



eStandards Roadmap for the collaborative development of standards for large-scale eHealth Deployment

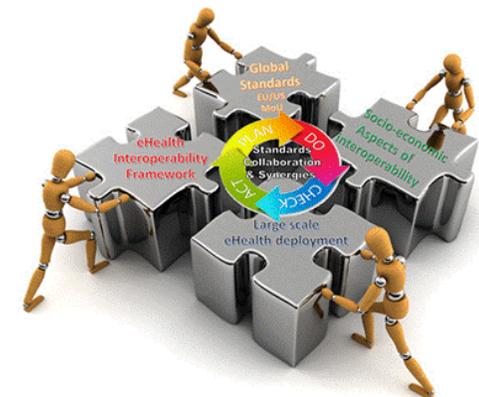
Health system	Workforce
Citizen	Market



eHealth
DSI



STARTUP
EUROPE



Health Informatics
TC251



SPMS
EPE
Serviços Partilhados do Ministério da Saúde

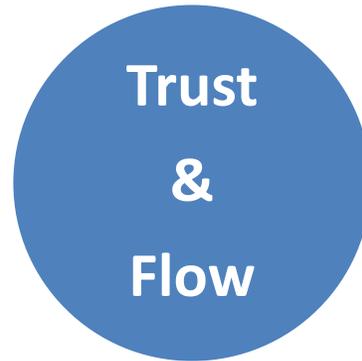
VIP Tour response

- What is the benefit of a Connectathon in
 - Design
 - Development
 - Deploymentof eHealth solutions?



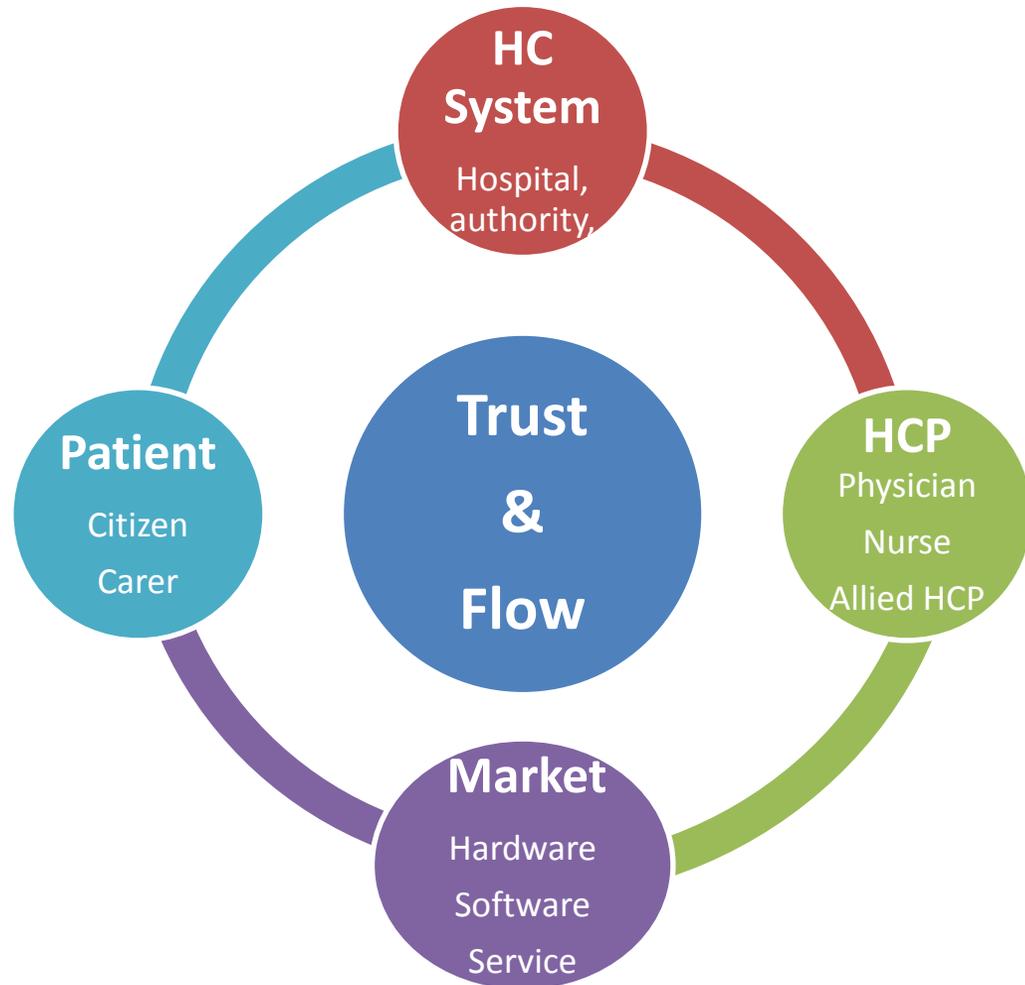
Overarching objectives of using ICT for healthcare across stakeholders

