



InfAct: External Evaluation Final Report III

May 2021

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Introduction

This report, commissioned by the InfAct consortium, evaluates the third year of the project. InfAct (see Box 1) kicked off in March 2018. The external evaluation committee members came together in March 2019 and March 2020 to track the progress made, critically review advancements towards the key objectives of the project, and provide strategic recommendations. These meetings resulted in the first and second external evaluation interim report. Now, another year has passed, and the current report reflects on the final year of the InfAct project.

Box 1 – The InfAct project

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.

This report is the third joint deliverable of the service contracts of the Health Sciences Institute in Aragon (IACS) with the European Public Health Association/EUPHA and the Association of Schools of Public Health in the European Region/ASPHER (with File numbers 7/2018 and 8/2018 respectively) for the external evaluation (WP3 Task 3) of the Joint Action on Health Information (grant agreement 801553 under the Third Health Programme 2014-2020).

This report is based on the documentation provided by the InfAct consortium¹:

- Sustainability Plan 2020
- Population Health Information Research Infrastructure (PHIRI) – One Page Summary 2020
- A Distributed Infrastructure on Population Health (DIPoH) High Level Summary

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

- Compiled Fact Sheets 2020
- Business Plan for a European (Research) Infrastructure for Health Information 2020
- Third and Final Internal Evaluation Report 2021

Furthermore, this report is based on the presentation given by the InfAct coordinators at the external evaluation committee meeting held 12 April 2021 online via Webex (see InfAct external evaluation committee 12 Apr 2021 meeting report) and written feedback from the external evaluation committee members.

This report is structured in five sections, (1) tracking progress, (2) major outcomes, (3) sustainability (4) critical review of outcomes and strategic recommendations, (5) final remarks.

Extended Project Period

It is important to note that during the time of this project many deadlines were postponed due to the COVID-19 pandemic. The Internal Evaluation Committee report acknowledged that this was a major obstacle to most of the WPs. A project extension was granted to end of May 2021. All of the WPs did their best to follow the primary deadlines although in some cases that was not possible due to the challenges posed by COVID-19. Many of the deliverables' deadlines were postponed to May 2021.

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 third internal evaluation report 2021 (reporting period Months 23 to 36 excluding Months 37 to 39 since those deliverables will be finished after the report).

Twenty-six deliverables were due in this reporting period:

1. A flagship training programme to improve MS capacities in population health and
2. Health Information web platform (D7.4)
3. Health Information System development: data collection and quality assurance for a common health information system (D8.1)
4. Fact sheets (D4.3)
5. Training Piloting and Flagship Training Programme Evaluation (D6.3)
6. HIREP- ERIC: Business case and Road map for implementation (D7.2)
7. Guidelines, case study and best practices (D9.2)
8. Report: Interoperability landscape in Europe (D10.1)
9. Reports on key holders and relevant EU-international partners meeting (D4.4)
10. Sustainability Plan: follow-up of integrated proposals and long-term reporting scenarios (D4.5)
11. Pilot HI system peer assessment and review of experience (D5.1)
12. Cataloguing health information networks, projects and indicator sets (D5.2)
13. Prioritisation in HI development and recommendations (D5.3)
14. Sustainable ECHI process from technical, content and user perspective (D8.2)
15. Guidelines for accessibility and availability of health information (D8.3)
16. Guidelines for MS and regions for health report (D8.4)
17. Report series on the application of the best practices (D9.3)
18. Tool kit to produce better health indicators (D9.4)
19. Road map for uptake of indicators – opportunities and obstacles (D9.5)
20. Final report (D1.4)
21. Layman version of final report (D2.3)
22. Conference and workshops (D2.4)
23. Interim and final report of the External Evaluation Committee (D3.1)
24. Reports on AoM assessments (D4.2)
25. Road map for capacity building programme (D6.4)
26. Technical report: interoperability implementation (D10.2)

All deliverables due at the time of the internal evaluation committee report had been completed on time or by the revised date determined by COVID-19 related adjustments with only minor discrepancies in three deliverables (D6.2, D6.3, D6.4) related to work packages failing to fill out internal evaluation questionnaires. Twelve deliverables were still pending

and are due at the close of the project (D1.4, D2.3, D2.4, D3.1, D4.2, D5.1, D5.2, D6.4, D7.2, D7.4, D8.2, D10.2).

In the external evaluation of the first period one deliverable was not achieved by the set due date. The governance structures of a sustainable HIS was delayed to M30 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. In this third external evaluation it is determined that this deliverable is achieved.

