to policy, especially policy translation tools and data presentation; data collection methods, sources of data, metrics, and indicators, especially issues related to health



examination surveys; and data privacy and ethical issues, especially how to deal with requirements of EU General Data Protection Regulation (GDPR).

It is important to acknowledge that the existing capacities and needs of health information on the EU and its MS constantly evolve independently of the positive or negative steps taken. Therefore, it is important to keep a regular evaluation of HI needs and inequities across MS.



II. European Health Information Training Programme (EHITP) Proposal

A. Justification/motivation

Given that the current European Health Information landscape faces challenges due to its heterogeneous capacity rather than its lack of capacity, as pointed out at the INFACT project's outset, the strategy for Health Information must envisage reducing inequities across all member states and include all relevant stakeholders and resources, in a sustainable way.

Therefore, the corresponding strategic plan should consider in its core the following :

Mission - Strengthening Health Information capacity in Europe in a harmonised and sustainable way

Vision - All European Union Member-States share high standard Health Information capacity using shared resources, integrated approaches, harmonized and sustainable methodologies

Strategy - Promoting the Integration, optimisation, harmonization of all existing Health Information Training resources systematised under a Health Information Training Framework

Plan - Establishing awareness, integration, harmonisation, and collaboration of all Health Information related European stakeholders towards a sustainable Health Information Capacity Programme

Programme - Framework for a systematic Health Information Training in Europe for a global harmonized and sustainable Health Information Capacity.

Therefore, the European Health Information Training Programme Proposal was designed in task 6.2, in the form of a flexible framework with the potential to guide future implementation of Health Information training in Europe while setting possible implications for what Health Information should be in Europe in the upcoming future; aiming at a global, harmonized and sustainable Health Information capacity. It implies a European integrated training programme, integrating all existing institutions already having training abilities, potentially all relevant courses from academia, specialized programmes,



and projects promoting methodological advances in Health Information. As we are entering the third decade of the 21st century, this training programme proposal must also be new, fresh, bold, and ambitious.

Differentiation from traditional training must, therefore, be based on greater flexibility regarding programmatic content, knowledge transmission, and emerging technologies and methodologies. Training needs in increasingly specific areas depending on specific needs and training modalities based on e-learning, shared resources, distributed datasets, and open programs' packages will be preponderant alternatives in the future.

Additionally, the increasingly effective and robust use of new data tools, like artificial intelligence, in the use of data and in the adoption of increasingly powerful and more easily usable tools in data processing, by a greater number of professionals and specialists from different areas, will culminate in the resurgence of a new stage in "Health Information". New skills, in different areas, are a key added value for information systems and to leverage the value of health information.

B. Main objectives

The European Health Information Training Programme (EHITP) - aims to be an umbrella for all current and future training activities in Europe, targeting professionals working in public health and health information at the national or European and international level. In general, the target audience is professionals in the EU MS, who can benefit from acquiring skills and competencies for addressing chronic threats to health and leverage the value of health information. The EHITP aims at meeting the institutional needs of countries to have a competent workforce, effectively working and interacting with experts of all areas at the European Level, other countries, and other international organisations at the EU-level.

The EHITP must also include lifetime learning of people working in the field of public health and health information. It should be dynamic and able to respond to emerging needs in the ever-changing health information environment (e.g. COVID-19). The ECDC Training



Programmes¹, as well as ESC Educational programmes², are good examples of the comprehensive capacity building programmes which support lifelong learning. They include different types of capacity-building activities targeted at people with different levels of expertise and different careers stages.

A flexible EU sustainable capacity-building programme for health information must enable a great adaptation to specific training needs. Whether for professionals who are at the beginning of their professional career and more senior staff, learning by doing should be the key approach. Activities for people from all levels of expertise must be provided. For people at an early stage in their professional career, programs such as EPIET/EUPHEM (ECDC onefellowship program) where there is work side-by-side with professionals in the field and learning through daily work in addition to some specific exercises or short courses are great and should be considered. The possibility of fellowships could also be promoted across the European MS. For more senior people, capacity building is needed on more specific topics, and these needs vary substantially among individuals, countries, and over time.

