

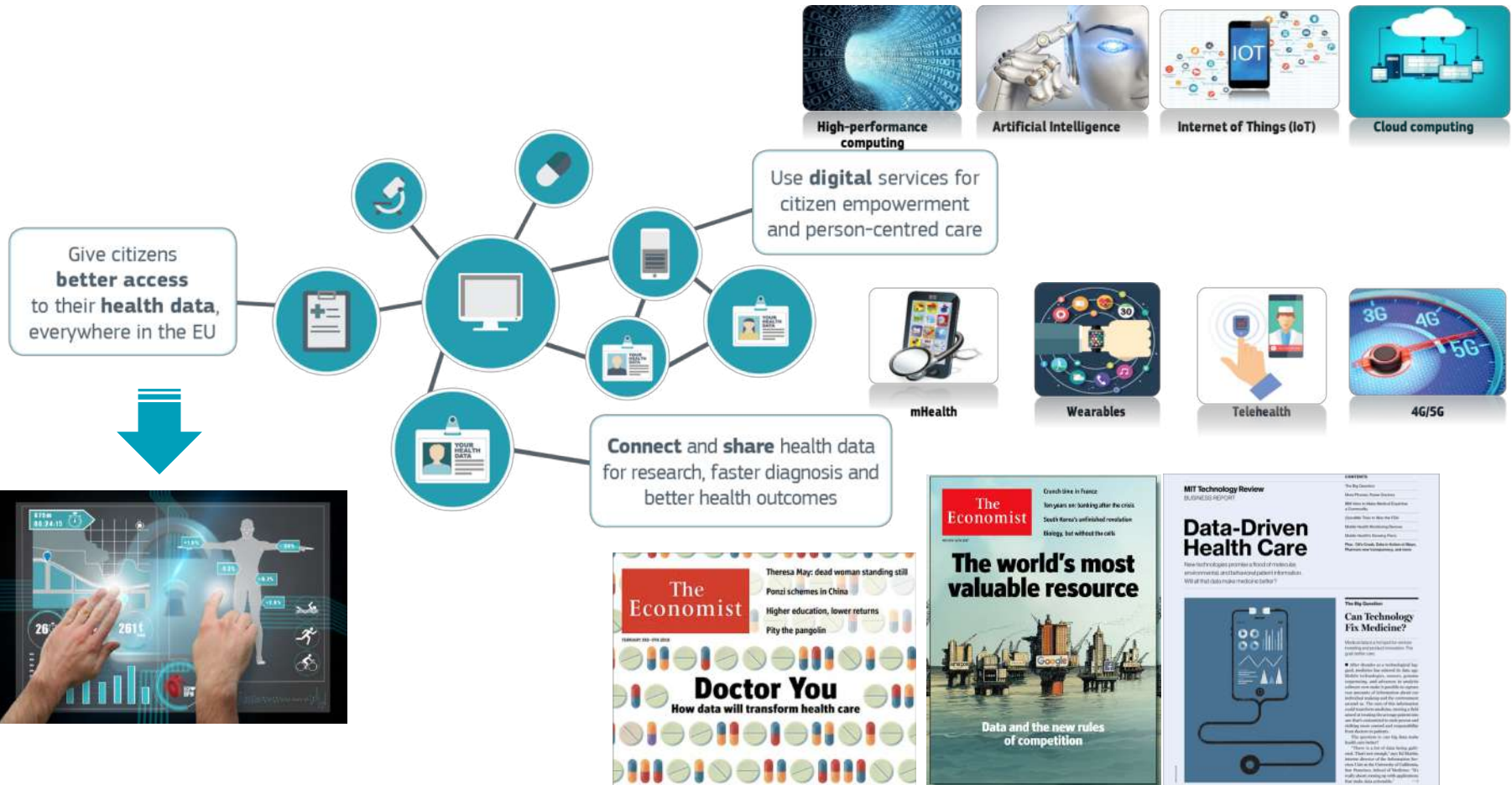


The Digital Transformation of Health and Care

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European Reference Networks
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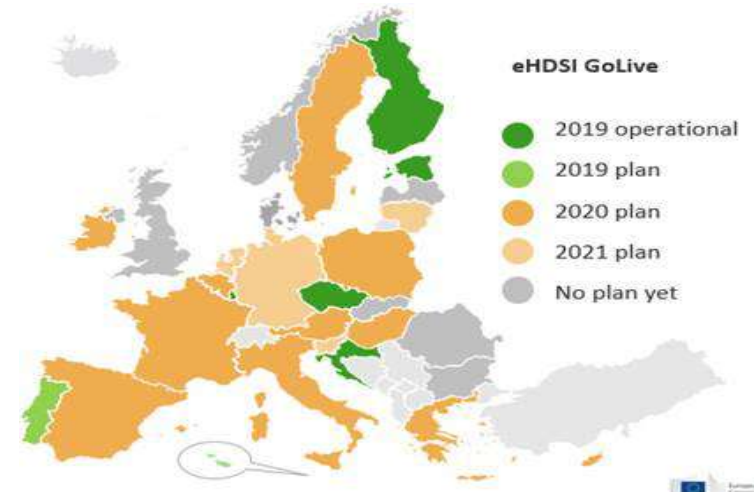
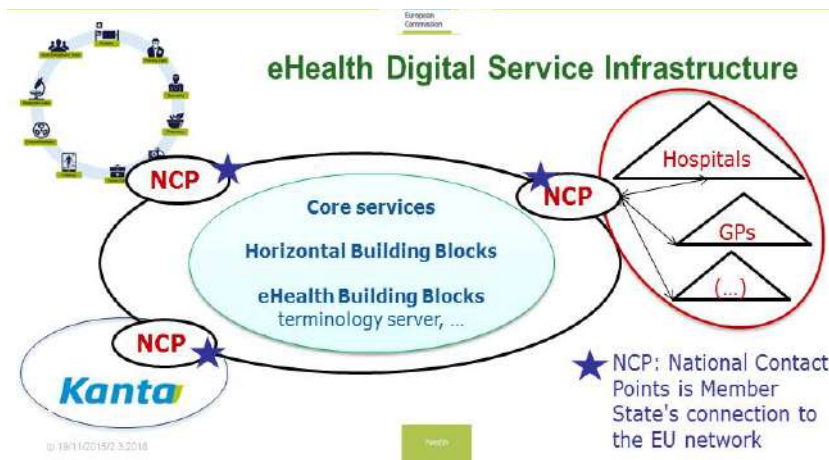
Digital Transformation of Health and Care



eHDSI: Better citizens' access to their health data

The eHealth Digital Service Infrastructure (eHDSI) enables exchange of patient data across borders

- **Patient Summary** provides access to health professionals to verified key health data of a patient during an unplanned care encounter while abroad
- **ePrescription** enables patients to receive equivalent medication while abroad to what they would receive in their home country





Recommendation on a Electronic Health Record exchange format

A framework for the further development of a European EHR exchange format

- ❑ **Principles** governing the access to and exchange of EHRs across borders
- ❑ **Common technical specifications** for the cross-border exchange of data
- ❑ **Joint Coordination Process** for the development of the European EHR format



Recommendation on a Electronic Health Record exchange format

Common technical specifications (baseline)

- ❑ Initial set of **health information domains**: patient summaries, ePrescriptions, laboratory reports, medical images and reports, and hospital discharge reports
- ❑ Common list of **interoperability specifications** (existing standards and profiles)
- ❑ **Incremental and selective approach** for adopting, refining, and maintaining the specifications of the European EHR exchange format

Pooling health data for research and personalised medicine

Declaration for delivering cross-border access to **genomic database**



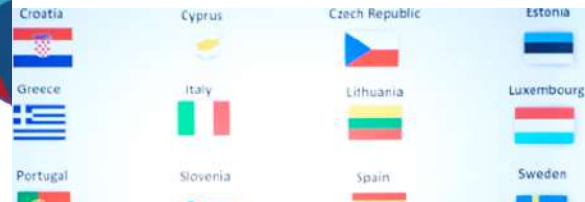
1 million **genomes accessible** in the EU by 2022



