INFACT
Joint Action on Health Information

InfAct: External Evaluation Interim Report I

March 2019

Content

Introduction

This report, commissioned by the InfAct consortium, evaluates the first year of the project. InfAct (see Box 1) kicked off in March 2018 and a year later the external evaluation committee members came together to track the progress made, critically review advancements towards the key objectives of the project, and provide strategic recommendations.

Box 1 – The InfAct project

The Joint Action on Health Information (InfAct) aims to strengthen national and European Union (EU) health information systems by:

1. Establishing a sustainable research infrastructure which will support population health and health system performance assessment.
2. Strengthening European health information and knowledge bases and health information research capacities to reduce health information inequalities.
3. Supporting health information interoperability and innovative health information tools and data sources.

The project runs for three years, starting from March 2018.

The InfAct partners are 40 institutions from 28 countries, including 20 public health or research institutes, 13 ministries, and 3 universities.

A total of three external evaluation reports will be provided. This first report is the interim report after the first year of the project. A second interim report will be provided after the second year of the project. A final external evaluation report will be provided at the end of the project.

This report is based on the documentation provided by the InfAct consortium, i.e. three reports[1]:

- InfAct interim report 2018
- Internal evaluation report 2018
- Meeting evaluation report I

Furthermore, this report is based on the presentation given by the InfAct coordinators at the external evaluation committee meeting (held 28 February in Brussels), and written feedback from the external evaluation committee members.

This report is structured in three sections, (1) tracking progress, (2) critically reviewing the InfAct outcomes, and (3) providing strategic recommendations for InfAct.

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[1] Upon request, these reports can be provided by the InfAct coordinators, infact.coordination@sciensano.be.

The InfAct external evaluation committee

The InfAct consortium invited several stakeholder groups to be part of the external evaluation committee. These different stakeholders represent the potential InfAct target audiences and are stakeholders with expertise in EU-wide action in the domain of public health with focus on health information (health status and health systems) and research. Two stakeholders (EUPHA and ASPHER) are tasked to coordinate the external evaluation committee and are responsible to submit the reports to the InfAct consortium.

The external evaluation committee members that contributed to this current report include representatives from:

- European Public Health Association (EUPHA), including EUPHA section Public Health Monitoring and Reporting, EUPHA section Health Services Research
- Association of Schools of Public Health in the European Region (ASPHER)
- Ministry of Research, Belgium
- Ministry of Health, Belgium
- Expert Group on Health System Performance Analysis (EGHSPA), European Commission
- iPAAC Joint Action, Innovative Partnership for Action Against Cancer
- EuroHealthNet

Tracking progress

To evaluate the progress of the InfAct project, the deliverables and milestones, as described in the InfAct grant agreement, are compared to the undertaken activities. The following summarises the findings of the internal evaluation report 2018.

Four deliverables were due in the first year:

1. Conceptual framework and vision
2. Risk management and contingency plan
3. Leaflet and website
4. The terms of reference and operating procedure of the Assembly of Members.

All deliverables - except one - were achieved by the set due date. The terms of reference and operating procedure of the Assembly of Members was delayed by 2,5 weeks.

Nine milestones (MS) were due in the first year:

1. Kick-off meeting (MS1, work package 1)
2. Dissemination plan (MS6, work package 2)
3. Agreement with sub-contracts (MS10, work package 3)
4. Assembly of Members (MS14, work package 4)
5. Method development for priorisation (MS20, work package 5)
6. Questionnaires for member states regarding data collection methods and procedures (MS27, work package 8)
7. EuroPeristat meeting (MS32, work package 9)
8. Health System Performance expert workshop (MS33, work package 9)
9. Report on mapping exercise, identification of inspirational experiences (MS35, work package 10)

Three milestones were not achieved yet. Milestone 14 (Assembly of Members) was not fully achieved as not all representatives for the Assembly of Members were identified. The members were supposed to be appointed by month 3 of the project, however, at the time of the external evaluation (28 February 2019) it was still unclear which representatives were identified for the Assembly of Members. Unfortunately not all countries managed to appoint a representative from the ministry of health and ministry of research, despite the multiple efforts to encourage this e.g. extending of the deadline, outreach by phone, face-to-face workshop to discuss approach, and outreach by the InfAct coordinator. Two other milestones were delayed until late 2019, i.e. two workshops (the EuroPeristat meeting and Health System Performance expert workshop). The reason provided for this delay, is that it is more useful to have the workshops after outputs of other work packages are delivered, such as the indicators and issues and potential structure of the health information system.