For the short-term, based on the INFACT proposal (Grant agreement) and what came out from the evaluation developed in Task 6.1, those broad thematic categories can be 1) data acquisition, including the collection of new data through standardized methods, secondary use of already existing data, interoperability between different data sources, big data, mydata, etc.; 2) quality assurance of data including post-harmonization, data cleaning, validation, etc.; 3) data analysis including different statistical tools/methods to be used for calculation of incidence/prevalence rates, trends, projections, Burden of Disease (BoD), associations, HSPA, derivation of standardized indicators, etc.; 4) transferring data to policy/actions/treatment guidelines, etc.; and 5) data privacy and ethics for health information including steps from data collection, data sharing, data analysis, and data dissemination.



¹ <u>https://www.ecdc.europa.eu/en/training</u>² <u>https://www.escardio.org/Education</u>

C. Framework model

The following scheme (figure 1) illustrates the general framework for EHITP, a flexible structure integrating the components of the thematic structure, tools (courses, portal, guidelines/protocols, etc.), and specialists' training programs, which allows adjustments according to specific training needs.



Strategy for EHITP

Figure 1. Schematic for a European Health Information Training Programme framework

1. Thematic Structure

In this framework, we can encompass different training actions, whether they are courses of different levels and duration, webinars, workshops, e-learning materials, using different online tools available. They may also have a face-to-face format. Given the diversity of contexts and situations in different MS, the mechanisms for validation and consolidation of the model should be widely flexible to make them more comprehensive.

2. Tools

A wide range of credible and easily accessible instruments should be the tools' component of the model. It will consist of diversified teaching tools and materials such as courses,



portals, MOOCs, e-learning courses, case studies, presentations, papers and reports, guidelines, protocols, among others.

Most of the remaining elements of this framework do not have particular infrastructural implications because they can be defined in abstract conceptual ways and be thought of as distributed by all MSs and institutions. European tools' definition implies a more centralized approach, not necessarily a unique structure, but definitively structured management appears to be important. A good example is the Eurostat approach to design and define specific data tools.

3. Specialists' training programmes

This component must also be contemplated within a more comprehensive EHITP. Emerging specific areas associated with technological advancements applied to Health point out the need for preparing specialists (e.g. Big Data, Data protection, Artificial intelligence, etc.) at the European or national level. It is also important to include continuous training in more specific areas and more focused on individual or even national or regional specificities.

D. Target groups

Health Information training is usually provided for Data Users. However, the European Health information Training programme must be flexible, dynamic, and inclusive to other professionals. While Data Users are the obvious target training group, the data owners are less obvious, and decision-makers are also important groups.



III. Example courses

To strengthen the European capacity for health information homogeneously in the different MS, EHITP should regularly promote training activities to different target audiences and oriented towards a set of themes whose priority should be reviewed regularly, according to the evolution of the Health Information complex and a continuous need reassessment.

Organized around a specific theme, courses may be more comprehensive and include diverse aspects of health information (such as the example below from the 1st European School of Health Information - piloted course under INFACT Task 6.3) or focus more specifically on concrete areas for strengthening Europe's information systems (like the example below of the Burden of Disease training).

Within this framework, to create an infrastructure for health information in Europe, strengthening networks and partnerships and common practices and mechanisms, member states can develop their national training under the umbrella of the EHITP and replicate courses locally.

A. A. European School of Health Information

The 1st European School on Health Information (ESHI) was a pilot course developed on the European Health Information Training Programme framework to test its capacity-building ability. It was conceived as a flagship course on Health Information based on currently identified need. It took place online between October 1st and November 5th, engaging lecturers from several universities, public health institutes and authorities, and 22 participants from 17 different countries in Europe.

The needs assessment initially carried out, the experience of designing and implementing the course, and the high-level satisfaction expressed by participants and experts involved in the sessions show the relevance of the proposal to build a structured training programme to improve capacity building in Health Information in Europe, as well as the feasibility of continuing it in future editions.

1. Structure

Initially scheduled to take place in a week of face-to-face activities in Lisbon (Universidade Nova de Lisboa), the ESHI was organized in five full-day online sessions. This change,



imposed by the COVID-19 pandemic situation, allowed to test the potential of online training and leaves open the possibility of organizing similar courses in formats that include online or on-site activities.