Linking access to existing and future genomic database across the EU



Providing a sufficient scale for **new clinically impactful** associations in research



IMPACT OF GENOMICS ON HEALTH

IMPROVING CANCER TREATMENT

LOUISE

Louise has a long family history of breast cancer. One day, she heard on TV that the BRCA1 and BRCA2 genes' mutation increases the risk of breast cancer by up to 80%. Although it turned out that she doesn't have this particular gene mutation, her risk of developing the condition is still high due to her family history. In order to detect early potential breast cancer, she started breast cancer screening at age 35, much earlier than the usual recommended routine screening (at age 50).

A few years later, Louise developed breast cancer. In order to determine the most suitable type of treatment, she underwent a genomic test predicting the risk of breast cancer recurrence and the need for chemotherapy. Test results showed that Louise would not have benefited from chemotherapy, so doctors opted for a more effective personalized treatment, which also prevented her from suffering the unpleasant side effects of chemotherapy.



IMPROVING PROGNOSIS FOR RARE DISEASES

MARTIN

In 2015 Martin was born in Dublin, Ireland. Doctors recorded an abnormally small head and face, as well as a slow development rate. Genome sequencing identified many possible candidates for the genes that were causing his slow development. However, a precise diagnosis would be needed to start treatment.

Launching a query through an EU federated platform facilitating matching of cases with similar phenotypic and genotypic profiles. This allowed his doctors to find a second case with similar symptoms and the same mutation in Spain, and therefore to reach an accurate diagnosis and treatment for Martin's condition.



PREVENTION OF COMMON AND COMPLEX DISEASES, INCLUDING PHARMACOGENOMICS

JUSTYNA

Justyna heard about the ongoing biobanking project in her country in the media, so she read more about the genetic risks of certain diseases. Her healthcare provider recommended her to take the polygenic risk score (PRS), which was just introduced as a new clinical trial in the university hospital. After a genetic analysis, it turned out she belongs to the top 5% of the PRS for coronary artery disease (CAD). Drugs such as statins and other preventive measures lower the cholesterol levels in the blood and reduce the CAD risk. Now, Justyna has to avoid one specific statin which could increase her risk for muscle inflammation. This information made Justyna more aware of how to prevent CAD and make adjustments in her life style, as well as receive treatment and regular check-ups, if needed.



The 1+ Million Genome initiative



- Federated framework that would allow **secure** and **authorised** cross-border access to **genomic** and other **health data** across the EU, supporting **research, health care and prevention**.
- To allow users to search and access the data through a user-friendly and effective data governance structure **building on existing national and European initiatives**.
- To ensure that citizens, researchers and health systems in Europe can benefit from the full potential of genomics to **advance targeted health care interventions** leading to better **prevention, early diagnosis and treatment of diseases**



1+MILLION GENOMES



Genomics has the potential for determining future risk of disabling diseases such as cancer, chronic disorders of aging and neuropsychiatric pathology. Through genome sequencing, clinicians can improve personalised treatment, predict the susceptibility to disease and even prevent life threatening adverse reactions to medication. Currently 30-40 million Europeans are affected by rare diseases of which over 80% have genetic origin. Genome sequencing and complementary molecular analysis will in the future help tailor treatments and preventive health measures. When scientific expertise and data are pooled across borders, waiting 5-6 years for a diagnosis has the potential to become history.

SECURE AND AUTHORISED CROSS-BORDER ACCESS TO GENOMIC AND OTHER HEALTH DATA IN THE EUROPEAN UNION IS NECESSARY TO:

- advance the understanding of genetic associations that cause or predispose complex diseases
- learn to identify cancer in a much earlier stage, improving preventive options
- identify new target genes for the development of new target drugs in less time
- strengthen the effectiveness of prevention by improving the screening accuracy and reducing its costs
- improve patient outcomes and ensure sustainability of health and care provision in the EU
- contribute to investments, economic growth and jobs.

