Milestone 1.1: Kick-off Meeting Report

7 March 2018, European Convention Center Luxembourg, Luxembourg
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InfAct: Report: kick-off meeting
This report provides the minutes of the kick-off meeting of the Joint Action (JA) on Health Information - InfAct.

I. Attendees

1. Alain Fontaine (AF)  
2. Alan Cahill (AC)  
3. Alicia Padron (AP)  
4. Anders Tegnell (AT)  
5. Angela Fehr (AF)  
6. Anne Gallay (AG)  
7. Ausra Zelviene (AZ)  
8. Beatriz Perez Gomez (BPG)  
9. Claudia Habl (CH)  
10. Daniel Benjamens (DB)  
11. Damir Ivankovic (DI)  
12. Dominika Urbanski (DU)  
13. Enrique Bernal-Delgado (EBD)  
14. Eugenio Mattei (EM)  
15. Giulio Gallo (GG)  
16. Hakon Haaheim (HH)  
17. Hanna Tolonen (HT)  
18. Herman Van Oyen (HVO)  
19. Isabel Noguer (IN)  
20. Ivan Pristas (IP)  
21. Janis Misins (JM)  
22. Jennifer Zeitlin (JZ)  
23. Jose Martins (JMa)  
24. Katarine Paulsson (KP)  
25. Kim Vyncke (KV)  
26. Linda Abboud (LA)  
27. Luigi Palmieri (LP)  
28. Luis Lapao (LL)  
29. Maja Krstic (MK)  
30. Maria Bratt (MB)  
31. Marie Delnord (MD)  
32. Mariken Tijhuis (MT)  
33. Metka Zaletel (MZ)  
34. Michel Vernay (MV)  
35. Mika Gissler (MG)  
36. Nathalie de Rekeneire (NDR)  
37. Pawel Gorynski (PG)  
38. Petronille Bogaert (PB)  
39. Philippe Roux (PR)  
40. Ronan Launa (RL)  
41. Rita Gaidelyte (RG)  
42. Ronan Lyons (RL)  
43. Sandra Caldeira (SC)  
44. Sandra Garcia-Armesto (SGM)  
45. Sarka Dankova (SD)  
46. Thomas Ziese (TZ)  
47. Vasilios Scoutellas (VS)  
48. Zeynep Or (ZO)

II. Welcome and overview InfAct

The meeting started at 9:30 at the European Convention Center in Luxembourg. Representing the government of Luxemburg, Ms Nathalie De Rekeneire (NDR) welcomed the delegates of the EU Commission, the WHO and OECD representatives, the project partners and other attendees. She expressed her gratitude for the EU Commission in supporting the Member States (MS) with developing the agenda of health information (HI) and facilitating the collaboration between countries. In addition, NDR elaborated on the necessity of this JA in building reliable HI knowledge on national, as well as, EU wide scales to inform policies and programs. Thus, enhancing population health and proving the importance of the joint work of MS. Recent developments in Luxembourg were mentioned, a new law named “loi hospitaliére” for better collected hospital data. A Health Observatory is also in development which will monitor the quality and the efficacy of the health system and identify health inequalities.
Additional opening remarks were given by Mr Philippe Roux (PR), representing DG SANTE. PR thanked the Ministry of Health of Luxembourg for their support and collaboration in organizing this event, and the Belgium Scientific Institute of Public Health (WIV-ISP) for coordinating this JA, and the participants. PR stressed the increasing role of health information in informing evidence-based policy developments. To be able to evaluate policies on public health and health systems, health data must be reliable and comparable among MS. However, the current framework of data collection lacks proper mechanisms to build consensus among EU MS on what data needs to be collected to support policy-making and which indicators need to be harmonised to facilitate comparisons and the exchange of best practice. Thus, presenting the unique position of this upcoming JA in identifying gaps in current data collection strategies and supporting EU-level efforts around aligning health data definitions to improve comparability and reduce the reporting burden on countries. This JA will be instrumental in joining forces and increase cooperation with International Organisations towards simplification, reducing duplication and creating synergy with already existing tools and activities. PR referred to collaboration with WHO, Eurostat and the OECD involving the various projects to improve data analysis and reporting.

This was followed by a brief welcome and overview of the aim of the meeting and the added value of this project, by HVO. LA presented a timeline of the deliverable and milestone for the first year of the project.

- Comment on the overview slides: WP4 activities and objectives to be corrected:
  - Involve MS, EU partners and International Institutions
  - Support countries to integrate deliverables into policies
  - Sustainability Plan
  - Support MS and EU-International Partners on the potential adoption of new identified best practices.
  - Provide MS elements to discuss infrastructure to assess long-term sustainability

III. Administrative aspects

KV presented the platform which will be utilized for file sharing- OpenLucius (https://workspace.inf-act.eu/) with a demonstration of use. KV mentioned that a teleconference will be scheduled for further explanation of use. All partners will be expected to deliver their milestones and deliverables through OpenLucius. The principle of the platform is the “only one” principle. All information will be pooled on OpenLucius and will replace unnecessary emails.

IV. Overview of WPs and discussion

Each WP leader presented their tasks, deliverables and milestone.

- **WP1**: It was mentioned that a meeting took place with the coordinators of all joint actions to present their JA and the activities that will be carried out. A new meeting will be organised with the coordinators of the different JA at EUPHA conference 2018.

- **WP2**: The partners were asked who is planning on implementing a survey as part of their WP tasks. For purposes of better coordination, an excel sheet will be prepared.
to be sent to partners to be filled with details of survey. All partners are asked by the coordination team to inform of any presentations they are giving at conferences or any papers they are publishing.

→ To do (coordination): to prepare and distribute an Excel sheet for details on planned surveys

→ To do (all): The coordination team will make a dissemination plan. All partners need to contribute by informing the coordination team of any presentations they are giving at conferences or any papers they are publishing. The coordination team will remind partners by email.

→ To do (all): when papers are being written in the context of InfAct reference need to be made to the financing sources in the European Health programme. A standard clause should be used.

- WP3: Peer review and evaluation process were discussed. Details in the slides.
  - Comment: the end it was found acceptable that WP4 could review WP1, not WP10.
- WP4: Comments on timeline of memorandum of understanding.
- WP5: In task 5.3, TZ mentioned that there was still a need for a task co-leader. CH expressed interest about Austria joining this task.
- WP6: With regards to the planned trainings, PR requested to stay informed about the potential collaboration with WHO.
- WP7:
  - CH commented that by the end of the three year initiative we should aim to have a plan for a pilot program in place (not only a roadmap).
  - Question TZ: what activities do you plan to communicate to the public health community? Answer: the interaction will take place through the platform and advisory board.
  - PR commented that all tasks should be implemented with sustainability in mind!
  - Ireland, Norway, Slovenia and Portugal indicated their interest in participating in WP7.
- WP8:
  - Questions LL: many countries are planning desk research in their WPs, possibility of collaboration?
  - CH commented that the term ‘guideline’ is too binding and suggested it to be changed into ‘guidance’.
  - Question about the accessibility and legal aspect is not clearly stated in the WPs? Answered by IN on the inclusion of this issue into the process of AOM, the connection to the authorities and the policy dialogue that is planned to take place in WP4.
  - PR stresses that the outputs of this project should be more than merely a set of recommendations. The outputs produced should be doable and accepted into the next level of (legal and political) authorities.
- WP9: Link with other WPs WP8 and WP10. Check link with WP6 (requested by LL).
- WP10: Suggested link to other JA that are working on e-health. DI pointed out a teleconference already took place with the JA coordinators of e-health.
V. Panel with WP leaders

A round table panel with all WP leaders took place and was chaired by HT. The discussed topics included:

- 10-15 years from now, what are the most important outcomes for each WP to support sustainable Health?
- Importance of the inter-usability.
- Potential issues with Big Data, including the ethical aspect.
- The importance of including the view of patients and reaction to different treatments (patient empowerment).
- The potential collaborations and important links between WPs, and how that will be dealt with.

VI. Comments European Commission

To conclude the day PR summarized the joint efforts by stressing the sustainability concept as the most important aspect. Whether this JA delivers big or small outcomes, as long as they are sustainable. Also, PR expressed content in seeing that all MS will contribute to reducing burden of disease and development of new data collection strategies contributing to better health information systems.

VII. Conclusions and any other business

Next general assembly meeting 26-27 September 2019, in Brussels.

VIII. Annex 1: Presentation of kick-off meeting

The following presentations can also be found on OpenLucius (https://workspace.inf-act.eu/)
InfAct: Joint Action on Health Information

Kick-off 7 March 2018

Name: Petronille Bogaert and Herman Van Oyen
Institution: Scientific Institute of Public Health
Country: Belgium
Contact: infact.coordination@wiv-isp.be

This project is funded by the Health Programme of the European Union
Aim meeting

1. Present InfAct and inform about our activities
2. Opportunity to interact with stakeholders
3. Overview technical aspects
Background
A healthy population is a prerequisite for economic productivity and prosperity.

Robust evidence in the form of high quality and timely data on population health and health systems

⇒ Health information system
“One of the clearest areas where the EU can add value to national efforts on health is through comparison of information and data, and synthesizing evidence and best practice.”

Greer et al. (2014). Everything you always wanted to know about European Union health policies but were afraid to ask. European Observatory on Health Systems and Policies.
EU health information “system”

European Commission
- DG SANTE
- DG RTD
- JRC
- Eurostat

Individual and independent EU projects

WHO Europe

OECD

This project is funded by the Health Programme of the European Union

EU health information “system”
Challenges in health information

1. Health information activities are often funded through ad hoc projects rather than through sustainable structures.

2. Much of the gathered evidence and knowledge is still dispersed, incomplete and difficult to access.

3. Large differences can be found in terms of quality and, as a consequence, in comparability of health information between and within EU Member States.
This project is funded by the Health Programme of the European Union

• Secondary data are comparable across EU member states.

• Data are timely available.

• There is a training and information hub that supports you in applying secondary & research data and in understanding their characteristics.

• Coordinated research actions lead to continuous improvement of data availability and comparability and the development of modern monitoring and reporting approaches.