With a focus on the development of Health Examination Surveys (HES), the programme covered a variety of aspects considered essential by experts in previous need assessment. Each day was dedicated to a relevant topic related to health information and included theoretical and practical sessions, group work among trainees and trainers discussing practical cases on health information.

The trainees were asked to invest a few hours for reading and research on the learning materials previously provided in the week before the course. In the week following the course, they were required to write an essay to consolidate contents and final evaluation. Figure 1 represents the comprehensive course framework.



Figure 2. Course Comprehensive Framework

The final evaluation of the 1st ESHI showed that its comprehensive framework proved to be adequate to the defined objectives and identified needs and can serve as a reference for future editions.

This model's success is also related to the availability of an online platform for the repository of course material and the definition of a communication plan that allows involvement and permanent interaction with the participants.



2. Learning objectives

Participation in the ESHI course should give trainees a set of knowledge, skills, and competencies, enabling them to:

1- Understand health information systems as maturing processes that include procedures resulting from data collection, analysis and management, indicator development, information management, and translational research for developing new policies.

2- Know how to mobilize health data collection methods, tools, and key primary and secondary data sources available at the national and European level.

3- Recognize the current and future importance of using big data tools, artificial intelligence, eHealth or mHealth, and the "internet of things" in health information-related activities.

4- Develop skills to collect and manage data using health data collection methods, eHealth or mHealth, and the "internet of things", adopting a European perspective.

5- Improve the ability to interpret and communicate data, facilitate its use outside the health system, and policy translation purposes within the European context.

6- Understand key aspects of data privacy, data security, and ethics in data collection, management and use.

7- Mobilize efforts to ensure the implementation and application of GDRP requirements in their area of activity.

In future editions, comprehensive learning objectives that are appropriate to the programme's central themes should also be defined.

3. Duration

This course can be offered in different terms, formats, and configurations. Being the topics quite edgy being dominated mostly by a few Health Information Specialists, it makes some sense to make it a rapid course, i.e., a course with a duration of up to two weeks. One week seems reasonable here.

As an indication, it is suggested that the duration of the activity of contact with trainees (online or face-to-face sessions, group work, tutoring) should not exceed 40h and a



maximum of 20h should be considered for individual work (previous readings, exercises, final evaluation).

The planning of new editions should always guarantee the balance between theory and practice, the promotion of critical analysis, thematic deepening, and the networking between interns and specialists.

4. Target audience

Considering that the EHITP main objective includes, currently, to address the European inequalities on practice-oriented health information training, the target audience can be defined as:

- Professionals working in health information-related contexts (for more than 2 years): Health Information Specialist, Statistician, Epidemiologist, Economists, data analysts, social scientists, Health Professionals, Health Researchers, etc.

- National and international members of Health information institutions.

- Junior health professionals aiming at obtaining, due to professional reasons, a training specialization in health information;

According to the objectives of each course, training groups can include elements with different profiles. An option that allows the sharing of experiences among participants of different generations, with different institutional responsibilities and knowledge, allows more in-depth exploration and discussion of topics.

5. Evaluation

In the framework of the 1st ESHI, an assessment of trainee satisfaction was conducted, consisting of a daily survey and a final survey to find out their opinions and collect suggestions for improving future editions of the course. The speakers were also invited to give their opinion on various aspects of the course, through a final survey.

As an expected good practice, evaluation of training must be performed. In the EHIT Programme tools, sets of training evaluation instruments should be progressively available. However, any educational partner institution may freely define their evaluation instruments



aligned with programme objectives. For this, example course evaluation instruments could be:

- Pre-evaluation, either by a test/survey or through a call;
- Knowledge and competency test, at the end of the training;
- Satisfaction test, at the end of the training;
- Impact tests, after a certain period, to evaluate the impact on job performance;

B. Burden of Disease course example

Topic specific courses like the developed BoD workshops are an integral part of a European Health Information Training Programme (EHITP). EHITP aims to respond to the different needs of the MS through a flexible strategy. In this way, it is possible to improve each MS's capacities concerning the analysis and monitoring of public health and health systems performance.

Ultimately, the EHITP will eventually reduce or eliminate capacity-building iniquities among EU MS, creating more cohesive and uniform EU critical areas of health information use and management.

