



RD-CODE

Integration with other eHealth activities & projects

Support for discussion



Prague - 22 June 2020



★ <http://rd-code.eu>



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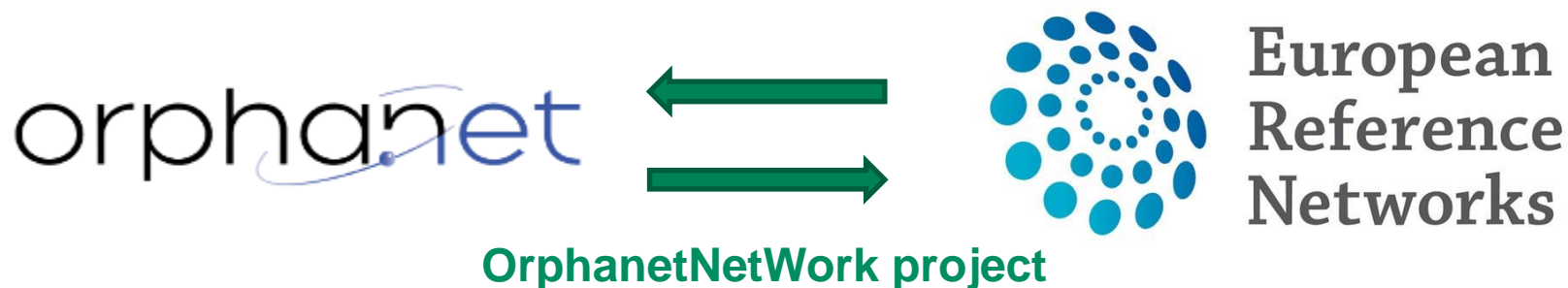


European Reference Networks
Clinical Patient Management System



Need for implementation in HCPs hosting ERNs

Improving ORPHAcodes



Research setting: Implementation, exploitation



> **RD-CODE**

- > ORPHAcodes (and ORDO) are a core standard for RD interoperability in the research setting
 - ★ ERNs' registries: data capture from eHR?
 - ★ Research infrastructures
 - ★ Need for mapping & agregation tools
- > Training for implementation, use and exploitation
 - ★ Train the trainers & training modules

The mission letter of Commissioner Designate for Health, Stella Kyriakides states:

*“We need to make the most of the potential of e-health to provide high-quality healthcare and reduce inequalities. I want you to **work on the creation of a European Health Data Space** to promote health-data exchange and support research on new preventive strategies, as well as on **treatments, medicines, medical devices and outcomes**. As part of this, you should **ensure citizens have control over their own personal data**.”*

- Data exchange for cross-border care
 - **ePatient Summary**
 - ePrescription
- **Re-use of data** for research and innovation
- Data protection
- Support **MS** in their **digitalisation** efforts

A **common EU health data space** would enable secure access to different kinds of health data (Electronic Health Records, Genomic data, lifestyle/behavioural) for healthcare, research and innovation purposes, but also for policy making. This requires consideration of infrastructure, common standards and European approach to accessing health data sets. (*EHN new strategic priorities*)