*IMAGINE*

- Interoperability (WP10)
- Capacity building (WP6)
- Inequalities in health information (WP5)
- Innovation in HI (WP9)
- Tools and methods for health information support (WP8)
Sustainable solid infrastructure on EU Health Information to improve availability of comparable, robust and policy-relevant health status, health determinants and health system performance information.
Specific objectives

1. To reduce the health information inequality between and within EU MS
2. New methods of understanding and targeting health information
3. To prepare MS for the start of the HIREP-ERIC (ERIC on Health Information for Research and Evidence-based Policy) → sign memorandum of understanding
Strategic objective 1: prepare the MS for the start of the HIREP-ERIC

**Process**
- Overview and assess HI system
- Develop criteria for common HI priorities & identify good practices
- Business case and roadmap HIREP-ERIC

**Output**
- Catalogue networks
- Memorandum of understanding (MoU)

**Outcome**
- HI consortia in MS
- MoU signed
Strategic objective 2: Reduce HI inequalities between and within MS

Process
- Peer review learning
- Roadmap HI training programme
- Learning through good practice case studies

Output
- Evaluation of peer review tool
- Report training programme and support MS

Outcome
- MS ownership review process
- Pilot training and workshop
Strategic objective 3: strategy to promote implementation of HIREP-ERIC

Process
- Assembly of Members with key stakeholders
- Encourage support through partners

Output
- Active participation on debate with stakeholders
- Feedback to tailor content HIREP-ERIC

Outcome
- Consensus on the way forward
- Awareness among stakeholders
Participating countries

- 28 participating countries:
  Austria, Bosnia Herzegovina, Belgium, Croatia, Cyprus, Czech Republic, Estonia, Finland, France, Germany, Greece, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Moldova, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, United Kingdom

- Collaborating countries
  Bulgaria, Iceland, Denmark, Slovakia and Switzerland

- 3 years with budget of €4 million EU co-funding
This project is funded by the Health Programme of the European Union.

InfAct constitution

41 institutions: 28 CA & 13 AE

28 countries

10 WPs

InfAct
This project is funded by the Health Programme of the European Union.

Sustainable EU HIS

Political support

WP4. Integration in national policies

WP7. Proof of concept of sustainable structure

WP5. Status of health information systems in MSs and regions

WP8. Tools and methods for health information support

WP9. Innovation in health information

WP10. Interoperability

Capacity building

WP6. Capacity building

Health information tools

WP10. Interoperability

WP9. Innovation in health information

WP8. Tools and methods for health information support

Sustainable EU HIS

Political support
<table>
<thead>
<tr>
<th>WP</th>
<th>WP Name</th>
<th>WP Lead</th>
<th>Contact</th>
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<tbody>
<tr>
<td>WP1</td>
<td>Management of the Joint Action (JA)</td>
<td>Belgium Institute of Public Health (WIV-ISP)</td>
<td>Herman Van Oyen <a href="mailto:Herman.VanOyen@wiv-isp.be">Herman.VanOyen@wiv-isp.be</a></td>
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<td>Petronille Bogaert <a href="mailto:Petronille.bogaert@wiv-isp.be">Petronille.bogaert@wiv-isp.be</a></td>
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<td>or <a href="mailto:infact.coordination@wiv-isp.be">infact.coordination@wiv-isp.be</a></td>
</tr>
<tr>
<td>WP2</td>
<td>Dissemination</td>
<td>Belgium Institute of Public Health (WIV-ISP)</td>
<td>Herman Van Oyen <a href="mailto:Herman.VanOyen@wiv-isp.be">Herman.VanOyen@wiv-isp.be</a></td>
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<tr>
<td>WP3</td>
<td>Evaluation</td>
<td>Lithuania Higienos Institutas (HI)</td>
<td>Ausra Zelviene <a href="mailto:ausra.zelviene@hi.lt">ausra.zelviene@hi.lt</a></td>
</tr>
<tr>
<td>WP4</td>
<td>Integration in National HIS and Sustainability</td>
<td>Spain Instituto de Salud Carlos III (ISC III)</td>
<td>Isabel Noguer <a href="mailto:inoguer@isciii.es">inoguer@isciii.es</a></td>
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<tr>
<td>WP5</td>
<td>Status of health information systems in MS and regions</td>
<td>Germany Robert Koch-Institute (RKI)</td>
<td>Angela Fehr <a href="mailto:FehrA@rki.de">FehrA@rki.de</a></td>
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<td>Thomas Ziese <a href="mailto:zieset@rki.de">zieset@rki.de</a></td>
</tr>
<tr>
<td>WP6</td>
<td>Strengthen EU countries health information capacity</td>
<td>Portugal Directorate-General of Health (DGS)</td>
<td>Paulo Nogueira <a href="mailto:paulo.nogueira@dgs.min-saude.pt">paulo.nogueira@dgs.min-saude.pt</a></td>
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<tr>
<td>WP7</td>
<td>Proof of concept of sustainable structure on health information</td>
<td>Belgium Institute of Public Health (WIV-ISP)</td>
<td>Herman Van Oyen <a href="mailto:Herman.VanOyen@wiv-isp.be">Herman.VanOyen@wiv-isp.be</a></td>
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<tr>
<td>WP8</td>
<td>Tools and methods for Health Information Support</td>
<td>Italy Istituto Superiore di Sanità (ISS)</td>
<td>Luigi Palmieri <a href="mailto:luigi.palmieri@iss.it">luigi.palmieri@iss.it</a></td>
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<tr>
<td>WP9</td>
<td>Innovation in health information for public health policy development</td>
<td>France Santé publique France (SpFrance)</td>
<td>Anne-Catherine Viso <a href="mailto:Infact-FRANCE@santepubliquefrance.fr">Infact-FRANCE@santepubliquefrance.fr</a></td>
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<tr>
<td>WP10</td>
<td>Assessing and Piloting Interoperability for Public Health Policy</td>
<td>Croatia Croatian Institute of Public Health (CIPH)</td>
<td>Ivan Pristaš <a href="mailto:ivan.pristas@hzjz.hr">ivan.pristas@hzjz.hr</a></td>
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Contact: infact.coordination@wiv-isp.be
This project is funded by the Health Programme of the European Union

Timeline: InfAct
Kick-off Meeting 7 March 2018

Linda Abboud
Scientific Institute of Public Health -Belgium
infact.coordination@wiv-isp.be

This project is funded by the Health Programme of the European Union
This project is funded by the Health Programme of the European Union

### Important dates

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Dates</th>
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<tr>
<td>Steering Committee meeting #2</td>
<td>20-21 September 2018 in Brussels</td>
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<td>Steering Committee meeting #3</td>
<td>27-28 February 2019 in Brussels</td>
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<td>Steering Committee meeting #4</td>
<td>25-26 September 2019 in Brussels</td>
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<td>General Assembly meeting #2</td>
<td>26-27 September 2019 in Brussels</td>
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<td>Steering Committee meeting #5</td>
<td>13-14 February 2020 in Brussels</td>
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<td>Steering Committee meeting #6</td>
<td>11-12 June 2020 in Brussels</td>
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<tr>
<td>Steering Committee meeting #7</td>
<td>20-21 January 2021 in Brussels</td>
</tr>
<tr>
<td>General Assembly meeting #3</td>
<td>21-22 January 2021 in Brussels</td>
</tr>
</tbody>
</table>
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Timeline: First year

23 March 2018
M1.1 Kick-off meeting report (WIV-ISP)
M1.2 SC meeting report (WIV-ISP)

25 May 2018
D1.1 Conceptual framework (WIV-ISP)
D1.2 Risk management & contingency plan (WIV-ISP)
D2.1 Leaflets & website (WIV-ISP)
M2.1 Dissemination plan (WIV-ISP)
M4.1 Assembly of members list (ISCIII)

24 Aug 2018
D4.1 Terms of Reference & Operating procedure of the AOM (ISCIII)
M9.2 Euro Peristat meeting (SPF)
M9.3 Health system performance expert workshop (SPF)
Timeline: First year

20-21 Sep 2018*  
Steering Committee meeting #2 - Brussels

14 Dec 2018  
M3.1 Agreement with subcontracts (IACS)  
M8.1 Questionnaires for MS regarding data collection & procedures (ISS)

21 Feb 2019  
M5.3 Method development for prioritization (RKI)  
M10.1 Report on mapping exercise (CIPH)

27-28 Feb 2019  
Steering Committee meeting #3 - Brussels
This project is funded by the Health Programme of the European Union.

Timeline: First year

- **22 March 2019**: M3.2 First Interim internal and external evaluation report (HI)
- **24 May 2019**: M9.1 Workshop on BoD (WG)
- **26 July 2019**: D4.3 Fact sheets (ISCIII)
- **23 Aug 2019**: D1.3; M1.4; D2.2; D6.1; M6.1; D7.3; M7.1; M7.3; M7.4; M10.2; M10.3
- **25-27 Sep 2019**: Steering Committee #4 meeting, General Assembly#2 meeting – Brussels
Deliverables and milestones

- Output for deliverables and milestones: report, screenshots,...
- Upload on Openlucius
- **Friday before end of the month!**
- Keep in mind: time for internal evaluation of reports

For any questions contact: infact.coordination@wiv-isp.be
Administration

Kick-off 7 March 2018
Administration

1. EC Participant Portal
2. InfAct OpenLucius (online collaboration platform)
3. Reports, deliverables & milestones
4. Templates
5. Contact information
1. EC Participant Portal
Beneficiary’s responsibilities:

- **Roles:** keep this up to date at all times
- **Financial report:** submission & signing in PP
Coordinator’s responsibilities:
- Submission of technical reports
- Submission of deliverables & milestones
1. Participant Portal

In case of technical problems
- Check the PP online manual, FAQ,…
- Contact the PP helpdesk
- Inform the coordinator of delays due to technical problems
2. InfAct OpenLucius

- **What?** Online collaboration platform
- **Who?** All InfAct partners
- **Why?** To facilitate collaboration & document/news sharing, to avoid email trees
- **Features?**
  - Task assignment & follow up, file sharing, calendar, messaging, ...
2. InfAct OpenLucius

Login: - [https://workspace.inf-act.eu](https://workspace.inf-act.eu) > account information received by email
- link on [www.inf-act.eu](http://www.inf-act.eu) > currently under construction