To build, nurture and maintain **trust in data**



To facilitate a **dynamic flow of data**

Trust and dynamic flow of data will be nurtured from four different perspectives



Henk's Personal Health Record today and tomorrow

Henk Today

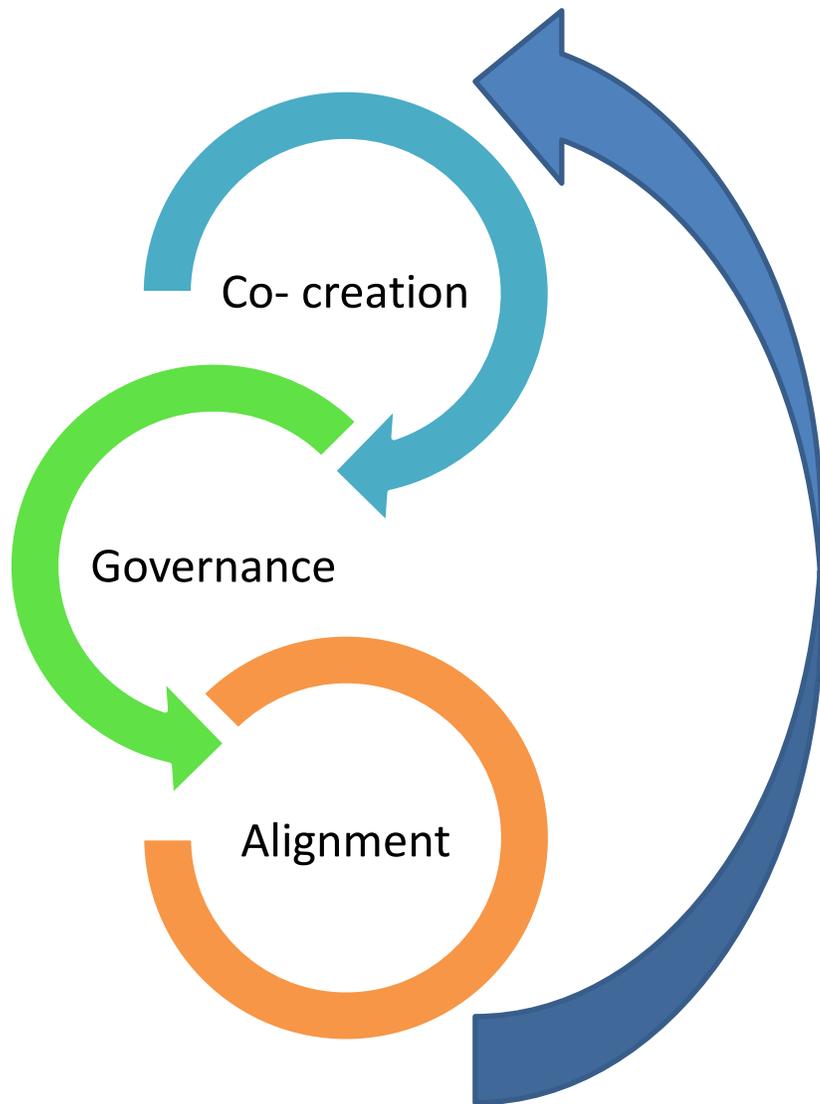
- Attends several health care professionals: lung specialists, cardiologist, physiotherapist, General Practitioner (GP) and pharmacist.
- Uses “Patients like me” PHR to store test results and personal measurements.
- Gets insights into his current health situation and how it develops overtime.
- Uses PHR during his regular consultations with health professionals.
- Can authorize professionals to access his PHR but only his GP uses this facility.
- Can assemble his care team, which is something care providers really have to get used to.
- Today Henk is generating a summary of his health measurements to take with him on consultations.

<https://www.youtube.com/watch?v=4U0pil-2fgo>

Henk imagines the perfect PHR

- PHR tailor-made to his health needs and lifestyle.
- Medication data be added automatically to his PHR.
- Link between his medication use and the effect it has on his health and wellness.
- PHR be continually improved and re-adjusted to his changing health needs.
- Clearly view how he can affect his health through physical activity.
- Daily activities along with his sleeping patterns entered directly in his PHR and related to his health indicators.
- Get an integrated view to set and achieve health goals.
- Summary offers a complete picture of his medical situation.