eHealth Network CSS

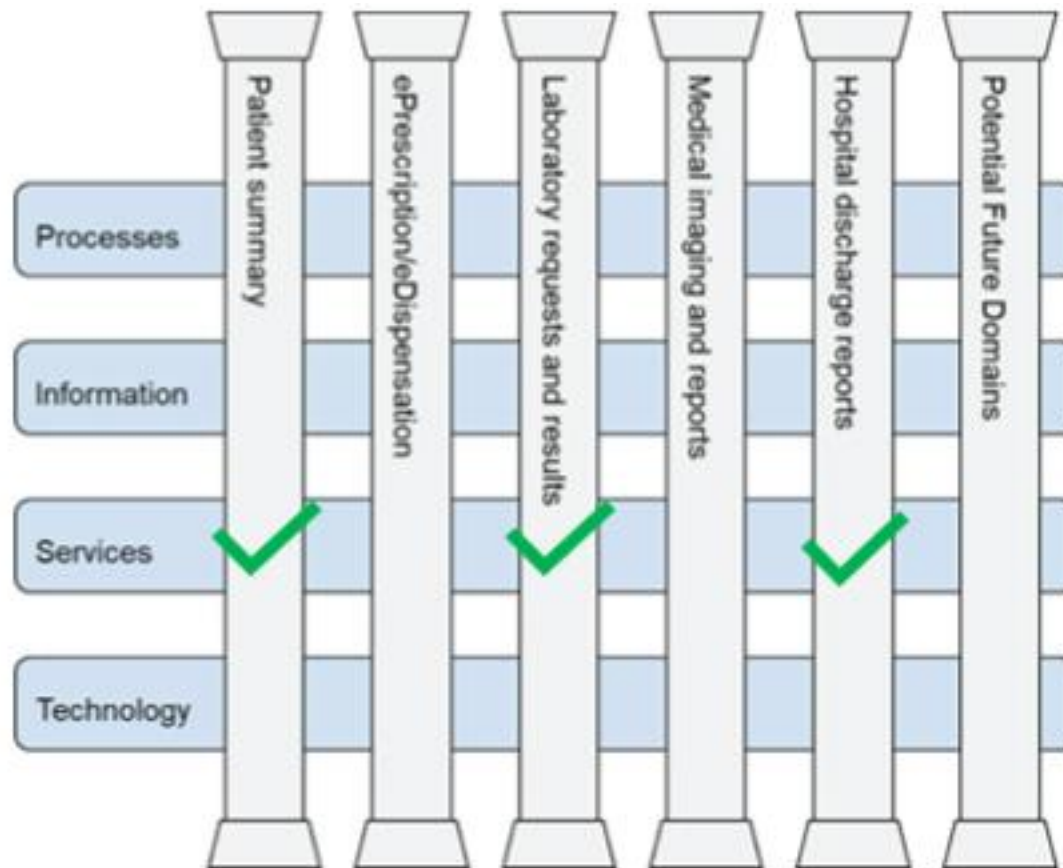


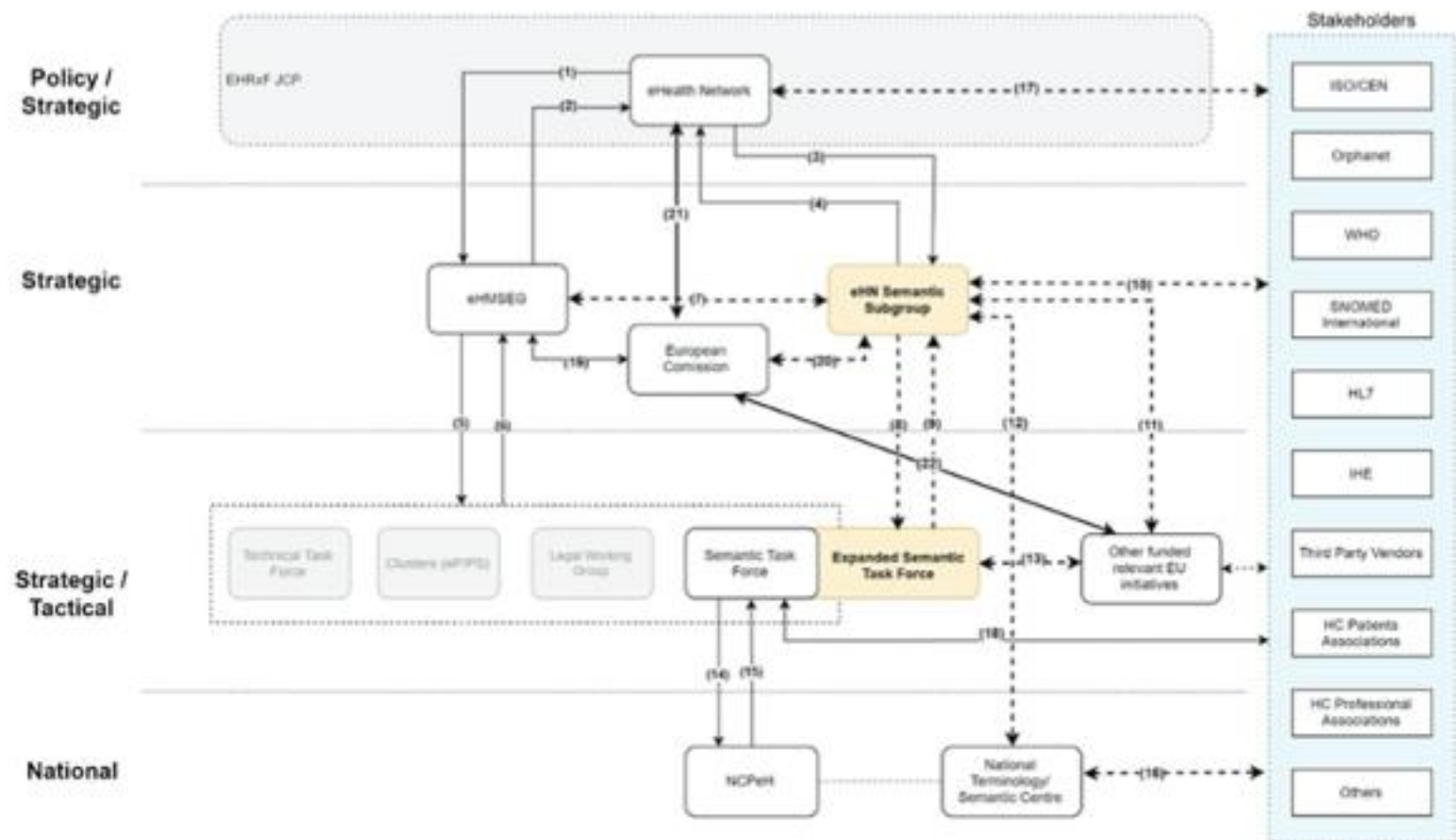
Figure 1 - Transversal health information domains among the semantic layers.