Support: - short introduction videos on youtube channel « OpenLucius »
- [https://blog.openlucius.com](https://blog.openlucius.com)
2. InfAct OpenLucius

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2. InfAct OpenLucius
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General principles:

- Collaboration in « Groups »:
  - Group « General Assembly » by default: used for general communication/collaboration
  - Groups for Steering Committee and WPs
- Use « member profile » to indicate affiliation (team= institute), role(s)
- Use « member », « group » or « team » to contact exactly those people you need
2. InfAct OpenLucius

To start using the platform:
- GoToMeeting sessions will be organised for detailed explanations
- Message thread « OpenLucius platform: Problems, things to improve, questions ...” in group “General Assembly”: to be used for communication about the platform itself
3. Reports, deliverables & milestones

- Deadlines for reports, deliverables & milestones:
  Added as « tasks » in OpenLucius > visible in calendar
3. Reports, deliverables & milestones

Submission:
OpenLucius

Deliverables & milestones: added as tasks in OpenLucius
> files to be uploaded with corresponding task
3. Reports, deliverables & milestones

Submission

- Deliverables & Milestones on OpenLucius will serve as test-case for reports

- The « only once» principle

Important note: Financial reports are to be submitted through the EC Participant Portal
4. Templates

- Templates are/will be available for presentation and reports
- Available on OpenLucius, group « General Assemblee »
5. Contact Information

To contact the coordination:
- Use OpenLucius for submission of documents, presentations, etc.
- Use infact.coordination@wiv-isp.be for personal communication, questions, ... . Do not CC or « reply all » if unnecessary.
- Avoid mailing to personal email address, unless explicitly asked.
- Call us for urgent matters.
5. Contact Information

To contact partners:

- Use OpenLucius to contact the exact person or group of people you need
- Do not send emails to all partners if unnecessary
- Keep your contact information up to date in your OpenLucius member profile
- Inform the Coordination team of any personnel switches
Aim

- Manage InfAct
- Systematic monitoring of activities
  - Day-to-day follow-up of scientific, administrative and financial aspects
  - Fulfil contractual obligations
  - Expected results are delivered
Objectives

- The objectives are:
  1. To effectively monitor the JA and its scientific, administrative and financial aspects.
  2. To guarantee the adherence to the work plan, to the overall project aim and to the timing; to guarantee available resources and the signature of the contractual agreements (consortium and grand agreement).
  3. To secure timely submission of interim progress reports and cost statements.
  4. To facilitate and ensure convergence between WPs to work together towards a sustainable EU health information system and with other Joint Actions, e.g. eHealth.
  5. To coordinate actions of WPs that request active participation of MSs, EU DGs and institutions and international organisations. Examples of such actions are surveys or mapping exercises.

This project is funded by the Health Programme of the European Union
Tasks of WP1

- Task 1.1. Coordination of the Joint Action (Lead: WIV-ISP)

1. Timely delivery of reports;
2. Organization of the JA meetings;
3. Establishment of the JA information and communication flow and feedback to competent authorities (CAs);
   → Each CA is responsible for the coordination of its affiliated entities, subcontractors and collaborating stakeholders.
4. Reporting to relevant bodies;
5. Ensure continuity, coherence and reduce redundancy;
6. Coordinate with other Joint Actions.
Tasks of WP1

Task 1.2. Administrative and financial Project Management
- preparation, organisation, reporting and chairing of the meetings;
- the preparation and distribution of the status reports;
- the preparation and distribution of the financial reports;
- monitor the budget and the compliance with the contract and consortium agreement;
- respond to audits requested by CHAFEA.
Milestones and deliverables

Deliverables
- D1.1 Conceptual framework and vision by month 3
- D1.2 Risk management and contingency plan by month 3 (Task 1.3)
- D1.3 Interim report by month 18
- D1.4 final report by month 36

Milestones
- MS1 Kick-off meeting by month 1
- MS2 Coordination meetings with the WP leaders and coleaders (SC) by month 36
- MS3 Mid-term and final review by month 36
- MS4 Mid-term Assembly by month 18
- MS5 Final Conference by month 36

This project is funded by the Health Programme of the European Union.
Aim of dissemination

To ensure that
1. the results of the JA are available to the target audience;
2. the communication is most optimal to ensure the continuation of the JA in a sustainable structure is enacted;
3. the widest possible scale of implementation is reached after the end of the project and thus maximize the impact of the project.
This project is funded by the Health Programme of the European Union.

Lead and Co-Lead Partners

Gesundheit Österreich GmbH

Partners

HZJZ

Instituto de Salud Carlos III
Tasks dissemination

Task 2.1. Coordination of internal and external communication

- A communication strategy and dissemination plan
- A web platform, leaflets, flyers, newsletters, conference/workshop proceedings, press releases, social media (e.g. Twitter: @JA_InfAct) and scientific papers
- Website in construction: www.inf-act.eu

Task 2.2. Visual identity

- We will provide a template for the lay-out of reports
- Use logo and ppt template of InfAct
Tasks dissemination

Task 2.3. Audiovisual communication
- A collaborative online platform to share documents with all partners → OpenLucius
- Twitter account: @JA_InfAct

Task 2.4. Promotional video of a sustainable structure

Task 2.5. InfAct on tour
- EUPHA
- European health forum gastein

Task 2.6. Publications
- Leaflet
- Articles
- Layman version final report
### Deliverables

#### Deliverables linked to this work package

<table>
<thead>
<tr>
<th>Number</th>
<th>Title</th>
<th>Description</th>
<th>Delivery month</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Leaflet and Website</td>
<td>A leaflet to promote the project must be produced at the beginning of the JA. Each JA must have a dedicated website. The website has a public part and another restricted part accessible only to the applicants.</td>
<td></td>
</tr>
<tr>
<td>MD.1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MD.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.2</td>
<td>Promotional video</td>
<td>A promotional video will be produced to promote the ERIC on health information as sustainable structure favouring the maximal participation of MS.</td>
<td>18</td>
</tr>
<tr>
<td>2.3</td>
<td>Layman version of final report</td>
<td>Layman version of final technical report. This is a short (max. 10 pages) version of the final report, written for the interested public as a target group.</td>
<td>36</td>
</tr>
<tr>
<td>MD.2</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2.4</td>
<td>Conference and workshops</td>
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<td></td>
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This project is funded by the Health Programme of the European Union.
## Milestones to be reached by this WP

<table>
<thead>
<tr>
<th>Number</th>
<th>Milestone Title</th>
<th>Delivery month</th>
<th>Means of verification</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Dissemination plan</td>
<td>3</td>
<td>Dissemination plan</td>
</tr>
<tr>
<td>2.2</td>
<td>Update dissemination plan</td>
<td>24</td>
<td>Updated dissemination plan</td>
</tr>
<tr>
<td>2.3</td>
<td>Scientific/policy conference EPH 2018-2019-2020</td>
<td>36</td>
<td>Conference report (abstracts)</td>
</tr>
<tr>
<td>2.4</td>
<td>European Health Forum 2019</td>
<td>36</td>
<td>Conference report (abstracts)</td>
</tr>
</tbody>
</table>
This project is funded by the Health Programme of the European Union

WP3 EVALUATION

Ausra Zelviene
Institute of Hygiene, Lithuania
What is evaluation?

- **Evaluation:** Actions undertaken to verify if the project is implemented as planned and reaches the objectives.

The evaluation is the systematic appraisal of the success of a project. It is a rigorous process that must be planned from the outset and conducted throughout the project lifetime.
Aims of the evaluation are to:
- Monitor the implementation process.
- Improve the work in progress.
- Increase the likelihood that the project will be successful.
Overview

3 tasks:

1. **Internal evaluation (Lead: HI)**
   - One page questionnaire
   - Repeated M1, M12, M24, M35
   - Results for discussion on SC, GA, EGHI & EGHSPA and added to JA interim report

2. **External evaluation (Lead: INSP and IACS)**
   - External evaluation board
   - M13, M25, M35

3. **Impact Assessment (Lead: WIV-ISP)**
   - Perception of sustainable structure on M1 and M36
   - Evaluation sheet after each important meeting
Internal vs External

- The internal evaluation is based on the dialogue between WP leaders.

- The external evaluation focuses on the overarching InfAct outcomes (main deliverables) and their impact. The external evaluation is based on the expert advice of different stakeholders representing the potential InfAct target audiences.
Task 3.1 Internal evaluation

The internal evaluation consists of a periodic (M 1, 12, 24, 35) evaluation with the WP leaders through a **focused questionnaire**:
- the alignment of the tasks with the overall InfAct timeline,
- the feasibility of the specific actions to get to the milestones;
- the formulation of actionable outcomes;
- the potential risks in the achievement of the specified goals;
- possible contributions towards sustainability.

The results of the surveys are summarized for discussion in the SC, GA and EGHl & EGHSPA and added to the JA interim report.

The internal evaluation will organize a **peer-review of the deliverables**. The WP leaders will have deliverables assigned to them that they need to evaluate, review critically and provide feedback on using a predefined template.
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Organisation of peer review

- WP1: LEAD – WIV-IS
  - PEER REVIEWERS: WP9 (LEAD - SpFrance)

- WP2: LEAD – WIV-IS
  - PEER REVIEWERS: WP3 (HI)

- WP3: LEAD – HI
  - PEER REVIEWERS: WP1 (WIV-IS)

- WP4: LEAD – ISCI
  - PEER REVIEWERS: WP5 (RKI)

- WP5: LEAD – RKI
  - PEER REVIEWERS: WP2 (WIV-IS)

- WP6: LEAD – MS
  - PEER REVIEWERS: WP8 (ISS)

- WP7: LEAD – WIV-IS
  - PEER REVIEWERS: WP10 (CIPH)

- WP8: LEAD – ISS
  - PEER REVIEWERS: WP7 (WIV-IS)

- WP9: LEAD – SpFrance
  - PEER REVIEWERS: WP6 (MS)

- WP10: LEAD – CIPH
  - PEER REVIEWERS: WP4 (ISCI)
### Organisation of peer review (2)

<table>
<thead>
<tr>
<th>WP</th>
<th>WHICH WP IS REVIEWED?</th>
<th>WHO REVIEWS WP’S WORK</th>
</tr>
</thead>
<tbody>
<tr>
<td>WP1</td>
<td>WP3</td>
<td>WP9</td>
</tr>
<tr>
<td>WP2</td>
<td>WP5</td>
<td>WP3</td>
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<td>WP3</td>
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<td>WP10</td>
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<td>WP6</td>
</tr>
<tr>
<td>WP10</td>
<td>WP7</td>
<td>WP4</td>
</tr>
</tbody>
</table>
Task 3.2 External evaluation

Lead: INSP, Romania, Co-lead: IACS, Spain
An external evaluation occurs at 3 timepoints during the JA (M 13, 25, 35).
Members of the External evaluation are:
- EUPHA (1),
- EUPHA section on Public Health Monitoring and Reporting (1),
- EUPHA section on Health Services Research (1),
- ASPHER (2),
- EGHI (1),
- EGHSPA (1),
- Ministry of Research (1),
- Ministry of Health (1),
- Coordinators of other JAs (1),
- Advocacy group (1).