For a full description and evaluation of the deliverables and milestone for this first year the internal evaluation report can be consulted.[2]

The external evaluation committee's reflection on the progress of the InfAct project is that the coordination group was instrumental to mitigate against delays in those work packages that risked not achieving their milestones or deliverables. For example, the interim report mentions that the coordinators approached beneficiaries/stakeholders from countries that did not appoint any representative for the Assembly of Members during the Expert Group on Health Information (EGHI) meeting.

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[2] Upon request, this report can be provided by the InfAct coordinators, infact.coordination@sciensano.be.

Critical review of the InfAct outcomes

The InfAct project has three main objectives, as specified in the grant agreement:

1. To prepare Member States for the start of the HIREP-ERIC (European Research Infrastructure Consortium on Health Information for Research and Evidence-based Policy).

2. To reduce the health information inequality between and within EU Member States.

3. To develop a strategy promoting the implementation of the HIREP-ERIC strategy in participating Member States, including awareness and encouraging advocacy among stakeholders (especially policy- and decision-makers, stakeholders in health research and public health, and international organisations).

The external evaluation committee members were tasked to review the process, output, and outcome/impact indicators for these three main objectives, as specified in the grant agreement of InfAct. An assessment sheet was developed for the external evaluation committee members to review the main objectives. This assessment sheet is based on the indicators and targets, as specified in the InfAct grant agreement, and a list of questions to assess the actionability for policy and sustainability (annex 1).

The documentation that was provided by the InfAct consortium to the external evaluation committee (i.e. three reports: the InfAct interim report 2018; the WP3 Internal Evaluation Report 2018; and Summary of meeting evaluations I report), was not sufficient to evaluate all targets that were set for the three main objectives. For example, based on this documentation it was unclear how many and which member states are participating in the project, which did not allow assessment of process indicator 1 of objective 1 (i.e. "*MSs contribute to overviews and assessments of their HI systems, of their participation in international HI activities and data collecting networks and develop criteria and procedures to define common HI priorities (WP5, 7). Good practice examples are identified*").

One indicator that the external evaluation committee could reflect on was the target for the second objective, i.e. "*at least 6 MSs participate in 2 pilots of a circle of peer reviews.*" At the time of evaluation, two countries did a peer review (Norway and Lithuania) and one was planned (Romania in March 2019). Assuming that the first year of a project consists mostly of initiating the project, having achieved/planned already three peer reviews with member states is promising progress towards the set target.

The health information training as listed in the second process indicator and target of the second objective (i.e. "*A road map for a HI training programme is developed focusing on international HI aspects for professionals working in HI within MS institutions. The road map is put forward to the MSs through the EAB and the AoM (WP5, 6, 9); The EAB, AoM and all WPs analyse and discuss the road map and amend it to come to a consensus*") seems to focus on academic stakeholders. However, health information systems are mainly run by public authorities which might have separate institutions for capacity building. The external evaluation committee suggests:

- To reflect on the series of the European Observatory on Health Systems and Policies on the organisation and financing of public health services[3], which might be helpful for the development of the training road map.
- That the training should also be available for professionals at public health institutes, thereby having a continuous professional development approach.
- When mapping the needs, capacities and training programmes in health information (deliverable 6.1) the following can be consulted: the EPIET programme of ECDC[4] and the essential public health operations (EPHOs)[5].

The InfAct coordinators presented a revised approach for the project. Thus, it was determined that the external evaluation committee should focus its discussions on the changes and review progress in light of the revisions presented in the next section.

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[3] http://www.euro.who.int/en/about-us/partners/observatory/publications/studies/organization-and-financing-of-public-health-services-in-europe-country-reports-2018
[4] Fellowship programme: EPIET/EUPHEM, https://ecdc.europa.eu/en/epiet-euphem
[5] The 10 Essential Public Health Operations (EPHOs), http://www.euro.who.int/en/health-topics/Health-systems/public-health-services/policy/the-10-essential-public-health-operations

Strategic recommendations

A new approach

At the external evaluation committee meeting (held 28 February 2019) the InfAct coordinators presented a new approach for achieving the InfAct goals. The InfAct consortium envisions to achieve a one-stop-shop for EU health information research. This web-based platform aims to facilitate finding data, networks, experts, guidelines and tools for health information across Europe. The new approach that was presented by the InfAct coordinators is to apply for a European Strategy Forum on Research Infrastructures (ESFRI), instead of aiming for an ERIC directly.