The selection of this course's different components was based on the INFACT's Work Package 9 report (MS31), which addressed two workshops related to the Burden of Disease.

1. Main objectives

Given the different needs and training (academic or other types) that each MS can provide to health professionals, the EHITP mission is to provide a baseline training programme that can be applied anywhere in the EU. Since the EHITP can be adjusted according to national requirements, the different European health professionals have access to various topics, subjects, and teachings that allow them to be on an equal footing with other health professionals.

With a practical aspect, through the discussion and reflection of practical cases, health professionals will understand how BoD methods can be applied "on the ground" since usually the Global Burden of Disease (GBD) methodology is not part of the monitoring and reporting routine in Europe.



Given that there are different levels of knowledge, experience, and ability to apply and use the BoD methods, MS need some guidance and training to integrate these methods into the public health system. This course also aims to teach countries and their health professionals this new methodology while promoting their adoption. The course and its progressive evolution can be named "Health Information Training Course on Burden of Disease".

The course operates in three areas to meet the proposed objectives:

- The need for methodological pieces of training to strengthen skills in calculating and in interpreting the BoD estimates across the MSs;
- The encouragement of more collaborations across MS to share or exchange good practice on BoD;
- The importance of the implications of BoD data to guide policies across MS.
 - i. Target Audience

The BoD course is especially aimed at health professionals, with a particular focus on young health professionals who have less (or no) experience related to this topic. Also, the course is open to members belonging to national or international institutions related to Health Information.

With candidates presenting different Health Information levels experience, the BoD course reinforces its characteristic of knowledge exchange, practices, and methodologies on HI.

2. Duration

The course in its current formulation lasts 27h30, distributed equally over five days. During a full day, participants attend four sessions, totalling 20 sessions and themes throughout the course.

During the mornings, participants have up to three and a half hours of sessions. In the afternoon, the duration of the sessions should not exceed two hours.

3. Model

The BoD course is designed to run over just one week. This week of sessions is distributed among theoretical and practical topics, with space for participants to learn about other practices and exchange impressions about applied methodologies. At the same time, there should be a presentation and discussion of practical cases.



Table 1. Example of a BoD Course

	Monday	Tuesday	Wednesday	Thursday	Friday
Morning sessions	About the Global Burden of Disease Study	Computational problems and solutions using BoD methods	Opportunities and barriers for BoD studies	Methodological support to implement BoD approaches	Using data to inform policy: successfu l examples
(9000 - 12h30)	Introducin g the WHO BoD Manual	Using BoD to assess social inequalities	Methodological challenges in undertaking BoD studies and how to overcome them	Perspective from WHO Europe on BoD and recent policy developments	Pros and cons of using BoD as an indicator of policy
Lunch (1h)					
Afternoon session (13h30 ->	What type of data is needed to do BoD calculation s?	Subnational estimation of BoD - Case Study from the UK	Strengths and weaknesses of BoD methods	Perspective from OCDE	Use of Global Burden of Disease to monitor recent trends in life expectan cy across Europe
151150)	Intro to technical measures (YLL, YLD, DALYs, etc) with case studies	Social determinants of health as independent risk factors in BoD estimates	How to conduct a BoD study in a country? & How to guide a country without expertise in conducting BoD studies?	What do policymakers want/need from health statistics?	Country- specific case studies & Next steps

C. Assess Health Information Systems: from performance measurements to areas of action

To respond effectively to population health and health systems' challenges, policies must be based on the best scientific evidence derived from sound data and information, and relevant research. Health information systems (HIS), both at the national and international level, play an important role in ensuring that reliable and timely health information is available for operational and strategic decision making inside and outside the health sector.



How do you know if the HIS in your country is performing well? How can you identify potential areas of action in such a complex and multitaskholder system? Previous research has found that there is a great need for capacity-building activities to support strategic development and assessment of HIS.

The World Health Organization (WHO) Regional Office for Europe has created a practical support tool to assist MS in assessing and developing their national HIS and eHealth systems. The tool covers the domains of resources, indicators, data sources, data management, national HIS data quality/ and information products, and dissemination and use. Currently, the tool is being used by nine countries in the InfAct to peer review each other's HIS in rotating groups of three countries.