The external evaluation committee appoints a meeting chair among its members.
Task 3.2 External evaluation

The missions of the Committee are:
- to discuss and validate the activity report (achievement of the objectives and impact on the target groups) of the project for the previous period using the list of milestones and deliverables;
- to discuss and validate the work plan for the following period;
- to discuss and review critically the outcomes in function of action ability for policy; sustainability; success and/or pitfalls towards a sustainable structure.

• The JA coordinator participates to the meeting in order to provide additional information on request
• The role of INSP is to provide the logistics of the organization of the meetings (date, documents and reporting).
An impact assessment will be carried out measuring the perception of a sustainable structure at the start and at the end of InfAct through a survey. Additionally, each of the major meetings and workshops will be assessed. An evaluation sheet will be distributed at the end of the meeting or workshop in order to evaluate its impact.

→ The meeting organiser will be responsible
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Evaluation framework

Inputs:
- Resources
  - inputs

Activities:
- Planned work
  - WP 1, 2, 3 Tasks
  - WP 4, 5 Tasks
  - WP 6, 7, 8 Tasks
  - WP 9, 10 Tasks

Outputs:
- WP 1, 2, 3, 4 milestones and deliverables
- WP 5, 6, 7, 8, 9, 10 milestones and deliverables

Outcomes and impact:
- Specific objectives
- General objectives
- Outcomes and impact evaluation

Process evaluation

Output evaluation

Evaluation reports

Leads:
- Internal evaluation: Lithuania
- External evaluation: Romania, Spain
- Impact assessment: Belgium

Joint Action on Health Information

by

the Health Programme of the European Union
Deliverables:

- Interim & final report of “External Evaluation Committee” - Month 36
<table>
<thead>
<tr>
<th>Milestone number</th>
<th>Milestone title</th>
<th>Lead beneficiary</th>
<th>Due Date (in months)</th>
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<tr>
<td>1</td>
<td>Agreement with subcontracts</td>
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<td>10</td>
<td>Subcontracts are signed</td>
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<tr>
<td>2</td>
<td>First interim internal and external evaluation report</td>
<td>Lithuania</td>
<td>13</td>
<td>Report is distributed to partners</td>
</tr>
<tr>
<td>3</td>
<td>Second interim internal and external evaluation report</td>
<td>Lithuania</td>
<td>25</td>
<td>Report is distributed to partners</td>
</tr>
<tr>
<td>4</td>
<td>Final internal and external evaluation report</td>
<td>Lithuania</td>
<td>36</td>
<td>Report is published including both interim reports</td>
</tr>
</tbody>
</table>
Activities for next 6 months

- Making a questionnaire for internal evaluation;
- Completing the survey of WP leaders, summarizing results;
- Impact assessment;
- Results of feedback of kick-off meeting.
Thank You!
Wp4: Integration in National Policies and Sustainability

Sustainability of an EU health information system supporting country knowledge and capacities, health research and policy-making.
## Wp4: Integration in National Policies and Sustainability

<table>
<thead>
<tr>
<th>Country</th>
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<th>PM</th>
</tr>
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<tbody>
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<td>Instituto de Salud Carlos III (ISCIII)</td>
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<td>Santé Publique France (SpF)</td>
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<tr>
<td>Germany</td>
<td>Robert Koch-Institut (RKI)</td>
<td>0</td>
</tr>
</tbody>
</table>
Wp4: Integration in National Policies and Sustainability Objectives

GENERAL
- Sustainability plan and a follow-up method. Outcomes, activities and best practices to be integrated in National, Regional and EU policies.
- Contribute with other Infact-WPs in defining policy relevant data for Health Information.

SPECIFIC
- Involve MS, EU partners and international institutions.
- Support MS to integrate deliverables into policies.
- Propose a Sustainability Plan.
- Support MS and EU/international partners on the potential adoption of new identified best practices.
- Provide MS elements to discuss infrastructures to assess long-term sustainability (WP7)
Wp4: Integration in National Policies and Sustainability
Pillars of Sustainability Plan

a) MS involvement through MoH and MoR authorities in interaction
   with international institutions.

b) Integration of the JA outcomes into EU-National/regional
   policies.

c) Strengthen national JA partners/HIS-Nodes and its relation with
   Health and research authorities.
Wp4: Integration in National Policies and Sustainability Activities

Task 4.1.
Integration of JA activities in MS/AC through an Assembly of Members (AoM)

Task 4.2.
Policy dialogues.

Task 4.3.
Sustainability Plan.
Wp4: Integration in National Policies and Sustainability

TASK 4.1: ASSEMBLY OF MEMBERS

Objective:

AoM National representatives will act as liaison with their research, national health system, National Public Health authorities and institutions (including NPHI)
Specific Objectives:

- To give feedback/policy guidance to the JA counterparts.
- To foster proposals for long-term projection and identifying national nodes (with WP7).
- To assess structural alternatives for long term JA activities.
Wp4: Integration in National Policies and Sustainability
TASK 4.1: ASSEMBLY OF MEMBERS (AoM)

Targeted audience:

- Ministries of Health (MH)*.
- Ministries of Research (MR)*.
- All MS, EC/DGSANTE, ECDC, WHO-Europe**, EUROSTAT, OECD and IANPHI

*All MS participating in JA.
**Including the Division of Information, Evidence, Research and Innovation from WHO-Europe.
Wp4: Integration in National Policies and Sustainability

TASK 4.1: ASSEMBLY OF MEMBERS (AoM)

Task 4.1.1 Organization of AoM:

A) Nomination of AoM members: High representatives from MoH/MoR, EC, ECDC, WHO-EU, EUROSTAT, OECD, IANPHI
C) Meetings (M19 and M32).

Task 4.1.2 Reports AoM assessments (M21, M34)

A) JA progress and translational framework to EU/MS HIS
B) Assess structural alternatives for long term: legal data protection and EB policy recommendations
C) Report based on Agenda Meetings
Wp4: Integration in National Policies and Sustainability
TASK 4.2: POLICY DIALOGUES

Objective:
Awareness and acceptance in decision makers on innovative actions to improve EU HI systems and achieve sustainability.

Targeted audience:
- Head of National Nodes (WP7).
- WP leaders.
- EU-international partners. (WHO*, ECDC, OECD, EU-EGHI, IANPHI... )
Wp4: Integration in National Policies and Sustainability

TASK 4.2: POLICY DIALOGUES

Task 4.2.1 Fact-Sheets (M17,M29).

Task 4.2.2 Two meetings (3 activities) (M18,30).

A). Meetings-Workshops. NN and WP-leaders (M18,30).

B). Dialogues between National Nodes (NN) and EU-international organizations (M18, M30).

C). Workshop all together with Division of Information, Evidence, Research and Innovation (WHO) to integrate evidences into HIS (M18).
Objective:

Translate JA outcomes into policies/decision-making evidence-based recommendations for MS

Extended Integration JA findings in MS HI-Systems in the long term
Wp4: Integration in National Policies and Sustainability
TASK 4.3: SUSTAINABILITY PLAN

- Integrate InfAct in MS protocols and policies/decision-making evidence-based recommendations.

- Translate JA outcomes into MS-HIS

- Include a follow-up system regularly updated quantifying MS incorporating JA outcomes, best practices, evidence-based policy recommendations and national and EU-Entities involved.

- Collect other deliverables, that will be mapped/monitored (national/regional levels) and assessed their sustainability/contribution to sustainability.
Wp4: Integration in National Policies and Sustainability

**TASK 4.3: SUSTAINABILITY PLAN**

- WP5: Peer review assessment, sustainable process to update the health information networks/projects/indicators, prioritization in health information.
- WP6: Roadmap for capacity building programme.
- WP7: Roadmap for HIREP-ERIC, governance structures of a sustainable HIS and web platform.
- WP8: Sustainable ECHI process from technical perspective.
- WP9: Roadmap for further development HIS, new data sources.
- WP10: Interoperability
| M/D | Name Deliverable and Milestone                                                                 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | 32 | 33 | 34 |
|-----|-----------------------------------------------------------------------------------------------|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
|     | **D4.1** Terms of Reference and Operating Procedure of the AoM                               |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **D4.2** Reports AoM assessments                                                               |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **D4.3** Fact Sheets                                                                           |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **D4.4** Reports on key holders and relevant EU-international partners meeting.             |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **D4.5** Sustainability Plan.                                                                  |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **M4.1** Assembly of Members. Appointed                                                       |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **M4.2** Review and analysis on implementation from other WPs by AoM                           |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **M4.3** Policy dialogues with key stakeholders at the national and international level      |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
|     | **M4.4** Sustainability Plan. Approval                                                          |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |    |
## Wp4: Integration in National Policies and Sustainability OUTCOMES