The InfAct coordinating team clarified this new approach in their presentation. By first applying for an ESFRI, the InfAct consortium ensures becoming a sustainable structure. Setting up an ERIC would require more resources and time than is available in the InfAct project in order to ensure sufficient support from member states. Applying for an ESFRI requires one coordinating country and memorandum of understanding from at least three member states (though preferably more) and comes with European Commission financial support for four years if successful in the application to ESFRI roadmap calls. It is clarified by the InfAct coordinators that InfAct would still need to be successful in their application in order to get financial support ones InfAct is on the ESFRI roadmap. However, the calls are restrained to projects on the ESFRI roadmap. The ESFRI is a long procedure (with final application due 2021 which could result in a health information research infrastructure to be in the implementation phase in 2026), but provides a sustainable path and business plan to build to an ERIC. Activities of the research infrastructure can be implemented already in the interim phase (so before the implementation phase in 2026). Based on the presented considerations of this new approach, the external evaluation committee agrees with this change of approach and advises to reflect:

- The one-stop-shop contains health data, a catalogue of expertise and reports. This could be a challenge in terms of resources, manpower, follow-up, and maintenance.
- Consider the possibility of the one-stop-shop to include a repository of thematic policy briefs (considering its mission of policy support).
- Going for the ESFRI implies this becoming a strategic objective of InfAct. Would this entail that a budget is produced to enable members of the AoM to decide on their participation?

Dissemination and sharing the InfAct outcomes

Some suggestions from the external evaluation committee to improve and increase dissemination activities:

- The external evaluation committee advises to do a stakeholder analysis, in order to better identify the target groups for the dissemination of the project outcomes. As it appears, both ministries of health and ministries of research are target groups. These two stakeholder groups have different needs, hence would require a different dissemination approach.
- In terms of stakeholders, it could be beneficial if researchers in each of the 28 countries could provide feedback to the InfAct project. These researchers (e.g. economist working on welfare issues and using health data in their research) are the future users of the

infrastructure and putting them in the loop from the beginning could reinforce the application in ESFRI.

- Creating and sharing a mock-up of what the ultimate portal would look like could facilitate the presentation to ministries and other stakeholders. With such a tool stakeholders can more clearly see what they are investing in. The tool could clarify some questions that stakeholders might have e.g. Is it open to the public? How many steps would it take to find a piece of information from the main dashboard?
- InfAct could elaborate on what sets it apart from other health information initiatives in Europe and how they collaborate together.
- Opportunities to share the (expected) outcomes of InfAct are the European Health Forum Gastein (October 2019) and European Public Health conference (20-23 November 2019, in Marseille, France).
- Make a promotional video for the project with a strong story line.
  - Think about developing one story in which two perspectives are described (Ministry of Health perspective and Ministry of Research perspective) and end the story with a common goal for both.
  - Think about pitching the platform that is aimed for at the end of the process. How would it look like, who are the end-users, what is different to already available platforms?
- The project leaflet should be more visible on the website (e.g. by given it a prominent place at the top of the homepage).
- The internal evaluation report states that it is a challenge to use Twitter efficiently in reaching out to all stakeholders. The external evaluation committee suggests the coordination group to use a tool that allows to schedule tweets, i.e. tweetdeck (https://tweetdeck.twitter.com). If the internal evaluation concludes that communications in general should be strengthened, the need to employ a communication consultant could be considered.

Assembly of Members

During the external evaluation committee meeting (held 28 February 2019), the external evaluation committee questioned the composition of the Assembly of Members and whether it was a policy/governance group or a technical group. This could not be clarified. Hence, the external evaluation committee advised to clarify this before the first Assembly of Members meeting.

The composition of the Assembly of Members could be reflected in the name and functions of the group, as Assembly of Members suggests more policy level representatives that can aid the support for the project at ministerial level and that can function as a sounding board, whereas technical level representatives could be referred to as to (and could operate separately) a working group.

Further suggestions from the external evaluation committee:

- A barometer (or something similar) that shows how many member states are involved already would be useful to get an overview of the national support.
- Convinced representatives could write short testimonials, describing why they cooperate and why they think a European Health Information platform is important.

- Finalising the modifications to the Terms of Reference of the Assembly of Members and coming up with an appropriate description for the first Assembly of Members (e.g. 'ad hoc Assembly of Members,' since they had not yet conducted an official election).

Continuity after the ending of the project

The external evaluation committee suggest that InfAct should ensure consensus on the final deliverable, including the understanding of this deliverable. The sustainability after the project ends should be considered. If the application for an ESFRI is successful, some of these aspects will be covered (as ESFRI projects are supported with a budget).