Two skill-building seminars were developed and essayed at the Public Health World conference. In the first, an introduction was given on HIS's concepts and its core elements, the WHO assessment tool and its current format. In the second, experiences were shared using the support tool. Practical exercises were performed in groups after the participants choosing the HIS tool domain of their particularly interest. Each group will carry out a mock exercise of the chosen domain of the tool for their own country: the strengths and weaknesses identification and the groups members' exchange experiences of how these have been addressed.

Through this kind of skill-building seminars, participants build a clear picture of what HIS entails. They familiarise themselves with the existing HIS assessment tool and how it is used. Finally, learning about common strengths and challenges in HIS across Europe.



IV. Health Information Capacity Building Sustainability Plan

A. HI Sustainability: Coping with HI inequalities

The capacity to collect, analyse and translate Health information is critical for the development of research and policymaking for a healthier Europe. Sustainability describes the extent to which an evidence-based intervention can deliver the intended benefits over a long period. Three operational indicators of sustainability are:

- 1) maintenance of a programme's initial benefits;
- 2) institutionalization of the program;
- 3) capacity building in the recipient setting;

Whereas maintenance refers to the beneficiaries' ability to continuously provide the gains achieved with the initial implementation of the intervention. The institutionalization assesses the extent to which intervention is integrated through policies and practices. Three stages that determine the extent of institutionalization are (Rabin et al., 2008):

1) passage (ie, a single event that involves a significant change in the organization's structure or procedures such as a transition from temporary to permanent funding),

2) cycle or routine (ie, repetitive reinforcement of the importance of the evidencebased intervention through including it into organizational procedures and behaviours, such as the annual budget and evaluation criteria),

3) niche saturation (the extent to which an evidence-based intervention is integrated into an organisation's subsystems).

Therefore, capacity building is any activity (e.g., training, identification of alternative resources, building internal assets) that builds durable human resources and enables the recipient setting or community to continue delivering an evidence-based intervention after the external support from the donor agency is terminated.

If global health systems are to be sustainable, they will need to adapt to the ever-evolving challenges and constant pressures wrought by rapid and unprecedented change (Braithwaite et al., 2018). Common pressures or stressors are manifesting in every healthcare system; these include scarcity of financial and staff resources, expectations of the public, and



maintaining healthy relationships with multiple stakeholders as well as crisis management due to large scale pandemics such as COVID 19. Given this, achieving a balance between quality of care and affordability of care is difficult. Health systems everywhere need to enhance their workforce, provide efficient development and ensure clinicians keep up to date with technological changes, but all at an appropriate cost. The question of how to provide financially viable, efficient, accessible, and affordable healthcare for all, challenges everyone and everything.

Emerging forms of digital technology and clinical technology are altering health services. While the rise of e-health technology is improving patient-centred care, at its heart, eHealth technology is about the enhancement of electronic data management, storage, and capacity, while simultaneously providing accessible information to patients, clinicians, and providers.

Health, information, and health information, as many other matters, while being diverse across Europe are also facing the challenges posed by modern social and technological advances (Lapão et al., 2019). A currently data-driven society poses both challenges and opportunities that must be faced and conquered. Through the diversity of available health information in the EU MS, it is also clear that knowledge and capacities on health information are diverse among EU MS.

Sound and reliable information are essential to structure, develop, and guarantee health systems' sustainability and ensure their interventions' success. The results are very enlightening: public health information is a growing field, and health information systems are essential to support public health activities. As a result, it is necessary to provide rigorous training and education for professionals, giving them knowledge, skills, and tools to produce, manage and use information robustly and reliably. Now, in the next 10 years and beyond.

There is evidence that health information availability and the possibilities for using it for evidence-informed policymaking varies among EU MS. Due to the contributions of the MS teams, it is clear that the existing capacity building is growing. With mapping exercise made in task 6.1. of our WP, despite limitations, it was possible to identify a multiplicity of training initiatives throughout Europe, undertaken by universities, public health organizations, associations, and private organizations, as well as initiatives of capacity building that happen regularly. However, the experts, and the literature, point to the necessity to reinforce the training.