COUNTRIES AGREED TO COOPERATE IN LINKING GENOMIC DATA ACROSS BORDERS:

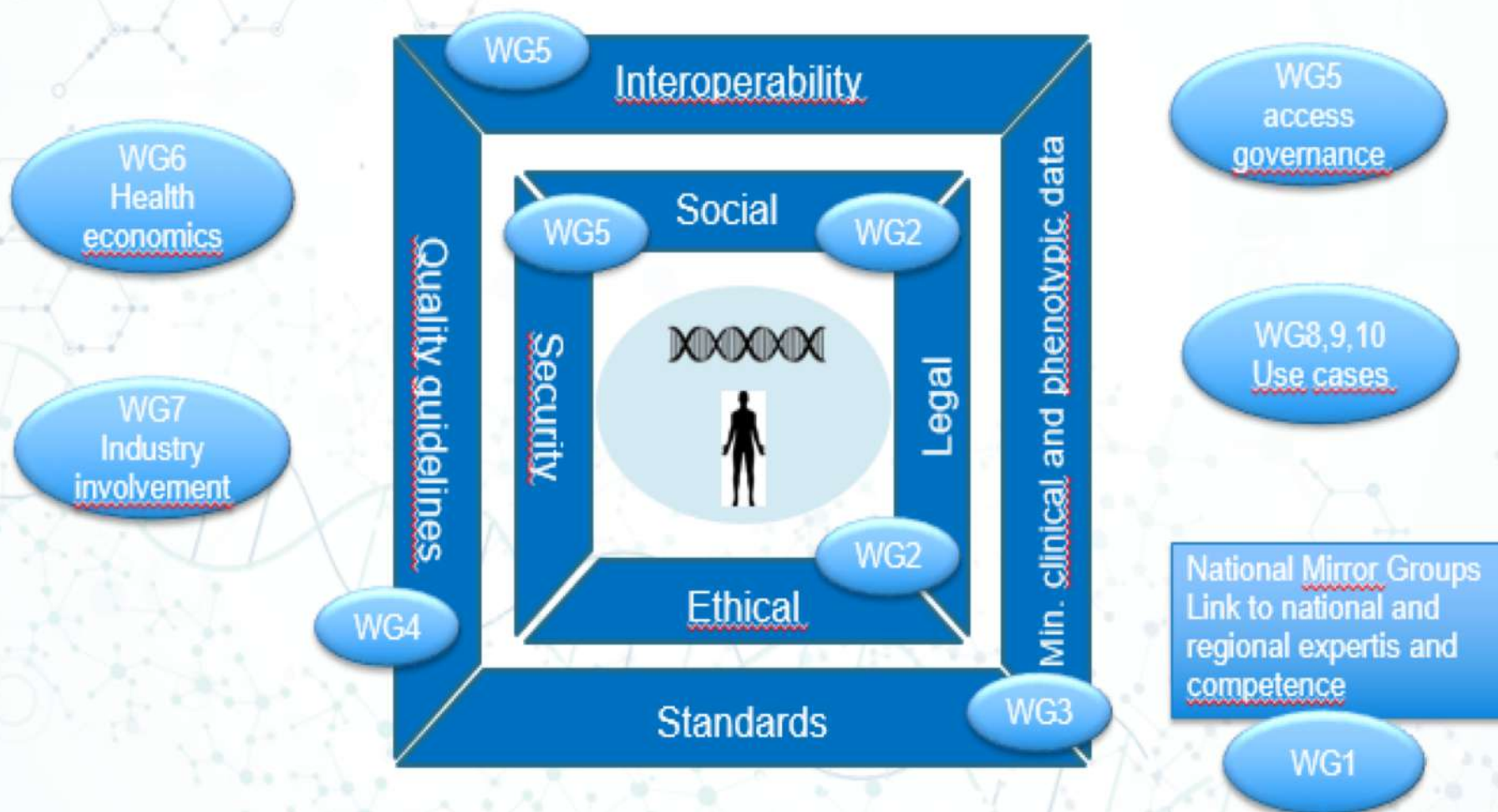


The initiative is open to Member States of the European Union, the European Economic Area (EEA) and the European Free Trade Association (EFTA) and it is facilitated by the European Commission.



