InfAct: External Evaluation Interim Report II

May 2020

Content

Introduction

This report, commissioned by the InfAct consortium, evaluates the second 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. This resulted in a first external evaluation interim report. Now, another year has passed, and the current report reflects on this second year of the InfAct project.

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 in 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 second report is the interim report after the second year of the project. A first interim report was provided after the first 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], one plan and one grant agreement amendment:

- Periodic technical report 2020
- Second internal evaluation report 2020
- Summary of meeting evaluations II report
- Update dissemination plan 2020
- Amendments to the grant agreement InfAct proposal Sept 2019

Furthermore, this report is based on the presentation given by the InfAct coordinators at the external evaluation committee meeting (held 4 March 2020 in Brussels), and written feedback from the external evaluation committee members.

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

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

Amendment to the project

There has been an important amendment to the InfAct project. Where it initially intended to work towards an European Research Infrastructure Consortium (ERIC) application, it now focusses on the European Strategy Forum on Research Infrastructures (ESFRI) roadmap application. At the first external evaluation committee meeting the InfAct coordination team presented this new approach for achieving the InfAct goals. The external evaluation committee agreed to this new approach (instead of aiming for an ERIC directly).

In this second year of the InfAct project a new concept is introduced i.e. the Distributed Infrastructure on Population Health (DIPoH). DIPoH is a research infrastructure which functions as a health information portal: a gateway to data, services and tools on population health.

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.

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 second internal evaluation report 2020 (reporting period month 11 till month 22).

Four deliverables were due in this reporting period:

1. Interim report (D1.3)
2. Promotional video (D2.2)
3. Mapping needs, capacities and training programmes in health information (D6.1)
4. Governance structures of a sustainable health information system (HIS) (D7.3)

All deliverables - except one - were achieved by the set due date. The governance structures of a sustainable HIS is delayed to M30. This change is in line with the new approach i.e. applying for a European Strategy Forum on Research Infrastructures (ESFRI), instead of aiming for an European Research Infrastructure Consortium (ERIC) directly (see external evaluation report I, 'a new approach').

In the external evaluation of the first period one deliverable was not achieved by the set due date. The terms of reference and operating procedure of the Assembly of Members was delayed by 2,5 weeks. In this second external evaluation it is determined that this deliverable is achieved.

11 milestones (MS) were due in the second reporting period:

1. Mid-term assembly (MS4) (report of the meeting)
   Was planned for August 2019, took place November 2019.
2. First interim internal and external evaluation reports (MS11) (report is distributed to partners)
   Completed as planned. Internal evaluation report even on month earlier than planned.
3. Method development for prioritisation (MS20) (Report presented on website)
4. Mapping of health information education/training programmes and needs (MS21) (task 6.1 completed)
5. Guidelines for national consortia and domain specific nodes (MS23) (guidelines and criteria are described)
6. Memorandum of understanding HIRP-ERIC (MS25) (number of MSs have signed)
7. Business structure web platform (MS26)
8. 3 workshops on BoD (MS31) (workshop reports)
9. Report on mapping exercise: identification of inspirational experiences (MS35) (report)
10. Report on mapping exercise: legal and organisational interoperability (MS36)
11. Report on mapping exercise: semantic and technical interoperability (MS37)

Two milestones are delayed: the Memorandum of understanding HIREP-ERIC (milestone 25) and the three workshops on Burden of Diseases (milestone 31).

For a full description and evaluation of the deliverables and milestones for this second 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 remains instrumental to mitigate delays. The coordination team keeps the project officers updated on any delayed deliverables and milestones, which is considered a good practice.

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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

To set-up a research infrastructure for population health in Europe the main task within the InfAct project is currently the application for the ESFRI roadmap. The minimum number of supporting Member States joining the application is four (either ministries of health or ministries of research). Though the application requires a minimum of four supportive member states, the external evaluation committee strongly urges applying with a higher number of member states. The stakeholders that are gathered in the InfAct consortium and the project partners represent an opportunistic group of potential supporters for the ESFRI roadmap application and eventually a European research infrastructure. The health and research institutes could support the ESFRI roadmap application through a letter of support. The committee recognizes that lobbying to gain support from member states is difficult in times of COVID-19 and related travel bans.