As in other public health-related areas, the diversity of concepts, professional profiles, and training initiatives associated with HIS that our results show, indicate the importance of continuing the effort to harmonize concepts like Public Health Information Systems (PHIS), public health professional or specialist, and requirements for the training of professionals in the use and management of these systems in public health activities in Europe. Such importance should have institutional support at the highest level.

It was also possible to understand that public health information specialists more commonly use HISs, public health researchers, epidemiologists, and data analysts. Training needs subsist for public health researchers, public health information specialists, epidemiologists, data analysts, and health professionals. In a 10-year development period, training needs seem to change somewhat, but not substantially. However, the identification of new profiles of specialists is emerging. Although these data help to understand HIS's evolution better, we have to bear in mind that results are only indicative of what can be expected for the future.

Despite the limitations, the research on the availability of training initiatives in each country shows a large supply, diversified and spread throughout Europe, and an opportunity to standardize, even with defined credits, a training offer directed to Health information. On the other hand, partners have been involved in international capacity-building initiatives, namely in short-, medium- and long-term training initiatives to define guidelines or standardized protocols.

The importance of training professionals in the immediate and long-term emerge from the analysis of the results. As in other studies, the skills for data analysis and empowerment of professionals to use the data are the most valued by the specialists, but other areas of knowledge, such as system's design or ethics should also be integrated into the training programmes.

There are specific issues that still require more extensive capacity-building at the EU level. In the area of data sources, standardized data collection tools, and epidemiological methods, most of the topics were already relatively well covered with existing training activities in the MS. In the case of health examination survey (HES), additional capacitybuilding activities might be needed. In the area of data collection, several topics seem to require additional capacity-building activities: interoperability of data sources, derivation of indicators for the ECHI (European Community Health Indicators) shortlist and foresight/scenario analysis. For translation from data to policy areas, all topics lacking



systematic training throughout the MS but especially training on policy translation and data presentations would need strengthening at the EU level.

Concerning the HIS capacity building, the scoping review performed identified a set of issues that can be systematized around three interrelated axes relevant to the definition of the flagship training:

1) Collection, management, and use of data: Several papers address the need to increase the skills of professionals to use clinical data collection tools, such as electronic health records or tally sheets, as well as improve their technical capacity for sampling design, conducting research and for processing, managing and analysing data. Data presentation and communication are also referred to as skills to be developed.

2) Health Information System design, implementation, and development: Some authors argue that although short-term training programs are important, they are not sufficient, even advocating the need to empower the workforce for different aspects of HIS like architecture and design (e.g., user-centred design or usability assessment), as well as for the implementation process, to promote motivation and adhesion while preventing problems of lack of usability.

3) Informatics and technology (IT): The improvement of computer skills is a recurrent subject, often referred to by professionals as a major need, along with the capacity to use digital tools for recording, processing, and storing data. IT training includes basic skills and the use of digital tools to manage data and eHealth devices or geographical information systems (GIS) for mapping the health of populations.

From the survey results analysis (task 6.1), including lack of existing capacity-building activities and the need for topics identified by respondents for future sustainable capacity building programmes on health information, the following areas with a clear need for coordinated EU level capacity building activities were identified and piloted during the 1st European School on Health Information:

• Data analysis and interpretation, especially interoperability of data sources, derivation of ECHI indicators, and foresight/scenario analysis.

• Translation from data to policy, especially policy translation tools and data presentation.



• Data collection, sources, metrics, and indicators, especially issues related to health examination surveys.

• Data privacy and ethical issues, especially how to deal with requirements of GDPR.

Additionally, one should also consider new, emerging topics such as mydata, big data, and artificial intelligence in public health and how they could be integrated into a comprehensive health information system.

B. Leveraging INFACT European School on HI and other training initiatives

The results of the 1st European School on Health Information were extremely positive and encouraging. This 1st European School on Health Information was to pilot a flagship course in several MSs within the capacity building programme framework and to provide evaluation for its implementation, contributing to the Roadmap for Sustainability.

The Course on "Health Information Training Course on Health Examination Survey: From Data Collection to Policy Dialogue and Translation" aimed at addressing Fundamental Health Information tools and methods used by public health professionals and, likewise to contribute to the European Health Information Training Programme and Strategy, with a clear example of a course that could be offered by InfAct and by a Distributed Research Infrastructure on Population Health (DIPoH) in the future, contributing to improving capacity and equity in Europe.