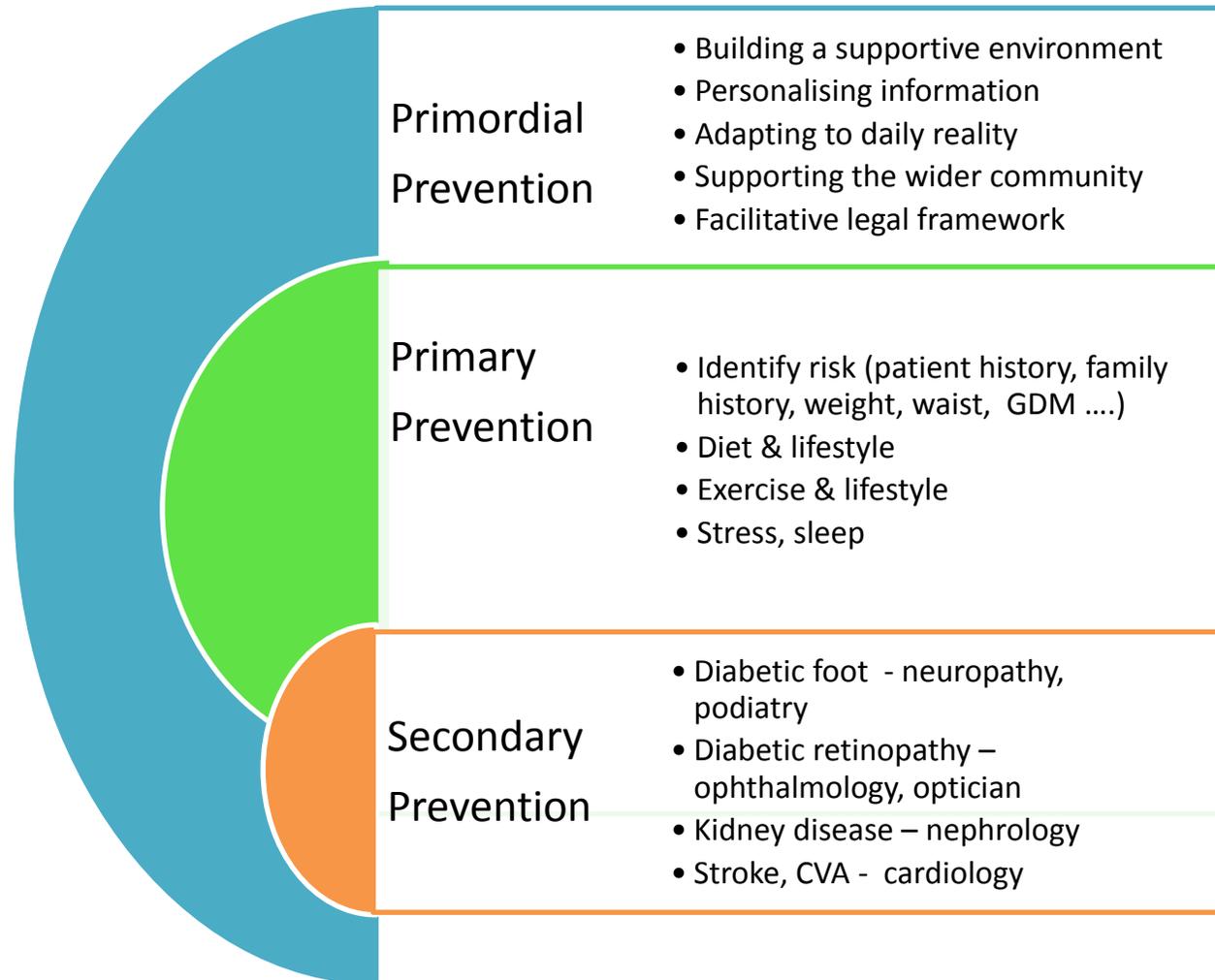
Different types of activities are needed



To develop standards sets which are properly adapted to a dynamic healthcare system, we need a constant flow of interaction between three types of activities:

- **Co-creation** between all relevant stakeholders
 - to make it *real* using standards
- A supportive and appropriate **governance** system
 - to make it *scale* toward large-scale deployment
- The flexibility to **adapt and align** as needs and requirements change
 - to make it *stay* in a sustainable way

Chronic disease management - using diabetes T2 as an example



Guidelines, protocols, and disease specific datasets have been developed mainly for Secondary Prevention – the regular checkup.