Another important review from the external evaluation committee is that while committing to ambitious plans and long term goals, there is a risk to overshadow the deliverables that have been completed. The numerous outcomes from the various work packages are valuable and the impact of those individual deliverables should not be forgotten (see Dissemination and sharing the InfAct outcomes in the next section).

Other points on the critical review of the InfAct outcomes are:

- The InfAct Assembly of Members continues to be an important mechanism to ensure support for achieving the InfAct objectives. For this assembly to support the moving forward towards the ESFRI roadmap application, continuity in the assembly should be ensured. Hence, it is recommended to have the same representatives attending the Assembly of Members meetings.
- The national nodes that have been set up in the first year of the project, represent an important mechanism for networking on national level. The national nodes have the relevant contacts and existing trust of important individuals at national level that need to be convinced in supporting the setting up of a European research infrastructure for population health.
- Work package 4 aims to integrate national policies towards a sustainable health information system. A helpful start could be to have an outline of bullet points with the opportunities of a national node for health information at state level.

Strategic recommendations

As the external evaluation committee already stated in the first external evaluation report, it supports the approach in working towards setting up a research infrastructure. In parallel, the project could explore a 'plan B'. A potential 'plan B' could be to explore the options for the European Centre for Disease Control and Prevention (ECDC) to expand its mandate. ECDC's current mandate is to identify, assess and communicate current and emerging threats to human health posed by infectious diseases. In setting up the ECDC in 2005 it was discussed that health information systems and health promotion could also be part of its mandate. Designing an infrastructure that is flexible could allow to, at a later stage, integrate it into possible ECDC, pending expansion of the Centre.

Design and development phase

Learning from existing initiatives

The EU Health Data Space is an important initiative that relates to the InfAct project's goals and objectives. A thorough monitoring of the discussions regarding the EU Health data space should be continued and could guide the design and development of the InfAct project.

Competitor analysis

An important step in the design and development phase of a new solution (for InfAct this is a health information system) is an analysis of the competition. The external evaluation committee recommends analysing whether there are commercial entities that are working on (similar) population health information systems.

User friendly

The technical design team that builds the health information system online platform should include the skills and knowledge of building a user friendly system. An important question that must be asked is: what can the system offer the user when entering the platform? This question should steer the work of the technical team. One important functionality would be for users of the system to quickly check information. The platform should be easy to use for occasional users, too.

A training course for using the portal could be considered. As an example, look at the online course provided by INHERIT project. Also see the example of ECDC using QR-codes in their manuals, which are linked to documents for more expert users.

Sustainability of the IT platform

The envisioned IT platform i.e. the Distributed Infrastructure on Population Health (DIPoH), which is to host the health information portal, should be sustainable. It has been clarified that Finland is listed as the country to host the portal for the pilot in the design study and will continue to use if after, too. The external evaluation committee recommends investing in political commitment to the health information research infrastructure, including the online portal, as political commitment is needed to translate to financial commitment.

Stakeholder involvement

There was discussion on how to reach important stakeholders last year. InfAct now seems to be in touch with many, but consider if there are any others that are still missing. Some important stakeholders highlighted during the committee meeting are: the Employment, Social Policy, Health and Consumer Affairs Council configuration (EPSCO) and the Presidency of the EU and DG CONNECT.

Also the external evaluation committee can be considered as a relevant stakeholder. The committee can always be contacted on specific items to provide input and feedback. For example, the business case (in questionnaire form) can be shared for the members of the committee to give input on.

Dissemination and sharing the InfAct outcomes

Having a promotional video was recommended in the first external evaluation and is produced in the meantime. The short video (1min35sec) is very informative (available on the home page of the project). It is recommended to have a longer version of the video that includes which action is needed to join the initiative and practical examples of how the proposed infrastructure may benefit ones work (if the budget allows this).

There have been many outcomes of this second year of InfAct. However, these outcomes are not disseminated to the fullest extend and could be more visible on the website. One recommendation is to provide newsletter with outcomes and make website more user-friendly. In addition, a tweet can go out once a new publication is published. Furthermore, it is recommended to make use of communications teams of consortium members.

In the follow-up projects and initiatives it is recommend to include budget for a communications officer. It can be instrumental to have a dedicated officer concentrate on the communications and dissemination work, rather than this being a sub-task for various partners and groups involved. The person in charge of communication and dissemination could for example take care of testimonials and having a powerful elevator pitch for the initiative.