Fifteen milestones (MS) were due in the third reporting period:

1. Second interim internal and external evaluation report (MS12)
2. HI system peer assessment country reports (MS18)
3. Policy dialogues with key stakeholders at the national and international level (MS16)
4. 5-year operational plan HIREP-ERIC (MS24)
5. EHLEIS meeting (MS34)
6. Review and analysis on implementation from other WPs by AoM (MS15)
7. Sustainability Plan (MS17)
8. Review of pilot HI system peer assessment experience including scientific publication and manual for peer assessment (MS19)
9. ECHI documentation, format, technical and content update (MS30)
10. Mid-term and final review (MS3)
11. Final conference (MS5)
12. Scientific/policy conference EPH 2018-2019-2020 (MS8)
13. European Health Forum 2019 (MS9)
14. Final interim internal and external evaluation report (MS13)
15. Empirical case studies (MS38)

One milestone (MS34) EHLEIS meeting was delayed from August 2020 due to difficulties to find the right people who could present their work at the meeting. The Milestone was ultimately achieved in February 2021. All other milestones were achieved on time or at the adjusted time given due to the COVID-19 pandemic. Six deliverables were still pending and are due at the close of the project (MS2, MS3, MS13, MS19, MS30, MS38)

The InfAct coordination team will provide final deliverables to the Evaluation team when they are available.

Major Outcomes

Population Health Information Research Infrastructure (PHIRI)

In a major development, the Commission was impressed by the DIPoH research infrastructure, which led to a COVID-19 project proposal over summer 2020 with the successful launch of Population Health Information Research Infrastructure (PHIRI) COVID-

19 data depository during Nov 2020.

As a practical rollout of DIPoH, the PHIRI project, is being financed through EC Horizon 2020 for three years starting from 1 November 2020. PHIRI involves 41 partners in 30 countries based on the InfAct Consortia.

Building on InfAct's health information system assessments and extending the work of InfAct, PHIRI provides for a health information portal for COVID-19 relevant health information; supports structured exchange for countries and promotes interoperability to tackle health information inequalities.

Health Information Portal

Work was still underway on the Health Information Portal (HIP) (D7.4) at the time of the external evaluation meeting and is expected to be hosted at URL: <https://www.healthinformationportal.eu/>.

The HIP is intended to facilitate access to health and health care data and it supports structured information exchange between EU countries. It was started in InfAct and continues within PHIRI. It covers broad population level data. The HIP will be a one-stop shop facilitating access to DIPoH health information from National Nodes, research networks, data catalogues, capacity building initiatives, and legal and ethical issues. The portal does not provide the data, but rather the means to access data with search options by topics and key words.

Sustainability

Business Plan

The DIPoH Business plan lays out the timeline for the next 5-6 years and the financial costs needed to further develop and implement the Health Information Portal; engaging with users and implementing services; finalising organisational, financial and legal frameworks to achieve the status of a legal entity; realising a sustainable management plan and funding for operation. From 2028 onwards DIPoH will serve as a fully operational research infrastructure.

Expected costs include:

Development and implementation costs: all resources needed to further design, prepare and implement DIPoH.

Operating costs: housing and equipment costs, personnel; consumables and maintenance from 2028 onward.

Financial aspects are estimated at ~ 10 million EUR/year based on profiled needs and tech resources in national nodes and how to link them electronically as well as technical expertise needed in each hub.

The DIPoH financial plan is for mixed funding model with revenue streams built over time on membership contributions, in-kind contributions and grants. Revenue would include Membership fees, service fees for specific services, EU grants and national-level investments.

At the time of the External Evaluation meeting, a total of 10 countries had provided political support through ministries, 8 of which also signed MoU through partner institutes. A total of 14 institutes signed A Memorandum of Understanding (MoU).

Continuity

The ESFRI roadmap application was submitted September 9th 2020 and DIPoH passed the eligibility criteria check in October 2020. InfAct will be defending the DIPoH ESFRI in its hearing on April 16th 2021 with a ESFRI forum decision expected in June-September 2021. If approved, the ESFRI roadmap would start in October-November 2021. The Joint Action is ultimately aiming towards an ERIC

If the ESFRI is not successful, InfAct will consider alternative plans including reassessing the possibility to join the ESFRI landscape through an application to the 2025 roadmap; and direct application for a European Research Infrastructure Consortium (ERIC) by developing statutes and establishing DIPoH as a legal entity through an external process to ESFRI.