More recent initiatives focus on Primary Prevention in a population that has been identified.

But to really help them we need to ensure the environment in which they live can really support them.

This requires close collaboration between all groups of stakeholders represented in the four perspectives.

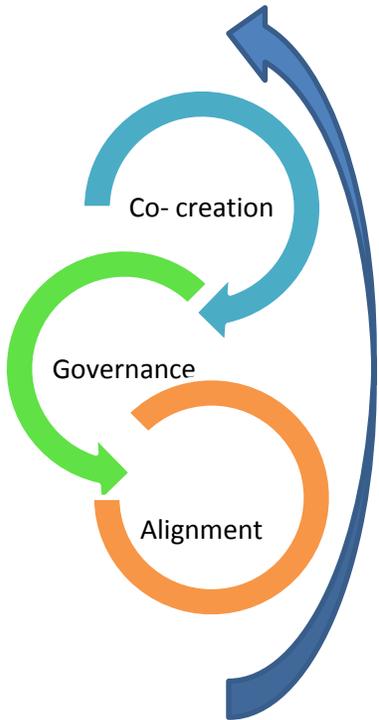
eStandards to support Chronic Disease Management

Need ?

- Extended Patient Summaries with disease specific indicators for primary / secondary prevention
- Quality of life indicators and active support in keeping up a healthy lifestyle
- Contextual data sets and triggers to support technologies for engaging with the care network and capturing the relevant data “on the fly”
- Incentives to invest in open and standards-based technologies to foster innovation in personal support and collaboration
- Coordination with European patient registries to drive further research on risk factors, early warning, and prevention

Use or Reuse ?

To be Developed



European Reference Networks for Rare Diseases



Share. Care. Cure.

- Treating patients from other Member States
- Supporting research and contributing to scientific findings.
- Rare Disease - fewer than 1 in 2,000
- EU 30 Million people affected by 6000 diseases
- In 2017 - 24 ERNs bringing together over 900 centres

Collaborative Platform

- online communication
 - document management
 - event organisation
 - ready, secure access
- NOT to exchange clinical patient data

Clinical Patient Management System

- Register the patient enrolled into an ERN consultation; confirm and record the patients' consent
- Share clinical, pseudonymised data on the patient; consultation process to arrive at clinical conclusions on diagnosis and treatment
- Archive the patient case data, forming the ERN patient register ; transfer data to research projects
- SaaS, pay-for-use

“We can expect many organisational, semantic and technical challenges”.

ERN Public Website

- Share knowledge with general public, patients and healthcare professionals

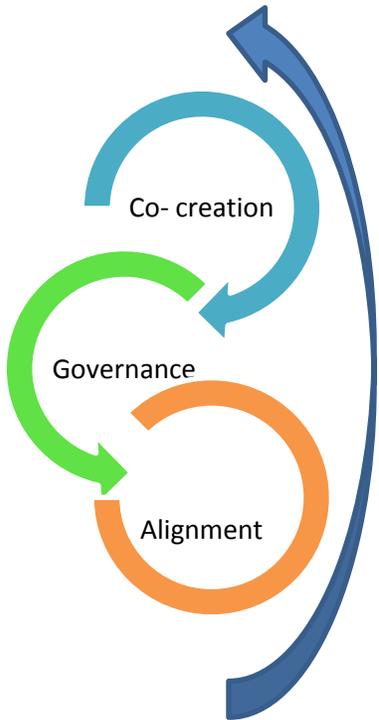
eStandards to support ERNs

Need ?

- Patient Summaries and shareable records, including free text
- Shared nomenclatures and
- Shareable images & lab results
- Stable and Secure video conferencing systems (registration, authentication , audit...)
- Dynamic consent system
- Shared governance and liability for ERN operations and its consequences
- Shared reimbursement calculations

Use or Reuse ?

To be Developed



The process to follow up on today

- The “To be developed” lists will provide the waypoints on which the Roadmap will be constructed, to which we will add the Patient Summary and the ePrescription topics
- We will circulate the lists among a broader audience for possible additions, refinements, and priorities
- We hope to get representation from all four perspectives, in order to better understand the different stakeholder needs in Co-creation, Governance, and Alignment
- We will cross-reference the recommendations and architectural artefacts from the Draft Roadmap, as well as the other eStandards deliverables
- The final Roadmap will be presented at the eStandards Conference, to be held in Brussels on June 26 and 27 2017.

Let's co-create the new digital culture for eStandards to advance and sustain large scale eHealth deployment



*Come join us to debate
eStandards
Brussels
26-27 June, 2017*

www.estandards-project.eu

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