Learnings from another Joint Action

A representative of the iPAAC joint action is invited as member of the external evaluation committee. For this second external evaluation an extensive description of good practices and lessons learned from the iPAAC Joint Action is provided, for the InfAct to benefit from. In Annex 1 the full description is added.

Annex 1 – Good practices and lessons learned from the iPAAC Joint Action

Work Package 4 planned to conduct a survey among Member States on the CANCON recommendations for implementation/sustainability according to the cross-cutting issues. The Work Package 4 Leader decided to change the methodology from surveys to country visits. Taking into account that several surveys will be conducted within the iPAAC Joint Action and that the scope of the envisaged initiative in this task is very broad, covering all aspects of cancer control, it was considered that a written survey was not the most optimal approach to gather information.

The written survey has been replaced by a semi-structured interview with representatives of each domain of cancer control in each EU Member State. An interview guide has been prepared by the WP 4 team and was sent to the MS representatives about two to three weeks before the visit. A one day visit (4 to 7 hours) by the WP 4 team was foreseen for those meetings. The methods for this task are in-depth interviews with EU MS local policy makers, advisors and health administrators. During the visits, the main objective is to collect information on the relevant contextual features for cancer control programs implementation; the experience of cancer control program implementation into 6 domains; and the expectations regarding the Roadmap (what are the needs related to the implementation of innovations in cancer control and from the EU). The WP 4 country visits do not evaluate the cancer control policies, but aim to collect examples of implementation experience, implementation plans and challenges and the main input for a mutual learning platform (Roadmap). The aim is to visit (at least) all the iPAAC JA Partners.

In addition, two reports are prepared by the WP 4 team: a detailed report of the discussion for internal use only and a summary report that is available on the iPAAC website, upon approval by the MS representatives having participated in the interview. WP 4 will use the received input as one source of information to develop the final deliverable - Roadmap.

MS Representatives from all involved countries in the iPAAC Joint Action are being contacted, in addition to the select EU Member States that are not involved as Associated Partners in the iPAAC Joint Action.

The visits have been conducted by the WP 4 staff. Contact point have been the MS representative in the Joint Action, who helped identifying the appropriate local representatives to be invited and facilitate the logistic and practical organization of the visit.

Challenges:

- The WP4 budget had to be adapted (transferred from one category to another);

- The challenge to visit all the countries in allocated time frames (solution: the milestone was postponed)

The main results of the WP 4 Member State Implementation Survey will be presented as a document on Cancer Control Policy Interview Survey (CCPIS). The finalization of this work is delayed due to the

change of methodology of this task. Firstly, the new methodology by country visits is more time-consuming and labour-intensive then initially planned by the online interview survey. As WP 4 is aiming to have face-to-face interviews, the data collection phase is still ongoing and will end by December 2019. Moreover, the CCPIS methodology is an interactive process demanding intense collaboration with the participants (national policy makers and health administrators). The approval of the WP 4 conclusions by the participants is still in process and will be finalized by the end of December 2019.

The key deliverable: the Roadmap on Implementation and Sustainability of Cancer Control Actions

The key focus of the iPAAC Joint Action is on **implementation,** reflected in the key deliverable: the Roadmap on Implementation and Sustainability of Cancer Control Actions, which will support Member States in implementing iPAAC and CANCON recommendations.

The Roadmap on Implementation and Sustainability of Cancer Control Actions has the objective to support EU MS in the implementation of cancer control (innovative) measures by providing examples on how MS implemented cancer control actions. The main target group of the Roadmap are health policy advisors and administrators (policy-makers), but also advocacy groups. The Roadmap can assist them in the implementation process by providing examples on how the implementation of an action was done in other EU MS.

At the start of the iPAAC Joint Action, partners discussed the conceptual differences between a book and a "Roadmap", reaching the conclusion that the final deliverable should be an interactive tool, which encompasses a collection of different strategies and key documents that could also take the form of a digital toolbox. The format of the Roadmap will be a web-based tool, which will provide different levels of information. The Roadmap will gather the information from the WP 4 visits, the WPs 5-10 results and it may include also the results from other JAs. Three types of action were identified during the WP 4 visits: examples of already implemented actions, examples of implementation plans of cancer control action and remaining challenges. These types of actions are later summarized in a list of issues, which could be included in the final deliverable Roadmap.