Based on the experience from the iPAAC Joint Action, represented on the external evaluation committee, it is critical that partners reach a consensus regarding the final deliverable from the very beginning of the Joint Action. The final deliverable of iPAAC is a Roadmap on Implementation and Sustainability of Cancer Control Actions. Since the term 'roadmap' may be understood in different ways, iPAAC allocated time to brainstorm about the final deliverable during various meetings (Joint Action meetings, Governmental Board meetings). Since the roadmap is a web-based tool, the question of sustainability was addressed early in the iPAAC project. Firstly, it is important to define who will be responsible to update the content of the roadmap after the end of the joint action. Secondly, it is important to consider which actions should be included in the roadmap after the end of the joint action.

Concrete advice

In addition to the strategic recommendations presented above, there are some short suggestions from the external evaluation committee to InfAct in the following bullet points:

- For the next external evaluation, it is advised to make more documents available to the external evaluation committee. Some key documents such as the Conceptual framework (deliverable 1.1) and Risk management and contingency plan (deliverable 1.2) were not included in the current evaluation. . A way to achieve this is by sharing relevant documents through OpenLucius (it was agreed that External Evaluation Committee members would receive access to relevant documentation via OpenLucius).

- There is a considerable overlap between the internal evaluation report 2018 (WP3) and the InfAct interim report 2018 (both prepared by the InfAct consortium), as they both include an evaluation of the deliverables and milestones for the first year. During the next evaluation moment (after year two of the project), time can be saved by producing only one report.

- The external evaluation committee stresses the importance of having a representative from the expert group on health information (EGHI, European Commission) to join the external evaluation committee. Even though members of EGHI are already involved in the project itself, it could be beneficial to also include a representative in the external evaluation committee (as long as no conflict of interest). The evaluation committee is aware that an invitation for a representative from EGHI was sent, and that there were two potential candidates, but unfortunately none of them were able to attend the first external evaluation committee meeting. As suggested by the InfAct coordinators, asking the chair of EGHI to appoint someone earlier could ensure that an EGHI member is available for the next external evaluation committee meeting.

- To ensure alignment with the Directorate Generals (DG) of the European Commission and other agencies/bodies, representatives of the DGs and other agencies/bodies can be invited to the key meetings of InfAct.

Looking ahead: the second interim external evaluation

At the next interim external evaluation, which will take place after the second year of the project, it will be essential to evaluate the progress of the Assembly of Members. At the time of this first interim external evaluation it was difficult to convince all member states to participate and find representatives for the Assembly of Members. Also, it was unclear who the members of this assembly are. The Assembly of Members is an essential element of the project, as it stands for getting national support for the project as well as ensuring sustainability after the project.

Also, an extra eye will be kept on work package 4, titled 'Integration national policies and sustainability', as two out of the three milestones for this work package were not achieved in the first year.

At the time of the second interim external evaluation (February 2020) the EU elections will have taken place. A short reflection of the impact of the elections (and any restructuring of the Commission as a result of this) on the project would be advisable.

Annex 1 – Assessment sheet for the InfAct external evaluation committee

Assessment sheet for the InfAct external evaluation committee

To be used by the members of the InfAct external evaluation committee.

Specific Objective 1	To prepare MSs for the start of the HIREP-ERIC (ERIC on Health Information for Research and Evidence-based Policy)	
Process Indicator(s)	**Target**	**Assessment**
MSs contribute to overviews and assessments of their HI systems, of their participation in international HI activities and data collecting networks and develop criteria and procedures to define common HI priorities (WP5, 7). Good practice examples are identified	100% of the participating MSs provide information	
The business case and road map including 5-year workplan scenarios for a sustainable HIREP-ERIC are developed and put forward to the MSs through the External Advisory Board (EAB) and the Assembly of Members (AoM) (WP4, 7)	The EAB and AoM analyse and discuss the business case and road map and amend it to come to a consensus	
Output Indicator(s)	**Target**	**Assessment**
A catalogue of international HI consortia/networks that collect comparable health data and information with an overview of the	100% of the documents are released as scheduled	

participation of MSs and with relevant achievements (reports, articles, other) (by month 22)		
Memorandum of understanding (MoU) between several MSs to start up a HIREP-ERIC (including the submission of a proposal for the ESFRI-road map (by month 18))	The MoU is sent out as scheduled	

Outcome/Impact Indicator(s)	Target	Assessment
HI consortia/networks to support a future ERIC are set up within MS	All MSs interested in participation in an ERIC have set up HI consortia/networks.	
MoU is signed by the second Assembly of Members	A necessary core set of 10 MSs sign the MoU and proceed towards the ERIC	