Dissemination and Sharing InfAct Outcomes

Acting on recommendations from the second report of the External Evaluation Committee, InfAct has designated a dedicated person serving for communications. In electronic platforms, InfAct has been active in Twitter (@JA_InfAct) reaching 304 followers with 346 tweets. The project website is available at <https://www.inf-act.eu/> and intranet is available through the OpenLucius platform at <https://workspace.inf-act.eu/>. A promotional video is available on the homepage. The Joint Action also maintains a site on the EHP Platform: <https://webgate.ec.europa.eu/hpf/network/home/55>.

Five newsletters were produced during the course of the action. Three workshops were held in the World Public Health Conference 2020. A layman version of the final report is in preparation and a joint publication in Archives of Public Health is in preparation.

Critical review of outcomes and strategic recommendations

External evaluators appreciated that the PHIRI result is a great proof of concept showcasing the need for comparable data and access to information and raising the profile of DIPoH on the European agenda. The EC has asked InfAct to join their meetings for feedback on IT development and extending data governance with the subsection on health. This need for access to comparable data must be kept at the forefront in future plans for the HIP/DIPoH to support health information interoperability and innovative health information tools and data sources.

However, the External Evaluation committee warns that it will be a challenge to ensure that the information in the portal remains up to date. Especially as input for the portal is fragmented, coming from multiple sources. There may be additional struggles in countries with autonomous regions (e.g. Spain) where it would be difficult to have a single National Node and a single focal point. Moreover, countries may be challenged with limited capacity at institutes. There will be a need to build capacity in every country. Individuals and young people will require training and motivation to be involved with the infrastructure. This has already been clearly demonstrated with trainings conducted under InfAct, which proved important for participants to understand health information inequalities and broad social determinants, triggering them to continue the work. A lesson to take from these trainings, is that they must be carried forward in order to build the capacity for a successful health information portal.

The external Evaluation committee felt there were elements missing to support countries in health reporting. The DIPoH approach presented is very data driven, however public health monitoring and reporting requires much more. As acknowledged by InfAct coordinators, the project falls between ministries of health and ministries of research. There is a need for prioritization of data and guidelines, but also to take a broader perspective to focus on policy when putting together reports in order to convince the ministries. The 4th pillar of the DIPoH services will need to be well thought out in order to stimulate researchers to think about how to interconnect and take action forward with partners. Opportunities to work with related sciences should be taken to fill gaps. We need to bench mark countries to present to governments, convincing, visualising data, cooperation across sectors, and the wider determinants of health.

There was significant concern amongst the external evaluation committee about the sustainability of the plans going forward in terms of funding. Will the mixed funding model lead to a sustainable situation? How much would be required in Member and Service fees, particularly if EU grant applications are not successful and national investment is not attained. Member states will be required to provide much of the financial support through membership fees and national funding, they need to be willing to pay. InfAct must capitalize and continue to build on the political support already attained during the project and emphasize how much COVID-19 has demonstrated the need for accessible and comparable health information from across countries and regions. There needs to be a commitment strategy for support of DIPoH. Country level budgetary deadlines should be taken into account and the project must be sure to demonstrate to stakeholders the specific need for DIPoH as a necessary distinct entity that does not duplicate other information sources. The project going forward must build on the outreach already achieved with stakeholders through national node meetings, training sessions and AoM meetings during the InfAct Joint Action.

The External Evaluation committee further recommends that the InfAct project outputs be made more readily available. Outputs are listed in the sustainability plan but they should be accessible, clearly guiding people unfamiliar with the Joint Action through the health information tools and guidelines. The Committee would also like to remind the Joint Action

of upcoming dissemination opportunities to broaden the reach of InfAct: Health System Response Monitor for publication of case studies, IANPHI Europe meeting for key contacts, European Public Health Week to present results, EPH conference (abstract due end of April), ASPHER Deans' & Directors' Retreat.

Final Remarks

The External Evaluators were impressed with the tremendous progress and work made by InfAct in the past year. The Joint Action rose to the challenges presented by the COVID-19 Pandemic and moreover made a significant proof of concept contribution to the sharing of health information on COVID-19 with PHIRI.

There is still substantial work ahead to sustainably implement the DIPoH and HIP. The efforts already undertaken, the business plan and the stakeholder support built through InfAct will serve as a strong foundation going forward.

The External Evaluators congratulate the InfAct Joint Action on its strong achievements and look forward to reviewing the final project deliverables. We will continue to follow the future developments and implementation of the Action outcomes.