Solutions:

Based on our experience, it is critical that partners **reach a consensus regarding the final deliverable** – Roadmap from the very beginning of the Joint Action. Since the term "Roadmap" may be understood in different ways, we 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** should be addressed early in the process. Firstly, it is important to define who will be responsible to update the content of the Roadmap after the end of the iPAAC Joint Action. Secondly, it is important to consider which actions should be included in the Roadmap after the end of the iPAAC Joint Action.

The sustainability of the Roadmap, in terms of its use, development and continuation is addressed in each GB meeting. The suggestions on how to further use, develop and manage the Roadmap will be described in the Final Report on Integration in National Policy and Sustainability.

The Roadmap IT tool – resources

A shift of funds to WP 2 for their IT work regarding the development of the Roadmap IT tool has been envisaged. The format of the Roadmap was not yet specifically defined at the beginning of the JA. It had been envisaged as a static, traditional output while it appeared during the very first months of the JA and in meeting JA partners and Member States, that it has to be be a more dynamic tool, i.e. an IT tool.

Additionally, **resources were not originally allocated to incorporating EPAAC and CANCON deliverables into the Roadmap**, which also required reshuffling of tasks and staff within certain WPs.

Solution: As the format of the Roadmap was undefined upon application of the JA, the decision that it would be an interactive web tool also meant later rescheduling of the Communication Team resources, as they were the key staff that will work on the development of the Roadmap as an IT tool.

Governmental Board meetings

To support the development of the Roadmap and to ensure to make it a useful instrument for policy makers and their administrations, (health) representatives of Members States are invited to participate to the Governmental Board. The Governmental Board meeting group was set up as the main avenue for participation of Member State Representatives in the iPAAC JA. Member State Representatives debate and discuss different perspectives with regard to the progress of the iPAAC JA, especially issues pertaining to the main iPAAC deliverable – Roadmap. Governmental Board representatives met twice in the first half of the iPAAC JA. Member States should be consulted on the form of the final document (i.e. Roadmap on Implementation and Sustainability of Cancer Control Actions) that is most useful to them, during the Governmental Board meetings. The aim of the Roadmap is to create a unique and useable tool to improve cancer control in EU Member States.

An important issue concerns the **participation of the right attendees to the GB meetings**. Each MS appoints a representative for the participation to the GB meeting, but the role of these appointed representatives at the national level does not always correspond to the actual expectations/intentions of the WP 4. It is difficult to motivate MS to participate and to gather the right people around the table, representing appropriate fields and a wide variety of countries.

Solution: Reminders sent and the assistance of iPAAC partners at the national level to identify the right participants for the GB meetings; greater GB representatives' involvement in the project can be achieved by sharing the main outcomes and deliverables throughout the project with them as well

as by informing them well in advance what is expected from them at the Governmental Board meetings (Assembly of Members in the InfAct JA).

Collaborating Partners

iPAAC Joint Action started to collect new requests for Collaborating Partners who act as iPAAC's external cooperation network from the beginning of the Joint Action. In order to comply with the General Data Protection Regulation (GDPR), those who wish to become an iPAAC Collaborating Partners need to register on the official iPAAC website. A Collaborating Partner provides added value to the Joint Action and participates in the Joint Action together with the Coordinator and Associated Partners, but has no contractual relationship with CHAFEA. A Collaborating Partner carries no legal link to the JA and does not receive any EU funding. Collaborating Partners can be added at any stage of the Joint Action and are not limited in number. To become an iPAAC Collaborating Partner one contacts the WP Leader of the WP they are interested in participating in. If they agree, the Collaborating Partner then send a formal request by e-mail to the Coordinator after which they are added to the official list.

This group is comprised of representatives of related projects and initiatives; these may include but are not limited to: related Joint Actions; EU funded initiatives; non-governmental organisations; professional organisations; industry organisations; and civil society groups, etc. All collaborating stakeholders are invited to attend the Stakeholder Forum. The meetings consist of presentations of the Joint Action initiatives and emphasis on networking and cooperation, with brainstorming sessions on synergy; meeting documents on related initiatives will be prepared in advance to allow for maximum efficiency of brainstorming sessions.