Examples of such services can be:

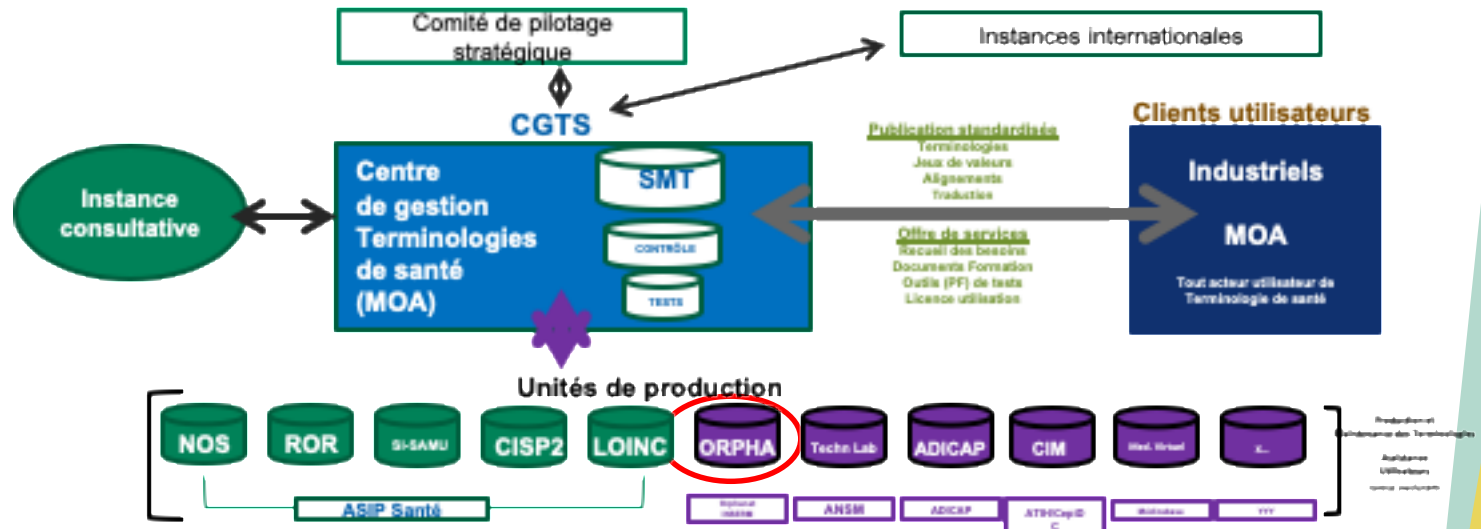
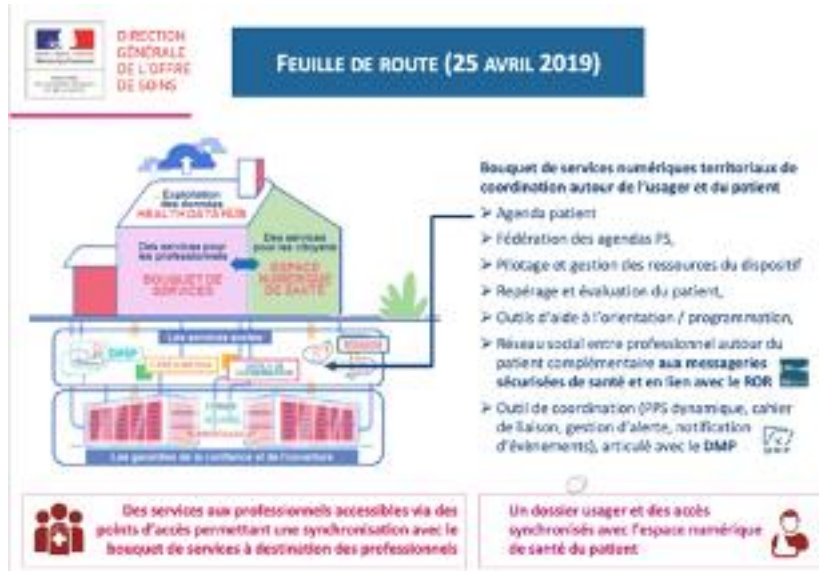
- Provision of a “Common European Network of Health Semantic Services” as a repository for standardised semantic assets
- Provision of testing tools and test plans, together with reference test data.