<table>
<thead>
<tr>
<th>DeliV</th>
<th>Title</th>
<th>Description</th>
<th>Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>D4.1</td>
<td>Terms of Reference and Operating Procedure of the AoM</td>
<td>These include identification of members, constitution, governance, mission, terms of reference and rules.</td>
<td>6</td>
</tr>
<tr>
<td>D4.2</td>
<td>Reports on AoM assessments</td>
<td>Reports based on agenda meetings of AoM, including procedures and activities regarding the sustainability plan on months 21 and 34.</td>
<td>21, 34</td>
</tr>
<tr>
<td>D4.3</td>
<td>Fact Sheets</td>
<td>To be used as a key toll for Policy dialogues to raise awareness and acceptance in decision makers on innovative actions to improve EU HI-systems (Months 18,30 key players, international organization and leaders of WP5-10. Contribution with deliverables and tasks from WP9,WP7 and WP5.</td>
<td>17, 29</td>
</tr>
<tr>
<td>D4.4</td>
<td>Reports on key holders and relevant EU-international partners meeting</td>
<td>Workshop or pre-conference in EUPHA</td>
<td>31</td>
</tr>
<tr>
<td>D4.5</td>
<td>Sustainability Plan</td>
<td>Integration of JA findings in MS HI-Systems and its projections in the future, following reasonable probabilities. It will translate JA/innovative outcomes into EU-National HI-systems, with the consensus provided by WP leaders, AoM, expert NN, and EU-international partners. It will include systematic EU-wide information and results on: integration of policy brief, identifying new approaches incorporated in National, regional and international systems, and its long term perspective.</td>
<td>21, 31</td>
</tr>
<tr>
<td>Milestone Title</td>
<td>Month</td>
<td>Means of verification</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
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<td>-----------------------</td>
<td></td>
</tr>
<tr>
<td>M4.1 Assembly of Members</td>
<td>3</td>
<td>Strategic Board National representatives appointed</td>
<td></td>
</tr>
<tr>
<td>M4.2 Review and analysis on implementation from other WPs by AoM</td>
<td>32</td>
<td>Meetings reports</td>
<td></td>
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<tr>
<td>M4.3 Policy dialogues with key stakeholders at the national and international level</td>
<td>30</td>
<td>Reports</td>
<td></td>
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<tr>
<td>M4.4 Sustainability Plan</td>
<td>32</td>
<td>Approval by AoM</td>
<td></td>
</tr>
</tbody>
</table>
WP4. Integration in National Policies and Sustainability

IMPACT ON SUSTAINABILITY
ACTIONABLE OUTCOMES
WP4. Integration in National Policies and Sustainability. Task 4.1.: ASSEMBLY OF MEMBERS (AoM)

Expected outcomes for sustainability:

• Integration of JA initiatives an innovative proposals in national/regional and EU information policies.
WP4. Integration in National Policies and Sustainability. 
Task 4.2: POLICY DIALOGUES.

Expected outcomes for sustainability:

- Translating JA results/innovative outcomes into policies/decision-making at MS/regional and International EU-level (WHO-OECD).
- Activities performed in line with HEN Network, EVIPNET network, e-Health network, EU-EGHI, HSPA, and the “Action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region” (66th session of the WHO Regional Committee for Europe. September 2016).
- Strengthened links between NN with relevant EU-international partners WHO, ECDC, OECD, EU-EGHI and IANPHI.
WP4. Integration in National Policies and Sustainability. Task 4.3.: SUSTAINABILITY PLAN.

Expected outcomes for sustainability:

- Translating JA results/innovative outcomes into policies/decision-making at MS/regional and International EU-level (WHO-OECD).

- Follow-up system to quantify MS incorporating JA outcomes, innovative best practices, evidence-based policy recommendations and national and EU-Entities involved.
WP4. Integration in National Policies and Sustainability.
<table>
<thead>
<tr>
<th>Country</th>
<th>Partners</th>
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<td>72</td>
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</table>

**WP4. Integration in National Policies and Sustainability.**

This project is funded by the Health Programme of the European Union.
WP4. Integration in National Policies and Sustainability.
Task 4.1.: ASSEMBLY OF MEMBERS (AoM)

- Spain. Instituto de Salud Carlos III (ISCIII) Lead.
  Identifying representatives. Coordination promotion AoM.
  Organisation of meetings with relevant with Ministries of Health & Research, NPHI, and research entities.

  Organisation of AoM meetings.
  Organisation of AoM meetings.
- UK. Welsh Government (WG)
  Organisation of AoM meetings.
  Liaise with national ministries & Co-represent WP7: input from business case for the ERIC
WP4. Integration in National Policies and Sustainability.  
Task 4.2: POLICY DIALOGUES.

- **Spain. Instituto de Salud Carlos III (ISCIII) Lead.**
  Coordination and promotion of Policy Dialogues and drafting of Fact-Sheets.

- **France. Santé Publique France (SpF). Co-lead.**
  Organisation of meetings for Policy Dialogues.

- **Belgium. Scientific Institute of Public Health (WIV-ISP).**
  Review.

- **Austria. Gesundheit Österreich GmbH (Austrian Public Health Institute)(GÖG).**
  National interface and Support in developing outline and structure linked to WP2

- **Italy. Istituto Superiore di Sanità (ISS).**
  Developing Fact-Sheets, the main outcomes of the JA for relevant dec.makers.

- **UK. Welsh Government (WG).**
  Holding consultation meetings across the UK and discussions with policy makers

- **Netherlands. National Institute for Public Health and the Environment (RIVM).**
  Co-represent WP5 via links with relevant EU-international partners. Contribute input from indicator mapping exercise

- **Germany. Robert Koch-Institut (RKI).**
  Review.
WP4. Integration in National Policies and Sustainability. Task 4.3.: SUSTAINABILITY PLAN.

Thank you !!
WP5: Status of health information systems in MS and regions

Kick-off Meeting, 07.03.2018

Thomas Ziese, RKI
Outline

1. Partners in WP 5 tasks
2. WP 5 tasks: Objectives, methods and planned outcomes
This project is funded by the Health Programme of the European Union.

WP5 Partner countries

- * Task lead
- ** Task co-lead

Task 1
Austria, Belgium**, Estonia, Latvia, Lithuania, Malta*, Moldova, Netherlands, Romania, Serbia

Task 2
Austria, Belgium, Croatia, Cyprus, Finland, Germany, Italy, Latvia, Lithuania, **Netherlands**, Norway**, Spain, United Kingdom

Task 3
Belgium, Germany**, Italy, Lithuania, Netherlands, United Kingdom

# WP lead
Task 5.1: Mapping and assessment of health information systems (WHO toolkit)

Support tool to assess health information systems and develop and strengthen health information strategies

- Training of (peer) reviewers
- Pilot peer review (3 countries)
- Apply method in other MS
- Review pilot
- Report on experience (publication, manual)

This project is funded by the Health Programme of the European Union
Task 5.2: Cataloguing health information networks, projects and indicator sets

Develop in-/exclusion criteria

Map
- international networks on
  - health data collection
  - indicator development
and
- existing indicator sets

Use expert support

Report results / scientific publication

Objective
- Less reporting burden
- More cooperation (WHO/OECD/EUROSTAT/EC)
Task 3: Prioritization in health information developments / Tackle health information inequalities

How is health information prioritized in different countries?

Delphi Survey

„Good practice“ examples! For a European prioritization strategy?
Thank you.
This project is funded by the Health Programme of the European Union.
This project is funded by the Health Programme of the European Union

Melhor Informação, Mais Saúde.

Agenda

- Participant MS
- WP Coordination
- WP Summary
- WP objectives
- WP Tasks
- WP deliverables
- WP Key Millestones
- WP effort and timetable
This project is funded by the Health Programme of the European Union

Melhor Informação, Mais Saúde.

**Lead:** Portugal  
**Co-lead:** Finland

**Other participating MS:**  
Belgium  
Croatia  
Greece  
Ireland  
Italy  
Latvia  
Netherlands  
Romania  
Slovenia  
Servia  
Spain
WP6 Coordination

Portugal
- MS - Direção Geral de Saúde - Ministry of Health
- IHMT - Instituto de Higiene e Medicina Tropical - Universidade Nova de Lisboa
  (WHO Collaborating Center for Health Workforce Policy & Planning)
- Instituto Nacional de Saúde Dr. Ricardo Jorge - Ministry of Health

Finland
- THL - Terveyden ja hyvinvoinnin laitos
WP6 Summary

- Capacity strengthening baseline in Population Monitoring and health system performance assessment
- Map current programmes
- Pool of experts
- Pilot flagship program
- Envisage evaluation and roadmap for sustainability
This WP aims at design, **developing** and evaluate a **capacity strengthening baseline program** at EU level that would support critical areas of health information use & management. Setting a European framework for the MS’s information capacity that reduces health information inequalities across MS.

The WP will identify, **map and summarise current programmes in “population health and health system performance analysis and monitoring” in the MSs**, including issues related with training, research and policy-making. A needs assessment in this area will also be performed.

A **flagship training programme** will be defined aiming at reducing HI inequalities within & between MS. This programme must result as practical approach, including field training and insights for its sustainability.

Document on how-to-do this programme and a proposal for the flagship programme will be produced. Two institutions will perform a pilot of key elements of this flagship program. The programme proposal will be evaluated. Final output will be a **Roadmap for capacity building programme for EU MS**.
Task 6.1. Mapping capacities and education/training programmes in health information across MS: months 1-18

Health Information (HI) is a comprehensive area, including indicators, data collection, data analysis, information management & translational research. HI is often taught in different courses or as modules of information systems or as part of epidemiology courses.

The WP will:

a. **Map and summarise MS’s health information needs** (technical resources, tools and training) and current existing programmes in “population health, health system performance analysis and monitoring” in the MS, including issues related with training, research (e.g. data protection) and policy-making

b. **Data will be collect from MS representatives and an expert panel**, but will consider also relevant EU and WHO-Euro projects, **key informers**, published literature search and a scoping search of internet sources, complemented with case studies to deepen understanding. Further MS needs on health information will be surveyed and assessed.

c. **Links with ECDC** (clinical data, TESSY), **European Observatory** (health indicators on health systems), ECDC One fellowship programme, OECD and WHO information educational programmes will be promoted.
Needs Assessment Survey

- **Health information needs** (technical resources, tools and training) and **current existing programmes** in “health information, population health, health system performance analysis and monitoring” in the MS

- **Existing Human Resources for Health Information**
  - Data analysts
  - Epidemiologists
  - Information Technicians
  - Public Health Information Reporting
  - Public Health Statisticians
  - Health Information Centres and Governance
  - Etc.
- Based on the results of Task 6.1, a **flagship programme** will be defined.
- The **capacity building programme** will cover different components such as longitudinal studies, surveys, population-based registries, healthcare & systems performance, and policy translation.
- The objectives are to increase knowledge on availability and use of standardized methods, common practices etc. within MS. The capacity building programme will **strongly build on e-learning tools** but also face-to-face activities such as workshops, seminars etc. are needed.
- The capacity building programme is oriented towards professionals working in public institutions.
- Some components of the capacity building programme will be piloted (in Task 6.3). The selection of the components will be done based on results of Task 6.1.
Task 6.3: Evaluating training program months: 24-30

- The proposal of the flagship capacity programme will be evaluated for its feasibility, coverage of required components, cost, target audience etc. using the knowledge and expertise of the experts of the consortium.