Collaborating Partners meet annually (three times during the course of the JA) to discuss iPAAC developments and synergies in the iPAAC Stakeholder Forum. The Stakeholder Forum is a meeting body that has been included in the JA meeting structure due to a recognised need for synergy and cooperation with other such initiatives. The objectives of the Stakeholder Forum are to: inform stakeholders and provide them with first-hand information; gather views and contributions on various elements of the Joint Action; assess the potential stakeholder contributions in each Work Package; disseminate results throughout the stakeholder groups. Meetings are provisionally planned to take place in Brussels in order to allow for the maximum number of representatives to take part, the last meeting is provisionally scheduled to take place alongside the Final Conference in order to allow participants to also attend the conference.

Dissemination of the iPAAC JA

There is generally a **low degree of willingness of project partners to provide comprehensive information about dissemination events that they organise**.

Solution: Constant reminders at the Joint action meetings regarding the importance to disseminate the iPAAC JA.

Organisation of the Local Stakeholder Forums

In addition to the iPAAC Stakeholder Forums, Local Stakeholder Forums have been introduced in the iPAAC Joint Action. Therefore, all 24 JA Associated Partners will organise one to two Local Stakeholder Forum events: for example, at the points of Month 5 and Month 32 of the Joint Action. Local Stakeholder Forums are small to mid-size events, with around 20-70 people.

The aim of the first Local Stakeholder Forum is to network amongst local stakeholder groups, gather Collaborating Partners, introduce the WPs and objectives, so that Collaborating Partners can actually participate in the JA. Specific local, regional and national barriers to implementation of the recommendations, starting with CANCON recommendations and continuing with iPAAC recommendations are also discussed.

The aim of the second Local Stakeholder Forum is to present the results with a focus on local/national uptake and implementation of the recommendations. Specifically, local stakeholders should discuss how best to implement the findings and discuss sustainability after the JA. Sustainable network of local experts, which we usually do not reach with EU-wide events, should be created, which can meet after the JA in their home countries. Partners are responsible for providing information and coverage of LSFs and importantly, share new contacts to extend the iPAAC network.

Challenges and solutions:

The project partners that have not yet organised Local Stakeholder Forums will do so by the end of the Joint Action. The Coordination Team and Work Package 2 Team will collaborate more closely together in order to motivate countries that have not yet organised a Local Stakeholder Forum. **Partners that have not yet organised Local Stakeholder event will be contacted individually and bilateral phone interventions will be established** with those that have not yet organised Local Stakeholder events. The aim of the video conference calls will be to support and encourage partners to organise one to two Local Stakeholder events during the iPAAC JA. The Coordination Team will help the organisers to prepare the agenda for the Local Stakehoder Forum meetings in line with the identified issues and topics that arose from the WP 4 country visits results. This will enable the participants of the Forums to discuss and reflect on the most up-to-date cancer related issues. The WP 4 team will share the country highlights per country (as available) with the local organisers and the Coordination/Dissemination Team. The country highlights will be used as a basis for the iPAAC Local Stakeholder Forum and will be used as a reference point in the bilateral teleconferences to be scheduled with all countries that have not yet organised their Local Stakeholder Forums. In this way, we will use already obtained results from WP 4 in WP 1,2 and WP 3 activities.

Deviations of the use of resources

While some of the Work Packages have been on track with its use of person-months in the first half of the JA, the majority of the Work Packages have not used all the person-month planned for the first half of the JA. Different reasons: Subcontracting in some WP has not yet been undertaken. Savings have mainly occurred in the category of travel costs. Savings have mainly occurred in the category of travel costs.

Solutions: 6-month analysis, regular contact with the financial administrators, reminders to use the allocated resources (LSF).

Compliance with the GDPR

The recent implementation of the GDPR (and, in some cases, its different interpretation by individual countries) has increased the administrative burden to access health information sources and to share individual sensitive data with research groups outside the registry (data sharing agreements).

Solution: milestone of the WP postponed

In terms of horizontal activities, in order to achieve adherence to GDPR, the Dissemination Team needed to renew the consents of recipients of iPAAC newsletter. This led to significant loss of contacts in comparison to the previous JA CANCON.

Low response rate for survey

For evaluation, the most important and challenging problem/risk that needed to be managed is **low response rate for surveys.** Although invitations for survey fulfilment were sent in time, right after the meetings, as well as reminders few days after, the response rate was sometimes still low. That, of course, brings up the problem of results relevance.

Solution: The Evaluation Team learned that the best option is to **repeatedly emphasize the importance of the evaluation surveys** more times during the meeting and afterwards, as well as to motivate participants to fulfil the survey right after the meeting so their answers could be more precise and relevant.