The course topics contributed to convergence in using European Methods and were based on HI fundamentals plus innovative contributions from the InfAct work packages and experts. The exercise provided additional information for further validation of the Programme. Additionally, the pilot enabled collecting important information, which informs the design of this roadmap for health information equity and sustainability report.

Each day was 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 (GDPR) and ethical questions for health information

The 1st European School on Health Information (course) was robustly evaluated, going beyond simply validating course designers' initial assumptions and aspiring to open new paths for health information training in Europe.

We want to draw attention to the following:

1) The importance of the need's assessment exercise;

2) The comprehensive planning approach of the WP6;

3) The contribution from European Health Information Experts, mostly from INFACT members;

4) The innovative pedagogic approach for health information, including the working groups;

5) The recruitment and the active participation of the selected trainees.

C. HI Capacity Building Sustainability Plan

1. The Roadmap for Sustainability

The activities developed at WP6 enable us to reach the following recommendations on the sustainability of Health Information in Europe:

1) CONCEPTS: Efforts should be made to clarify concepts regarding the professions involved in public health activities.

2) RESEARCH: More research is needed on HIS topics and their relationship with public health activities and the training of professionals for their use. More research is needed on HIS topics and their relationship with public health activities and the training of professionals for their use.

3) CAPACITY BUILDING: A sustainable capacity building programme in health information should be established, aimed at increasing knowledge on the availability and use of standardized Health Information methods, common practices within MS.



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, MS and European Institutions should develop initiatives according to specific needs and, at the same time, that contribute to a European perspective of health information. The coordination of the EHITP should be assumed by the INFACT partners engaged in the DIPOH RI, eventually those also engaged in the new Horizon2020 project PHIRI.

5) THE 1ST EUROPEAN SCHOOL ON HEALTH INFORMATION: 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 General Data Protection Regulation (GDPR). These thematic areas are also priorities in other training types, even more so for those more specific training activities.

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

7) LEARNING PROCESS: Include a cycle of learning. Guidelines and recommendations are produced and can 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.

8) VISION: The EHITP establishes the vision on a more equitable Health Information capacity building among EU MS, as well as a set of steps to make it happen. The first steps were the 1st ESHI and the course on burden of disease.

9) MILESTONES: The 1st ESHI and the course on Burden of Disease represented the first milestone (done by INFACT in 2020). New milestones imply the continuity of the ESHI as a regular activity, the leverage of other INFACT member's capacity building



activities and the development of a yearly Health Information Programme (as the one defined by EUROSTAT) aiming at future DIPoH research infrastructure. The first programme should be defined and issued for 2022, by the institutions that will be involved in the future DIPoH.

10) FUNDING: The future sustainability of EHITP largely depends on both the success of DIPoH RI and the collaboration of the different HI organizations in Europe. European health information-related projects (PHIRI, European Health Data Space) and European Health Information-related organizations (e.g., WHO Europe, ECDC) should be engaged in health information training that could be shared and developed in promotion of a more equitable Europe. Moreover, European universities and Researcher centres should also contribute to this effort (e.g. Master and PhD). The risks associated with the development of these activities can be mitigated by both the collaboration (risk sharing) and by the distribution of the risk by the many actors in the field. The promotion of DIPOH will represent a strategic opportunity.

This set of conclusions led to the definition of a ROADMAP FOR SUSTAINABILITY.



EUROPEAN ROADMAP FOR HEALTH INFORMATION (EROHIN)

This Roadmap for sustainability on health information starts from identifying HI needs across Europe, from which the European Health Information Strategy has emerged. This strategy



includes the development of the 1st European School on Health Information, and what we have learned from it, the other INFACT outcomes, and very importantly the dynamic network of health information experts that this initiative established.

The 1st European School on Health Information contributed to the test that comprehensive training on health information was possible and could reduce inequities. Many ESHI participants came from European Easter and Southern countries, which were identified the countries with larger shortages of HI resources. It also strengthens the capacity of the INFACT team to understand capacity building and to promote it further. The success of this initiative is opening the opportunity to organize the 2nd European School on Health Information in 2021, which represents another milestone for the sustainability of EHITP.