Specific Objective 2	To reduce the health information inequality between and within EU MS	
Process Indicator(s)	Target	Assessment
In the framework of mutual learning, MSs initiate a peer review process of their HI systems to identify in a standardised way the strengths and limitations and suggestions for improvement (WP5)	At least 6 MSs participate in 2 pilots of a circle of peer reviews	
A road map for a HI training programme is developed focusing on international HI aspects for professionals working in HI within MS institutions. The road map is put	The EAB, AoM and all WPs analyse and discuss the road map and amend it to come to a consensus.	

forward to the MSs through the EAB and the AoM (WP5, 6, 9)		
Learning through good practice case studies in relation to standardisation and data quality methodologies, new methods of data gathering, analysis and interoperability of e-health sources (WP8, 9, 10)	100% of the WPs analyse the information and agree on conclusions and recommendations	
Output Indicator(s)	**Target**	**Assessment**
A set of documents describing the HI system peer review process, the evaluation of peer review tools, and lessons learned through the periodical review assessment both as assessor and as assessed (by months 28, 32)	100% of the policy briefs and documents are released as scheduled	
A set of documents describing the training needs based on the current capacity in MSs and supporting the framework and road map on HI training (by month 12, 18, 30)	100% of the documents and policy briefs are released as scheduled	
Outcome/Impact Indicator(s)	**Target**	**Assessment**
MSs take ownership of the review process	75% of the MSs in the JA participate in the meeting organised to present the peer review process methodology and results	
Pilot of training and workshops are organised in different domains (a.o. peer review of HI systems, composite health indicators and HSPA)	At least one third of the MSs in the JA participate in each of the training pilots	

Specific Objective 3	To develop a strategy promoting the implementation of the HIREP-ERIC strategy in participating MS, including awareness and encouraging advocacy among stakeholders (especially policy- and decision-makers, stakeholders in health research and public health, and international organisations).	
Process Indicator(s)	**Target**	**Assessment**
Identification by month 4 of key institutions at national, regional, EU and international level (such as EHII (WHO-Europe), IANPHI, JRC, OECD) able to contribute to the promotion of the HIREP strategy and setup of an interactive forum/e-community.	An interactive community is set up and the HIREP-ERIC is introduced.	
Output Indicator(s)	**Target**	**Assessment**
The audience in the forum/e-community actively participates in the debates and gives pertinent feedback to tailor the contents of the HIREP network consensus documents to the needs of both research and policy development.	75% of the participants give feedback on the consensus document of the HIREP-ERIC.	
Outcome/Impact Indicator(s)	**Target**	**Assessment**
The initial advocacy and awareness strategy promoting the HIREP-ERIC in MSs is designed by month 4 and a final version fully implemented by month 30.	The action plan of the advocacy and awareness strategy is implemented as scheduled.	

Actionability for policy criteria	Assessment
1. Is there a compelling story (need, added value) why to invest/change?	
2. Is it made clear what kind of benefits can be expected (social, economic, political, scientific, etc.)?	
3. Are the costs (financial, as well as human and technical resources) transparent (and are there any differences between MSs)?	
4. Did all MSs had the possibility to participate in the discussions?	
5. Was there a participatory approach in the discussion with MSs?	
6. Are there any barriers (political, economical, legal) and does the project consortium provide any solutions for this?	
7. How did the project consortium handle critical comments?	

Sustainability criteria	Assessment
1. What is the number of MSs that are willing to act?	
2. Does a network of promoting stakeholders (policy- and decision-makers, stakeholders in health research and public health, and international organisations) exist in each MS and do they know each other?	
3. Does each MS have named institutions responsible for the HIREP-ERIC?	
4. For how many years are the staff and other resources assigned to the HIREP-ERIC financed?	
5. If suitable: Have the MSs written official statements that prepare the ground for the development of a HIREP-ERIC nationally?	
6. Depending on the HIS in the MSs, how is the involvement and communication with regions and the local level ensured?	

Abbreviations

MS   Member States

HIREP-ERIC European Research Infrastructure Consortium (ERIC) on Health Information for Research and Evidence-based Policy

HI   health information

WP   work package

AoM   assembly of members

EAB   external advisory board

MoU   memorandum of understanding

HSPA   health system performance assessment

JA   joint action

EHII   European Health Information Initiative

OECD   Organisation for Economic Co-operation and Development

IANPHI   International Association of National Public Health Institutes

WHO   World Health Organization

JRC   Joint Research Centre

HIS   health information system