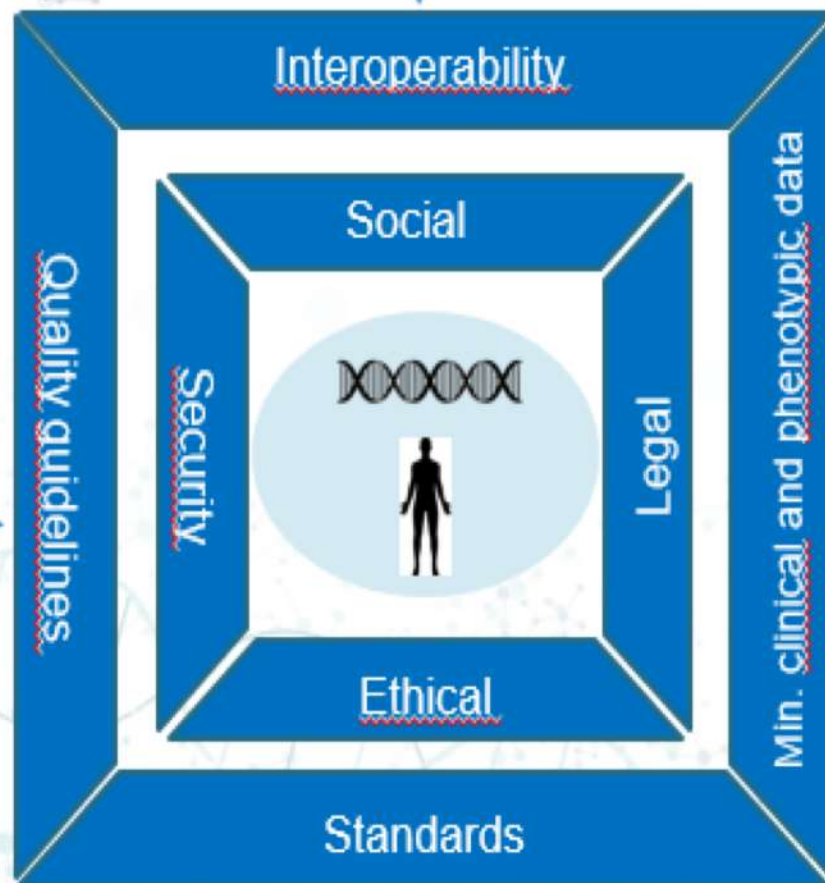
A common framework for federated cross border access

- A challenging task – working groups



Join forces!

1+MillionGenomes linking National clinical genomics initiatives



ICPerMed



Global Alliance
for Genomics & Health

European Alliance for
Personalised Medicine

GACD

EUROPEAN MEDICINES AGENCY
SCIENCE. MEDICINES. HEALTH.



