INFACT
Joint Action on Health Information

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

FACT SHEET

Connecting health information system's stakeholders through national nodes

Key outputs

1. **Background:** Health information activities are scattered in many countries. InfAct supports countries to set up national nodes that bring together key national stakeholders in the country in a systematic way and offers a structure to interact at European level.

2. **Innovative tools to improve the current EU-HIS:** InfAct identified best practices in countries with active national nodes and developed a stepwise approach to support countries to set up, define and organise a national node. A web based platform is set up to allow exchange of information on national nodes activities between countries and within the country.

3. **Most relevant results:** Countries have indicated benefits in setting up national nodes. 19 countries have provided regular updates to InfAct on their national node: 12 countries have a national node based on an existing group and 7 countries initiated first meetings in the framework of InfAct. Various stakeholders of national health information systems have shown enthusiasm in this endeavour.

4. **Feasibility of being integrated in HIS and translated into policies:** Setting up a national node brings together the key national stakeholders in a systematic way. It provides opportunities for better coordination and cooperation among stakeholders. Moreover, national nodes provide an opportunity to have a better overview of the national health data collecting agents and expertise as well as European exchange. National nodes will be an essential element in the Distributed Infrastructure on Population Health (DIPoH) and the Population Health Information Research Infrastructure (PHIRI).

Background and Rationale (What is currently known?)

In many EU Member States and associated countries, health information activities are scattered over several institutes. Regular coordination and communication among these institutes is often missing. This leads to duplication of activities, limited interoperability and linkage of data between institutes, inhibited exchange of data and lost opportunities for research or policy support.

InfAct supports European countries to overcome these barriers by setting up national nodes. The central idea is to increase communication among key players in a systematic way. The national node format is not fixed, but compatible and adaptable to the national organisation of the health information system. In some European countries, the national node function already exists in the form of a meeting organised by a coordinating institution or project. However, its function is often not clearly defined nor sustainably supported yet. InfAct provides support to countries in strengthening their function.

National nodes are foreseen to play a key role in the Distributed Infrastructure on Population Health (DIPoH) and the Population Health Information Research Infrastructure (PHIRI). The national nodes would feed DIPoH and PHIRI with relevant information, data, experts, tools and guidelines. Vice versa, they would feed relevant international information to the country.

Proposal (What tools have been used and which are the results?)

InfAct sees the national node as an opportunity to bring together regional/national stakeholders in health information in a more systematic manner. Setting up this national node brings forth discussions on core issues in health information domains that are nationally and internationally relevant for the country. Bringing together the regional/national stakeholders makes it possible to: (i) Share expertise at regional/national level; (ii) Share ongoing activities at regional/national level; (iii) Update on initiatives, meetings and expert groups at EU level and (iv) join forces for better research and policy support at national level. By enabling and strengthening national nodes, InfAct is working towards decreasing health information inequalities between countries.

InfAct reaches out to all InfAct partner countries to support them in the process of the development of the national node. To do this, InfAct initiated a national node survey to investigate the current status regarding any meetings that brought together health information stakeholders or partners at a national/regional level. More specifically, the survey collected information on how these meetings are organised, which national stakeholders are included, and what topics are discussed in these meetings in case such a meeting had already taken place. For the countries who indicate no such meetings occurred yet, the survey asked what are the potential barriers and benefits for the country to implement a national node.

The survey indicated countries saw a clear benefit of setting up a national node and countries that had already a node could witness of their added value e.g. it allows national stakeholders to work better together to respond to international request and store information centrally and accessible to all. Based on the collected experiences, InfAct developed a stepwise approach to set up a national node. The stepwise approach provides European countries with guidelines on how to set up, define, and organise a national node. Being aware that responsibilities, organisations and procedures are different in each country, the stepwise approach provided room for adjustments based on the specific situation within each country taking flexibility into account.

InfAct keeps a record on the current status of the national node in the partner countries. Countries have presented their national nodes during the General Assembly meetings and subsequent national node meetings. Opportunities for best practice exchanges and support have been organised through these regular meetings. 19 countries have provided regular updates to InfAct on their national node: 12 countries have a national node based on an existing group and 7 countries initiated first meetings in the framework of InfAct. Various stakeholders of national health information systems have shown enthusiasm in this endeavour.

Recommendations for sustainability (What should be done?)

Setting up a national node has a real benefit for countries. It brings together national data collecting agents and can optimise national data delivery. In the long term, the national node's 'spider in the web' role would also help to involve the right experts to support national capacity building, improve working towards international quality standards, and optimising the secondary use of national (and international) health data for purposes of health research, public health monitoring and health system assessment. As a result, better connected national research capacity and stronger national health information systems are facilitated by national nodes and health information inequalities are being addressed.