- The programme will subsequently be adjusted leading to the final objective.
- A roadmap for sustainable capacity building programme for EU MS will be prepared. This roadmap will include:
  a. **Description of already existing capacity building actions** and how those should be maintained and further developed;
  b. **Areas of health information for which adequate capacity building activities are missing** and how to start developing those;
  c. **How to get MS better informed** about already existing and new capacity building opportunities;
  d. **Ways to obtain future funding** for development and maintenance of a health information capacity building programme.
Understanding the HI Roadmap’s Main Trends

- Role of the Determinants of Health
- Chronic Diseases Epidemics
- New information technologies
- Human Resources for Health 2030
Apresentação - Sistemas de Informação em Saúde

Esta unidade curricular responde a uma necessidade crescente de profissionais na área da Saúde de desenvolverem competências relevantes no campo dos sistemas de informação em saúde (unidades de saúde, hospitais, administrações regionais saúde, telemedicina, etc.), que atendam às necessidades geradas pelas políticas governamentais ou dos projetos de desenvolvimento, apoiados na evidência e cientificamente para os resultados em saúde.

As competências a desenvolver são compreender a utilização e a gestão da informação, e o desenvolvimento e sistemas de informação em contexto dos serviços de Saúde, e aplicá-las em casos práticos, no contexto Português e dos PAULP.

Os objectivos desta unidade curricular são:
1. Identificar tipologias de sistemas de informação, de fontes de informação e de modelos de gestão da informação em serviços de saúde, e compreender os bases da Teoria da informação.
2. Explorar os vários métodos de gestão da informação em ambiente de Saúde.
3. Explorar a importância e a baixura à decisão, e a dependência de acesso à informação num contexto de organização de serviços e programas de saúde.
4. Mostrar a utilização de um conjunto de instrumentos de apoio à decisão, com base no acesso à informação através de sistemas de informação no contexto da Saúde.
5. Analisar e diagnosticar necessidades de sistemas de informação, do ponto de vista do gestão dos serviços de Saúde.
6. Desenvolver planeamento para implementação de projetos de sistemas de informação em Saúde.
7. Desenvolver intervenções de gestão da mudança para aplicar a implementação de sistemas de informação.
8. Compreender o papel dos gestores, técnicos de informação, profissionais de saúde e de outros actores no desenvolvimento do SI.
9. Compreender as dinâmicas do eHealth e das redes sociais na Saúde (nunca perspective Europeia e dos PAULP).

Ficha - Sistemas de Informação em Saúde

Referências

- 2007 Meth Inf Med - Paper - Future HIS_Kuhn-Lapac
- 2007 Meth Inf Med - Paper - PortugalSurvey Velic Lapao
- 2013 BMJ Medical Informatics Decision Making Analysis of the quality of Hospital Info Cornea Lapao
- 2015 Stud Health Technology & Informatics - Online Pharmaceutical Care Provision Design Science Research Gregorio Lapao
- 2016 MHP - Loan Geostar Qualidade Saúde Lapao
<table>
<thead>
<tr>
<th>Number</th>
<th>Title</th>
<th>Description</th>
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<tr>
<td>6.1</td>
<td>Mapping needs, capacities and training programmes in health information</td>
<td>A report summarising the existing health information programmes and their contents and other relevant pedagogic details. Identification of the most significant and relevant health information inequalities among MS. A detailed knowledge of existing health information systems and their capacity to respond to community requirements.</td>
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</tr>
<tr>
<td>6.2</td>
<td>A flagship training programme to improve MS capacities in population health and health system performance analysis and monitoring</td>
<td>Flagship Capacity Building Programme for “population health and health system performance analysis and monitoring” proposal Document</td>
<td>24</td>
</tr>
</tbody>
</table>
| 6.3    | Training Piloting and Flagship Training Programme Evaluation          | Piloting Training of modular key issues and Flagship Capacity Building Proposal Evaluation – three outcomes:  
1. One report will provide information about the experience of 2-3 key issues piloted in two groups of people from several MS  
2. A second report on the evaluation of the Flagship Capacity Building Programme proposal, resulting from formal evaluation, web meetings and a face-to-face meeting. This shall include improvements, guidelines and recommendations  
3. Improved version of the Flagship Capacity Building Program |
| 6.4    | Roadmap for capacity building programme                               | Roadmap for capacity building programme on health information in Europe: Implementation Guidelines for MS, including recommendations reducing information inequalities among MS and recommendations for sustainability | 36           |
## WP6 Milestones

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<td>Mapping of Health Information education/training programmes and needs</td>
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<td>D6.2</td>
<td>Flagship capacity build programme</td>
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<td>Tasks 6.2 completed</td>
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<td>D6.3</td>
<td>Training Piloting and Flagship Training Programme Evaluation</td>
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<td>Tasks 6.2 completed</td>
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<td>D6.4</td>
<td>Roadmap for capacity building programme</td>
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This project is funded by the Health Programme of the European Union.

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| WIV-ISP | GöG | MCA | CI PH | MoH | Cy | UZIS | MoS | A | THL | SPF | RKI | EOPY | A | DOH | ISS | CDPC |
| 2 | 7 | 19 | Fin scrolls | 1 | Gre ece | 1 | Irel and | 3.5 | Ital y | 3 | Latvia |
| Belgium | Croatia | 0.8 | Holland | 60 | Portugal | 8.9 | Romania | 4 | Serbia | 3 | Slov enia | 3 | Spain |
INFACT CONCEPTUAL FRAMEWORK

WP5. Status of health information systems in MS and regions

WP8. Tools and methods for Health Information Support

WP6. Capacity building

WP10. Interoperability

WP9. Innovation in Health Information

Strengthen + innovate EU HIS

Sustainable EU HIS

WP4. Integration in national policies

WP7. Proof of concept of sustainable structure
Obrigado. Thank you.
WP7 Proof of concept of sustainable structure on health information

Kick-off Meeting 7 March 2018

Name: Petronille Bogaert and Herman Van Oyen
Institution: Scientific Institute of Public Health
Country: Belgium
Contact: infact.coordination@wiv-isp.be

This project is funded by the Health Programme of the European Union
Challenges in health information

1. Health information activities are often funded through ad hoc projects rather than through sustainable structures.

2. Much of the gathered evidence and knowledge is still dispersed, incomplete and difficult to access.

3. Large differences can be found in terms of quality and, as a consequence, in comparability of health information between and within EU Member States.
What?

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

Comparable and policy-relevant health information on population health and health system performance

Core activities:
- Generate health information
- Manage health information
- Exchange health information
- Translate health information
How?

- Operates under strict Member State governance
- At the core of health information in the EU
- Benefit from relevant EU funding opportunities at a relatively low cost to its members
- Functions as a house for networks
  - Member States = national node
  - Research = domain specific node
This project is funded by the Health Programme of the European Union.

ASSEMBLY OF MEMBERS (AoM) [full-decision making power]

- Members and Observers
  - Select 1 Chair and 1 Vice-Chair
  - 1 observer in AoM

Scientific Advisory Board:
- Offer advice
- Scientific experts

Central Executive Management Office:
- Management, operational, and budgetary day-to-day decisions
- General Director and Core Team

Ethics and Privacy Board:
- Offer advice
- Scientific experts

Network Committee:
- Oversee national scientific activities
- Representative of national health information authorities and international research networks

Consultation Platform:
- Align with health information landscape
- International organisations and Commission services
- Lead and Co-Lead: WIV-ISP and RIVM
- Partners:
  - Participation in country nodes (Task 1): Belgium, Croatia, Czech Republic, Finland, France, Germany, Greece, Italy, Latvia, Lithuania, Malta, Netherlands, Poland, Portugal, Serbia, Spain, Sweden, Welsh government
  - Finland (THL) - Task 2, 3
  - Germany (RKI) - Task 4
  - France (SpF France, MoH France, INSERM) - Task 2, 3
  - Latvia (CDPC) Task 2
Task 7.1. A sustainable networks of networks

- Getting started with national nodes in MS
  - Aim: bring health information system players in one country together

- Develop selection procedure and functioning of domain specific networks

- Develop Network Committee composition and tasks
Task 7.2. Business case and road map for implementation

- Mission and vision of the HIREP-ERIC;
- Short-term and long-term sustainable strategy;
- Analysis of the information needs of current health policies in MSs and the EU;
- Development of the final management structure;
- Identification of users and criteria for development of service definition;
- A scoping study to select and specify services with highest utility;
Task 7.2. Business case and road map for implementation

- A short-term and long-term time planning and cost estimation, including high and low estimates for the tasks to be executed and personnel involved;
- Added value of the HIREP-ERIC for its financers;
- Market space of HIREP-ERIC in the EU health information landscape. Based on the experiences, pilots of the JA,
- Output: 5-year operational HIREP-ERIC road map with a detailed work plan including specific objectives, outcome and deliverables.
Task 7.3. Development of the governance structures of a sustainable health information system

- Develop Technical and Scientific description of HIREP-ERIC and defining statutes of HIREP-ERIC
- Define terms of reference of the different committees
- The development of the memorandum of understanding (MoU) of MSs regarding the setup of the HIREP-ERIC
- Apply to ESFRI roadmap and ERIC
Task 7.4. Health information web platform