EUROPEAN JOINT PROGRAMME
RARE DISEASES

European
Reference
Networks
Electronic
Health Records



imi
innovative
medicines
initiative

EOSC-Life



EU Can

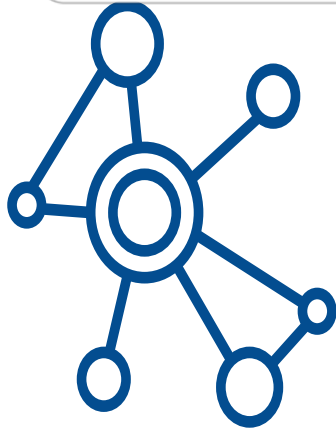


Canada-EC Joint Health
Data Flagship Collaboration

24 Networks



European
Reference
Networks



26 Countries



> 300
HOSPITALS

Full
Member

Affiliated
partner



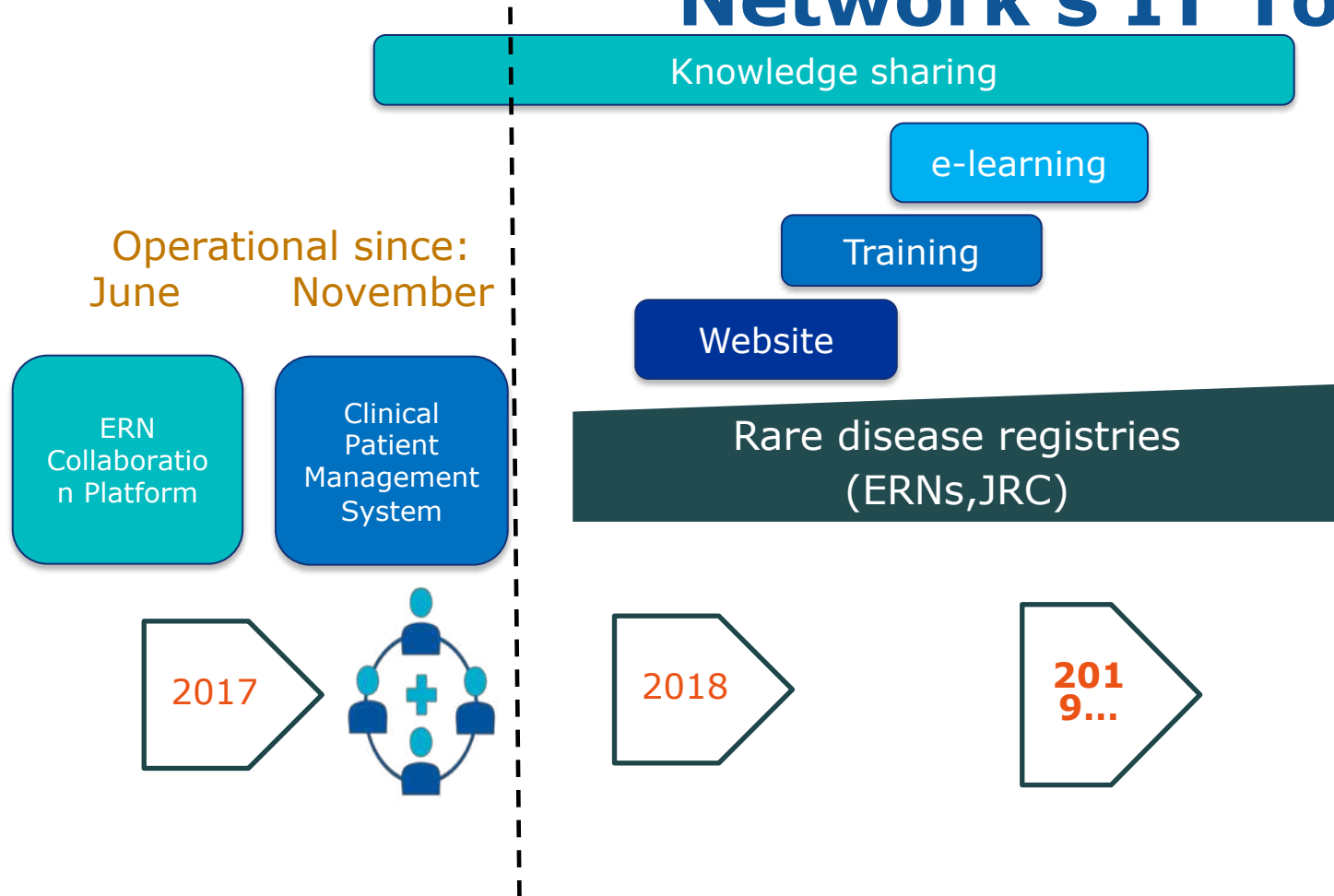
> 900
HEALTHCARE UNITS



CEF
programme

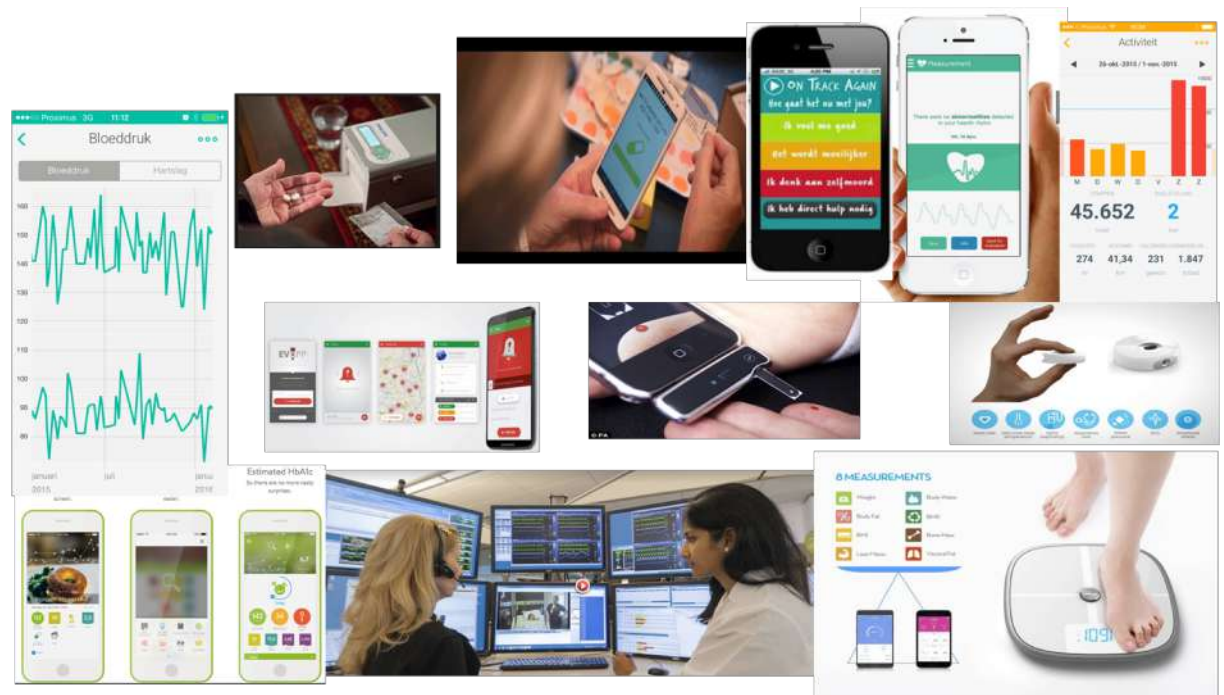


European Reference Network's IT Tools



Digital tools to foster citizen empowerment and person-centred care

By allowing feedback communication and interaction between users and health care providers, digital solutions can improve quality of services and better planning/management by healthcare systems.



AI – converging intelligences

Clinical applications

- **Radiology, pathology, Dermatology, Ophthalmology, Cardiology, Gastroenterology, Mental Health**

Health systems applications

- **Risk of readmission, risks of sepsis or septic shock, machine vision and microsurgery, wearables for continues monitoring, efficiency gains in workflows**

AI and patients

- **Medical adherence, digital twins, predict glycemic responses**

The European Strategy on AI



The new EU initiative on AI



Declaration of Cooperation on Artificial Intelligence for Europe, 10 April 2018

Commission Communication on Artificial Intelligence for Europe, 25 April 2018

Coordinated Plan on Artificial Intelligence, 7 December 2018

First draft of the European AI ethics guidelines, 18 December 2018

Publication of Ethics guidelines for trustworthy AI, 8 April 2019

Future proposal?
– needs of regulators ?

European Health Data Space

- space for sharing data safely accross borders, for treatment, research and public policy
- linking information accross the EU
- strict respect of data protection
- strong (public) governance
- cooperation between public-private
- funding – DEP

- Finish model?

European Health Data Space

Share data for better health, new therapies and better policy making

- Strong governance
- Build upon the existing infrastructures
- Primary and secondary use of data



Digital health 2021-2027

MFF under negotiations by co-legislators



*Digital Europe Programme
and Connecting Europe Facility*



Horizon Europe



*European Social Fund +
and European Globalisation
Adjustment Fund*



*European Regional
Development Fund*



Thank you!

DigitalSingleMarket@DSMeu
EU_Health@EU_Health



DG Health and Food Safety

http://ec.europa.eu/health/ehealth/policy/index_en.htm