Rare Diseases in CSS

- As a specific field in ePS
- Orphanet as a stakeholder in governance framework

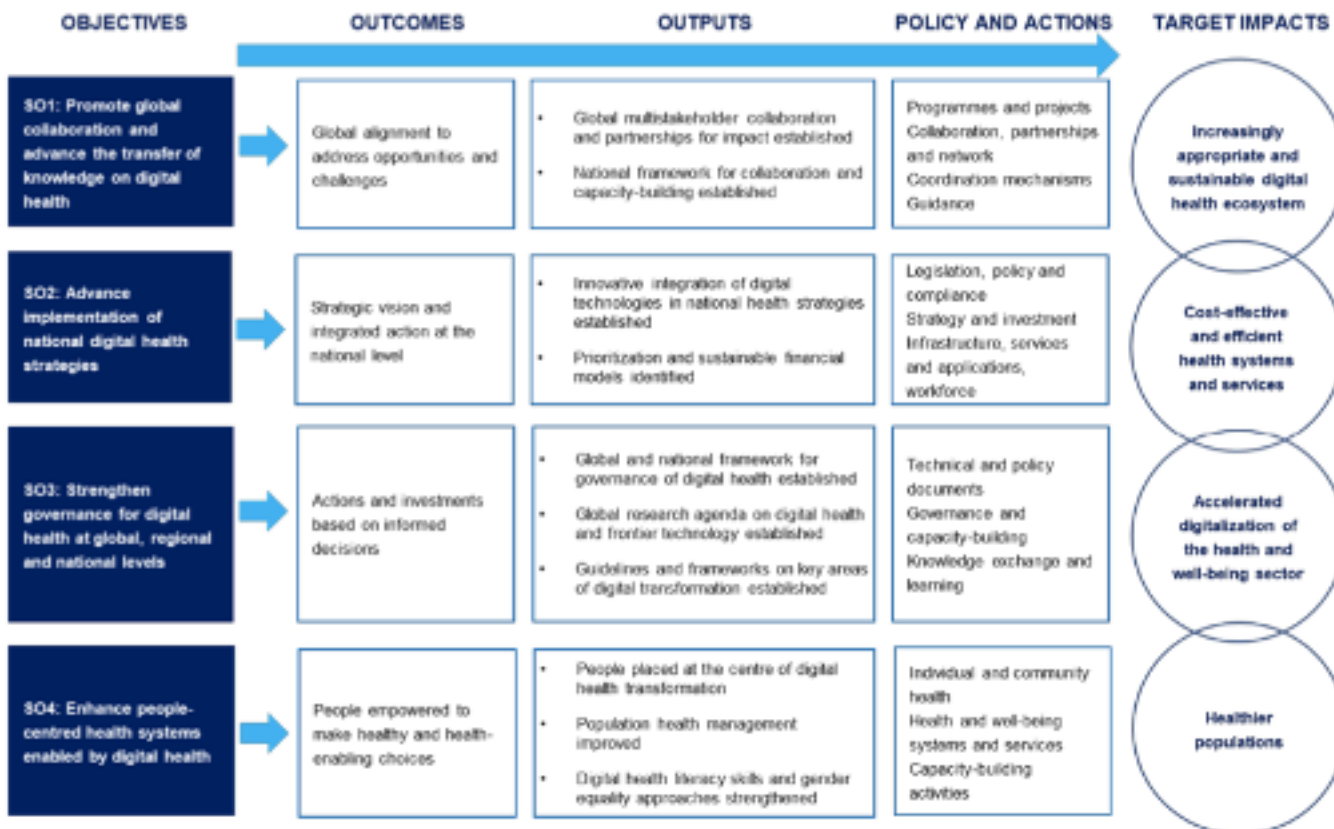


National digitalisation programmes



WHO Global strategy on digital health

Figure 1. Framework for action for the global strategy on digital health



<https://www.who.int/docs/default-source/documents/gS4dh0c510c483a9a42b1834a8f4d276c6352.pdf>

Hospital Alliances: to develop



We are building a network of children's hospitals across Europe to help member organisations improve the value and quality of the care provided to children and their families.



Barcelona - Berlin - Leuven - London
Milan - Paris - Rotterdam - Stockholm - Vienna

Discussions to start



How to capture undiagnosed patients from clinical records ?

RD-CODE: implementing Orpha codification in EU countries

THANK YOU FOR YOUR ATTENTION