- Functional design and development of a website providing the support platform for the HIREP-ERIC.
- The site contains repository functions for
  - technical reports and scientific articles,
  - methods and tools,
  - health information projects,
  - indicators/data sets,
  - information on NCs, DSNs, training programmes,
  - financial source information collected in the JA.
<table>
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<tr>
<th>Number</th>
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<th>Description</th>
<th>Delivery month</th>
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<tr>
<td>7.1</td>
<td>A sustainable network of networks</td>
<td>The deliverable (1) provides guidelines on setting up NCs based on good practices and experiences in this process by MS during the JA, (2) provides criteria for in- and exclusion of DSNs and (3) defines the terms of reference for the functioning of the Network Committee of the HIREP-ERIC</td>
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<tr>
<td>7.2</td>
<td>HIREP-ERIC: Business case and road map for implementation</td>
<td>The target population of this report are countries’ Ministries of Health and Ministries of Research. The report describes the Business case and a 5-year road map for implementation with a detailed work plan including specific objectives, outcome, deliverables and KPI for monitoring</td>
<td>30</td>
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<tr>
<td>7.3</td>
<td>Governance structures of a sustainable health information system</td>
<td>The deliverable contains the Technical and Scientific description of HIREP-ERIC and defining statutes of HIREP-ERIC and the list of MSs who have signed the memorandum of understanding</td>
<td>18</td>
</tr>
<tr>
<td>7.4</td>
<td>Health Information web platform</td>
<td>Web platform containing information on past / current health information-related projects, indicators; networks of national consortia, of domain specific nodes, of training experts, of financial resources; on data sources and methods</td>
<td>24</td>
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</tbody>
</table>
This project is funded by the Health Programme of the European Union

Infact.coordination@wiv-isp.be
Joint Action on Health Information
WP8-Tools and methods for Health Information support

Luigi Palmieri
National Public Health Institute-ISS, Italy
luigi.palmieri@iss.it

InfAct Kick-off meeting
Lux, 7th March 2018

This project is funded by the Health Programme of the European Union
WP8-Tools and methods for Health Information support

What we want to do

- Provide overview of data collection methods and procedures for input in the InfAct web platform
- Improve sustainability of ECHI-shortlist
- Provide best practices in accessibility, availability and reporting in health information
- Coordinate networks of experts

Lead: Italy
Co-lead: Netherlands, Slovenia
WP8-Tools and methods for Health Information support

What we want to do

- **Task 8.1.** Generating knowledge on data collection methods, availability and accessibility of HI
- **Task 8.2.** Sustainable use(ability) of the ECHI-shortlist and its future implementation
- **Task 8.3.** Guidelines for accessibility, availability and reporting of HI
- **Task 8.4.** Coordinating networks of experts involved in the InfAct JA
WP8 - How we will do it

Task 8.1-Generating knowledge on data collection methods, and availability and accessibility of health information (Lead: ISS)

- A: Selecting and defining health and health determinant related domains; identifying related sources of information

- B: Reviewing existing international organization data tools, websites, published reports, European networks collecting data on health monitoring and HSPA

- C: Preparing and submitting to participating countries a questionnaire to collect information on availability, accessibility, and quality assurance of health data

- D: Defining ‘best practices’ and stepwise approach to implement data collection methodologies (including use of routine data sources); providing material to the InfAct web platform

Research/desk work in collaboration with WP5, WP7, WP9, and other WPs
WP8 - How we will do it

Task 8.2 - Sustainable use(ability) of the ECHI-shortlist and its future implementation and alteration process (Lead: RIVM)

- A: Compiling ECHI relevant historical and technical background information
- B: Improving and implementing a sustainable ECHI update process
- C: Reviewing the ECHI format/structure and content
- D: Preparing dissemination on the InfAct web platform and a sustainable procedure for updating information
- E: Selecting advisory expert group (~5 countries) for activities support

Activities
- the established advisory group will be instructed and consulted
- (small) pilots will be included
- building on the BRIDGE Health project and previous ECHI projects
- collaborating with WP5, other WPs, International institutions, EU networks and groups
WP8 - How we will do it

**Task 8.3 - Guidelines for accessibility, availability and reporting of health information including quality of data/indicators and quality of reporting (Lead: ISS)**

- A: Collecting detailed case studies on HI reports
- B: Reviewing reporting and dissemination methods used in MSs and at EU level
- C: Elaborating guidelines and recommendations for accessibility, availability and reporting of HI

To avoid duplication of work, interaction and overlap with the Joint Assessment Framework (JAF) on Health and the Observatory of Health Systems and Polices will be evaluated

*Research/desk work in collaboration with WP5, WP7, WP9, and other WPs*
Task 8.4 - Coordinating networks of experts involved in all WP activities within the entire JA; contribution to web-based platform (Lead: NIJZ)

- A: Defining and providing standard approach for selecting and establishing health experts network

- B: Maintaining established network of experts following best practices and using the InfAct web platform

Research/desk work in collaboration with WP7 and other WPs

Together with WP7, virtual meetings and working groups
WP8 - Expected outcomes

4 Reports will be provided

• **D8.1.** Health Information System development: data collection and quality assurance for a common health information system
• **D8.2.** Practical recommendations for sustainable ECHI process from technical, content and user perspective
• **D8.3.** Guidelines for accessibility and availability of HI
• **D8.4.** Guidelines for MSs and regions for health reports

Standardised approach to create a sustainable network of experts with the support of the InfAct web platform will be defined
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Organization</th>
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<th>Tasks</th>
<th>WP8 Efforts</th>
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<td>1-WIV-ISP (IPH) (BE)</td>
<td>Institut Scientifique de Sante Publique</td>
<td>Belgium</td>
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<td>Istituto Superiore di Sanità</td>
<td>Italy</td>
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<td>14-CDPC (LV)</td>
<td>The Centre for Disease Prevention and Control of Latvia</td>
<td>Latvia</td>
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</tbody>
</table>

**Lead**

**Co-lead**
## WP8 - Collaborating partners

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Organizations</th>
<th>Country</th>
<th>Tasks</th>
<th>WP8 Efforts</th>
</tr>
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<tr>
<td>17-MFH (MT)</td>
<td>MoH-Government of Malta</td>
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<td>19-RIVM (NL)</td>
<td>Rijksinstituut Voor Volksgezondheid en Milieu</td>
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<td>20-HD (NO)</td>
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<td>21-MZ (PL)</td>
<td>Moh of the Rep. of Poland</td>
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<td>24-IPHS (RS)</td>
<td>Institut za Javno Zdravlje Srbije 'Milan Jovanovic - Batut'</td>
<td>Serbia</td>
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<td>25-NIJZ (SI)</td>
<td>Nacionalni Institut za Javno Zdravje</td>
<td>Slovenia</td>
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<td>26-ISCIII</td>
<td>Instituto de Salud Carlos III</td>
<td>Spain</td>
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<td>WP8 Tasks</td>
<td>Lead &amp; Co-lead</td>
<td>Partners</td>
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<td>--------------------------------------------------------------------------</td>
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<tr>
<td>Task 8.1: Generating knowledge on data collection methods, and availability and accessibility of HI</td>
<td>ISS, Italy THL, Finland</td>
<td>ISS(IT), THL(FI), NIJZ(SI), WIV-ISP(BE), EOPYY(GR), HD/NIPH(NO), WG(UK), FOHM(SE), UZIS(CZ), CDPC(LV), MoH/(CY), MZ(PL), IPHS &quot;Batut“(SR), SpF(FR) [14 MS]</td>
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<td>Task 8.2: Sustainable use(ability) of the ECHI-shortlist and its future implementation and alteration process</td>
<td>RIVM, Netherlands RKI, Germany</td>
<td>ISS(IT), RIVM(NL), NIJZ(SI), RKI(DE), THL(FI), HD/NIPH(NO), DHIR/MFH(MT), DoH (IE), UZIS(CZ), CDPC(LV), SpF(FR), ISCIII(ES) [12 MS]</td>
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<td>Task 8.3: Guidelines for accessibility, availability and reporting of HI including quality of data/indicators and quality of reporting</td>
<td>ISS, Italy RKI, Germany RIVM, Netherlands THL, Finland</td>
<td>ISS(IT), RIVM(NL), NIJZ(SI), RKI(DE), THL(FI), WIV-ISP(BE), HD/NIPH(NO), DoH (IE), MoSA(EE), UZIS(CZ), CDPC(LV), MZ(PL), SpF(FR) [13 MS]</td>
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<td>Task 8.4: Coordinating networks of experts involved in all WP activities within the entire JA</td>
<td>NIJZ, Slovenia</td>
<td>ISS(IT), RIVM(NL), NIJZ(SI), WIV-ISP(BE), UZIS(CZ), CDPC(LV), MZ(PL), ISCIII(ES) [8 MS]</td>
<td></td>
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</tr>
</tbody>
</table>
Team Project: Anne Gallay, MD, PhD; Emmanuelle Bauchet, MD; Michel Vernay, PhD (France - lead) and Ausra Zelviene, PhD (Lithuania - Co-lead)

Joint Action InfAct - Kick-Off meeting
Luxemburg, 7th March 2018
Currently, many Health Indicators collected at European level come from:

- Death certificates, Health Interview Surveys (EHIS, SILC...)
- Health Examination Surveys, Registries
- Hospital discharges (mainly Health Care Quality Indicators)

But:

- Cost of data collection such as HIS and HES remains high
- Many items are self-reported (HIS)
- Several MSs have no registries with national-coverage; not in capacity to easily provide estimates at regional level
- Participation rate to Health Surveys tends to decrease over time
Context (2)
In the same time:

- Availability of generated data from a variety of sectors is increasing,
  - such as Health Care Utilisation data (reimbursement data, data from hospital - general and psychiatric - and rehab units...)
- collected in a different purpose than epidemiological monitoring
- Data are:
  - comprehensive, available at different territorial levels,
  - could be linked to data already collected at European level (death certificates, Health Surveys...)
GOALS:
Increased needs to support public health policy and public health care

- Need for more efficient ways of generating comparable, relevant, reliable, updated and sustainable health information across Europe by using data collected for other purposes

- Assessment of the potential use of these new data sets for public health policy purposes

This project is funded by the Health Programme of the European Union
Aims WP9:

- New ways of using existing data using linkage, modelling and other techniques to enhance their value
- Producing timely and valid population health indicators at different territorial levels for better decision
- Investing in HSPA indicators
- Develop better narratives for policy makers
Task 9.1 Identifying and sharing inspiring examples...