2. The annual European Health Information Programme

The annual European Health Information Programme (EHIP) will be a structured collection of capacity-building initiatives to be issued each year. These initiatives include international capacity-building courses and workshops (e.g., WHO, ASPHER, ECDC, Universities, and Public Health Institutes) and programmes organized within the INFACT/PHIRI/DIPOH network.

a) These initiatives include post-graduate or Master courses, special training programmes (more than one week), 1 or 2 days and full week programmes, seminars, webinars, tutorials, etc.

b) 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 in EU Member-States; integrating all European institutions related to Health Information; and setting the way for a European core of Health Information specialists.

c) should support lifetime learning of people working in the field of public health and health information. It should be dynamic and able to respond to emerging needs in the ever-changing health information environment. Therefore, ECDC Training



Programmes³, as well as ESC Educational programme⁴ are good examples of the comprehensive capacity building programmes which support lifetime learning. They include different types of capacity-building activities targeted for people with different levels of expertise/different stages of their career.

d) This annual programme should be similar to the Eurostat's Training Programme. Eurostat has a consolidated track record at this level. The European Statistical Training Programme⁵ aims to provide continuous training in new methods, techniques, and best practices and integrate the application of European concepts and definitions⁶.

The Support of the member's states is very important. Mechanisms should be developed to support MS, mostly to address HI inequities. One could consider the Erasmus + programme for that purpose.

DIPoH Capacity Building Portal. Information about available capacity building activities and possibilities will be Combined and presented at a DIPoH capacity-building portal, integrating the capacity building activities of the European HI organizations. The annual EHITP will be accessible from this portal, as well as the application can be done from the portal. The funding is expected to be provided by both the DIPoH project and fees from specific valued-added seminars and courses. Other alternatives come from applying for EU-level funding from Erasmus+, Marie Skłodowska-Curie Actions, COST Action, Horizon Europe, or EU4Health,

Therefore, individual MS can use the DIPoH portal to be better informed about already existing and new capacity-building opportunities, as well as to apply for specific programmes to be supported by the DIPoH experts.

⁶ <u>https://ec.europa.eu/eurostat/documents/747709/6103606/2019-ESTP-catalogue-final.pdf</u>



³ <u>https://www.ecdc.europa.eu/en/training</u>

⁴ <u>https://www.escardio.org/Education</u>

⁵ https://ec.europa.eu/eurostat/web/european-statistical-system/training-programme-estp

Furthermore, the development of DIPoH as an ERIC is a natural progression from this work. Capacity building is an important pillar for sustainability and one of the services to be provided by the HI platform and which will be critical for the future.

Therefore, there are already significant results from INFACT that could be leveraged as a proof of concept as a platform for DIPoH.

As a result of research done on the InfAct Joint Action, particularly on WP6, it is clear that knowledge and capacities on health information vary among the European MS and that there is a need to improve common mechanisms for strengthening the capacity to use and manage health information that will be deeply addressed in DIPoH.

We have been focusing on having a clear Roadmap for Sustainability regarding capacity building. For that, DIPoH will enable more research on Health Information Systems topics and their relationship with public health activities and the training of professionals for their use.

Therefore, a sustainable capacity-building programme in health information should be established, aiming to increase knowledge on the availability and use of standardized Health Information methods, common practices within MS. And more importantly, collaboration among European MS and Institutions is critical for sustainability. Training will be provided in collaboration with different organizations (ECDC, EMCDDA, IARC, Eurostat, OECD, WHO, etc) should be considered on the training initiatives and already available academic and non-academic structures specialized training on Health Information.



V. Discussion and conclusion

At Task 6.1, the major HI inequities in Europe were identified, from which a strategy for HI capacity building was issued at Task 6.2. This strategy led to the design and implementation of a pilot course, structured as a European School on Health Information at Task 6.3. This activity went very well. It was evaluated accordingly to inspire the definition of a roadmap for HI's future in Europe at Task 6.4, which is the content of this report.

The fundamental ROADMAP next steps are the following:

- Keep betting on the DIPoH RI as the strategic platform for the future coordination of the EHITP;
- Organizing the 2nd ESHI to create more momentum for HI in Europe; and
- Organizing for issuing the first annual HI programme at the end of 2021, leveraging both the efforts from INFACT and PHIRI.

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