...from MSs with regards to emerging indicators and promising sources (lead: Public health France)

i) Identify emerging indicators

ii) Identify emerging and promising sources of data, with special attention to the utilization of data from different sources

iii) Share experience on the use of emerging indicators, promising sources and modelling techniques
Task 9.2 Develop and propose generic and shared methods, best practices, and standards...

...to define, construct, validate and disseminate relevant and reliable emerging indicators from new data sources, in addition to health data from death certificates, surveys and registries (lead: Public health France)

i) Health monitoring

ii) Health system performance assessment

...to support public health policy and public health care policy with more updated and reliable data
Task 9.3 Apply best practices
(lead: Public health France)

Apply these guidelines to health indicators and HSPA to a limited number of priority public health targets that are of interest.
Task 9.4 Development of composite indicators to...

...monitor the burden of disease at population level

i) Propose further development of composite health indicators, including health expectancies (ehleis), burden of diseases in collaboration with IHME (institute of health metrix and evaluation) and WHO Euro BoD

ii) Assess the feasibility of merging mortality and morbidity information among different geographical regions in different MS, to explore both the quality of health information systems and inequalities in access to health care
Task 9.5 Explore mechanisms for the uptake of indicators...

...into the regular EU data collection System (Estat regulations), WHO and OECD

....and for HSPA

- link with WP1, WP2, WP4, WP8 and WP10 (lead: public health France)
WP9 - OUTCOMES AND IMPACT ON SUSTAINABILITY

- next six months
  - A map of examples of emerging data sources and new indicators
  - Starting Guideline for method to build new indicators and modelling process

- Later:
  - 3 workshops on GBD, including one training workshop
  - Road maps of networks for
    - At short term: To identify one or two indicators (perinatology and EHLEIS)
    - At mid term: To define other potential indicators
    - At long term: Prospective exploration
Contact: Infact-FRANCE@santepubliquefrance.fr

Thank you for your attention
This project is funded by the Health Programme of the European Union

WP10 partners

Lead and Co-Lead

Partners

This project is funded by the Health Programme of the European Union
WP and task leaders and co-leaders will foster interaction with all the contributors privileging consensus as the decision-making method.

If required, subtask leaders will be named to increase efficiency in the development of the tasks.

All deliverables will be approved by all the contributors before release to the coordination.
What do we want to do?

Based on the building blocks of European Interoperability Framework (EIF) and inspired by the EIF for e-Health.

Map, structure and pilot interoperability levels as a support for policy making using services based on data linkage, sharing and management, and knowledge development.
This project is funded by the Health Programme of the European Union

Interoperability - ReELF

Legal
Organisational
Semantic
Technical
Legal and regulatory
Policy
Care Process
Information
Applications
IT Infrastructure
Legal and regulatory constraints
Collaboration agreements
Alignment of care processes
Defining and coding of information
Integration in healthcare systems
Communication protocols
How will we do it?

Mapping and analysing cross-national inspirational case studies on public health surveillance or research, where interoperability, data linkage, data sharing and data management are present.

Developing empirical work on interoperability for a number of topics, using a variety of data sources from different countries.
What will be the outcome?

The main objective is a thorough description of the methods and techniques used to get sound knowledge out of data linkage, sharing and management (i.e., semantic harmonization, quality assurance) and reporting.
This project is funded by the Health Programme of the European Union

Tasks

T10.1 Mapping exercise: identification of inspirational experiences
T10.2 Mapping exercise: legal and organizational interoperability
T10.3 Mapping exercise: semantic and technical interoperability
T10.4 Empirical case studies
Task 10.1

Mapping exercise: identification of inspirational experiences

„Best practices” in the MS participant countries according to the following criteria:
1) addresses the study of health status, health determinants, and/or health systems performance;
2) provides insight on surveillance and/or impact or effectiveness research;
3) includes a variety of data sources (e.g., patient registries, population-based registries, surveys, electronic health or medical records, administrative data, etc.) from different countries;
4) addresses data linkage, sharing, and management (quality assurance) activities;
5) produces outcomes reported to public health stakeholders, particularly policy-makers.
Task 10.2
Mapping exercise: legal and organizational interoperability

Each experience with required criteria will be analysed with a view to seek how legal and organizational interoperability was or is being addressed. The exercise will also contain the analysis of enablers and barriers to accomplish with these two EIF domains. Outcomes will be reported to public health stakeholders, particularly policy-makers.
Task 10.3

Mapping exercise: semantic and technical interoperability

Each experience will be analysed with a view to seek how semantic and technical interoperability was or is being addressed.

The exercise will also contain the analysis of enablers and barriers to accomplish with these two EIF domains.
**Tasks**

**Task 10.4**

**Empirical case studies**

Empirical work on interoperability in a number of topics of interest for public health policy-making in Europe. The different case studies should provide insight on the methods and techniques used to get sound and relevant outputs from different data sources in different countries.

- **Dimension 1** Domain including health status, health determinants or health system performance and
- **Dimension 2** Goal including public health monitoring/surveillance or public health effectiveness and efficiency (i.e., impact research).
This project is funded by the Health Programme of the European Union

**Deliverables**

**D10.1**
Report
„LOST and found: Interoperability and Health Information in Europe”

**D10.2**
Technical report
„Getting interoperability implemented”
Deliverable 10.1
Report: „LOST and found: Interoperability and Health Information in Europe”

a) A description of the experiences, enablers and barriers that influenced the achievement of EIF principles

b) Recommendations on good regulatory and organizational practices

c) Identification of key issues in the application of the GDPR (EU- 2016/679) with regard to the use of health information databases for epidemiological surveillance and public health research

d) Inventory of technical solutions that have been implemented in other regions and/or sectors like mediation systems between hospitals data warehouses

e) Recommendations on available technical solutions and digital services for federated data sharing and analysis

f) Recommendations on digital assets supporting interoperability for data re-use
Deliverable 10.2

Technical report: „Getting interoperability implemented”

a) A thorough description of the case studies: data sources linked, data management methods and reporting methods

b) Recommendations on how to develop the stakeholders’ requirements analysis

c) Recommendations on the architecture design pertinent to the type of business case to develop in an ERIC

d) Recommendations on how architecture and processes should serve to privacy, data transfer, data linkage, data management and reporting

e) Recommendations to develop a Health Information Systems’ Interoperability Action Plan (HISIAP) for an eventual ERIC

f) A list of capacity building needs that should be complemented in an eventual capacity-building program
<table>
<thead>
<tr>
<th>Milestone Number</th>
<th>Milestone Title</th>
<th>Lead Beneficiary</th>
<th>Type</th>
<th>Dissemination Level</th>
<th>Due Date (Month)</th>
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<tr>
<td>M10.3</td>
<td>Report on mapping exercise: semantic and technical interoperability</td>
<td>CIPH, Croatia and INSERM, France</td>
<td>Report</td>
<td>Joint Action Partners and Scientific Publications</td>
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<td>M10.4</td>
<td>Description of the case studies</td>
<td>IACS, Spain and ISS, Italy</td>
<td>Report</td>
<td>Joint Action Partners and Scientific Publications</td>
<td>24</td>
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JA Coordination feedback

Potential relationships to other WPs:

• **WP#4**: add technical insight to the technical and scientific description of an eventual European Research Infrastructure Consortium on Health Information?
• **WP#5**: could provide the EIF perspective to the mapping exercise on health information systems across Europe?
• **WP#6**: might provide insight on specific learning needs that should be present in an eventual capacity building program?
• **WP#7**: should contribute to the business case and implementation roadmap of an ERIC?
• **WP#8**: WP10 contents should feed the WP8’s knowledge base?

This project is funded by the Health Programme of the European Union.
JA Coordination feedback 2

Potential relationships to other WPs:

Conversely, WP#10 could be getting insight from WP#9 with regard to the validation of indicators carried out as part of WP9’s tasks?

In agreement with WP#1 on coordination, WP#4 on Sustainability, and WP#2 on Dissemination, WP10 will pay special attention to cooperation and communication with the ISA unit at the Directorate General for Informatics of the European Commission, the JRC offices in ISPRA for INSPIRE Directive implementation authority, and the upcoming Joint Action on e-Health – eHAction.
Mapping and case study empirical work will deliver recommendations on how to develop the stakeholders’ requirements analysis, how architecture and processes should serve to privacy, data transfer, data linkage, data management and reporting and recommendations to develop a Health Information Systems’ Interoperability Action Plan (HISIAP) for an ERIC.
## F2F meetings, (case) study visits and workshops

<table>
<thead>
<tr>
<th>Description</th>
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<tbody>
<tr>
<td>WP10 Kick-off Partners’ Meeting</td>
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<tr>
<td>WP10 First Case Study Pilots Workshop (combined with Steering Committee meeting #3)</td>
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<tr>
<td>WP10 Deliverable 1 Report Pre-Launch Meeting and WP10 Second Case Study Pilots Workshop</td>
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<tr>
<td>WP10 Closing Partners’ Meeting on Sustainable Approach to Interoperability (combined with Steering Committee meeting #6)</td>
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<tr>
<th>Location</th>
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<th>Due Date (Month)</th>
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<tr>
<td>Zagreb, Croatia</td>
<td>All WP10 Partners</td>
<td>M1-M3</td>
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<tr>
<td>TBD, Belgium</td>
<td>Leads, Co-Leads and T10.4 Partners</td>
<td>M12</td>
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<tr>
<td>TBD</td>
<td>Leads, Co-Leads, T10.1, T10.2 and T10.3 Participants and relevant JA partners from other WPs</td>
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<tr>
<td>TBD, Belgium</td>
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This project is funded by the Health Programme of the European Union.

Timeline:

- Kick-off (M3)
- M10.1 (M12)
- M12 (CS1)
- M12 (M10.2)
- M18 (M10.3)
- M18 (D1+CS2)
- M24 (M10.4)
- M30 (D10.1)
- M36 (Closing)

(*) F2F
Thank you

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