eHealth Strategies and Roadmaps supporting European Reference Networks and rare disease policies

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work carried out in in cooperation with the EUCERD Joint Action for RD, the PARENT Joint Action for Registries, and EURORDIS

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Issue at stake

- Rare disease and e-Health policies and strategies addressed separately and largely without coordination to-date
- interoperability remains an important challenge for sharing data for care and for research
- Need to create convergence between the eHealth and the public health communities

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Policy context

Directive 2011/24/EU on the application of Patients' rights in cross-border healthcare promotes MS co-operation in health care on

- recognition of prescriptions (Art 11)
- ERNs (Art 12)
- Rare diseases(Art 13)
- eHealth Network (Art 14) and
- HTA (Art 15)

eHealth Network –priorities for cross border eHealth supported through CEF

- ✓ Cross-border patient summary service
- ✓ Cross-border ePrescription and eDispensation service
- ✓ eHealth services for European Reference Networks
- ✓ Infrastructure services for European patient registries

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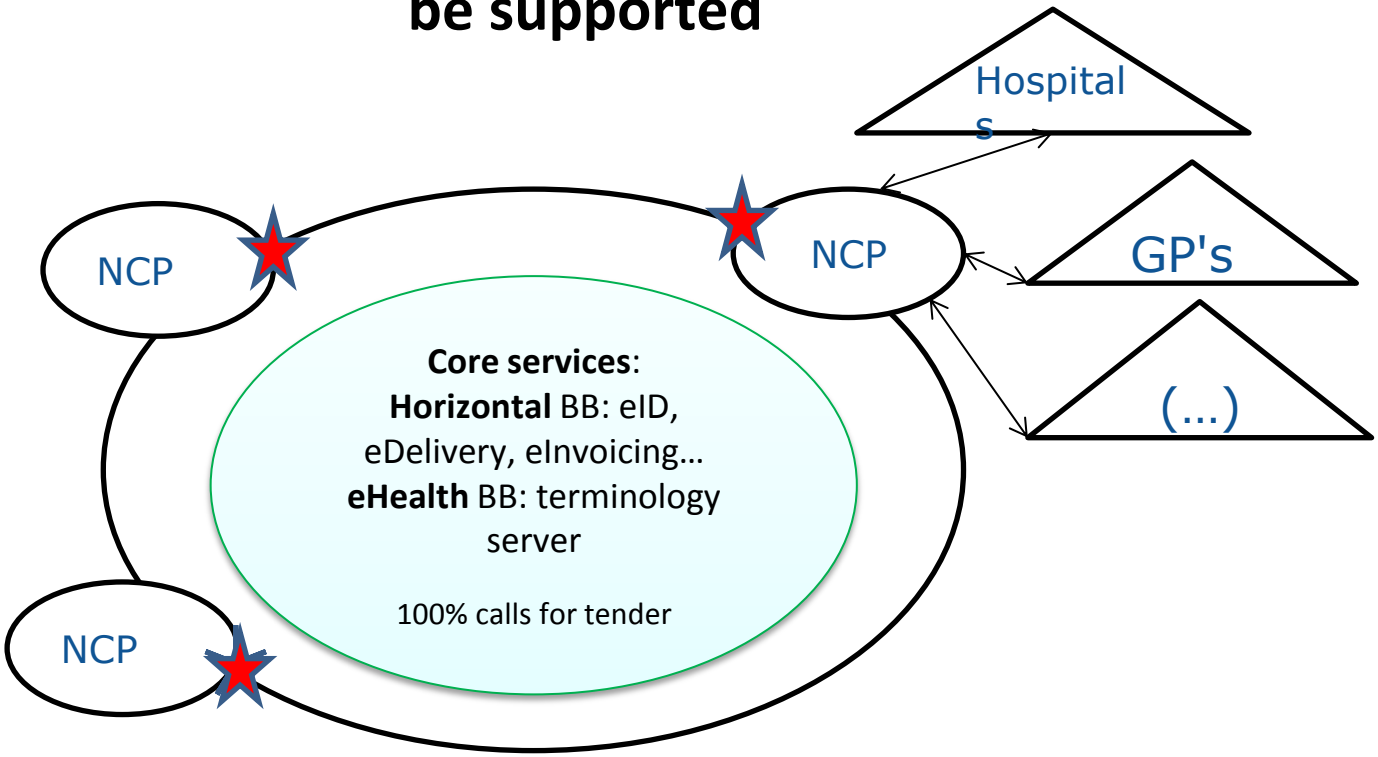
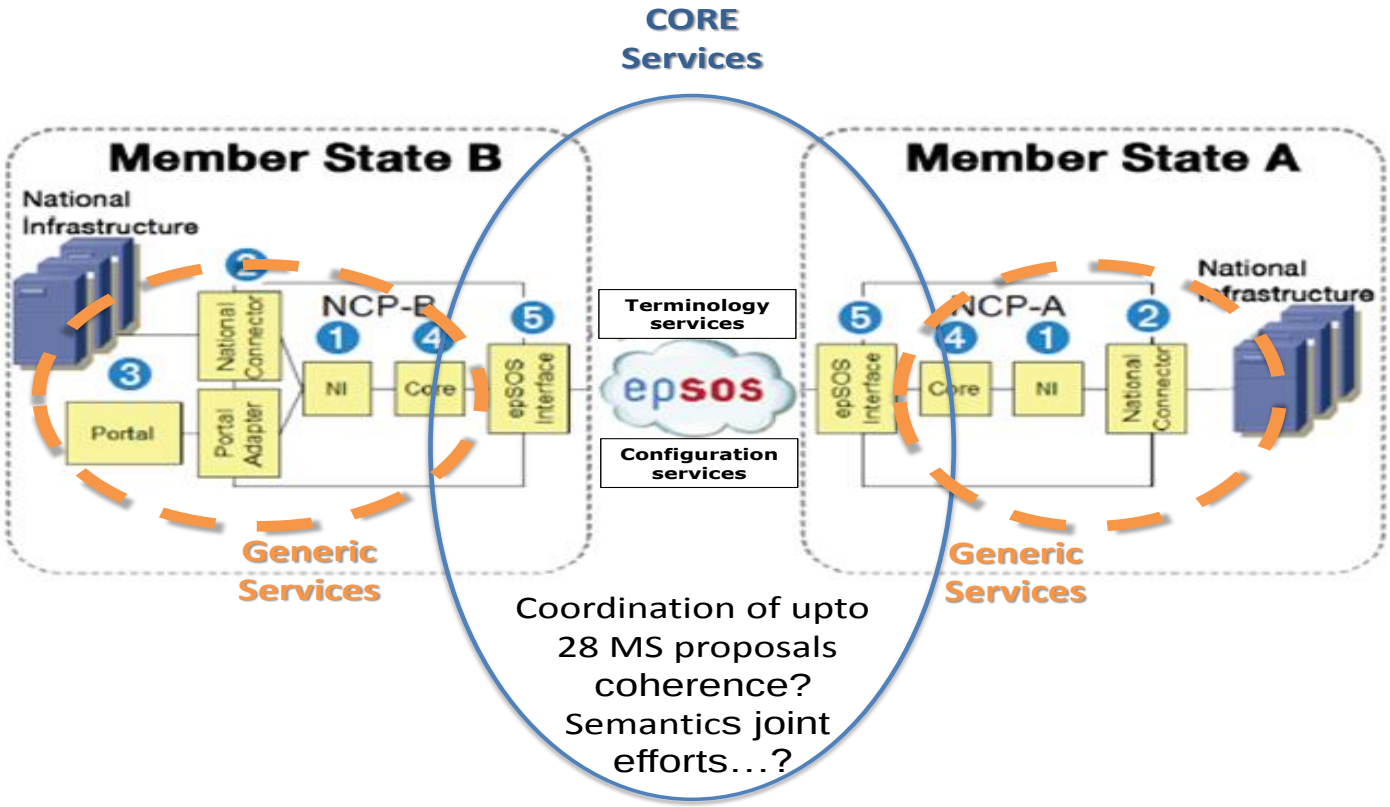
CEF: Description of eHealth DSI (Digital Service Infrastructures) to be supported



Generic services to be supported by CEF, 75% calls for proposal

BB: building blocks


CORE
Services
Member State B
National
Infrastructure
NCP-B
National
Connector
Portal
Portal
Adapter
NI
Core
epSOS
Interface
Terminology
services
epsos
Configuration
services
Member State A
NCP-A
epSOS
Interface
Core
NI
National
Connector
National
Infrastructure
Generic
Services
Generic
Services
Coordination of upto
28 MS proposals
coherence?
Semantics joint
efforts…?

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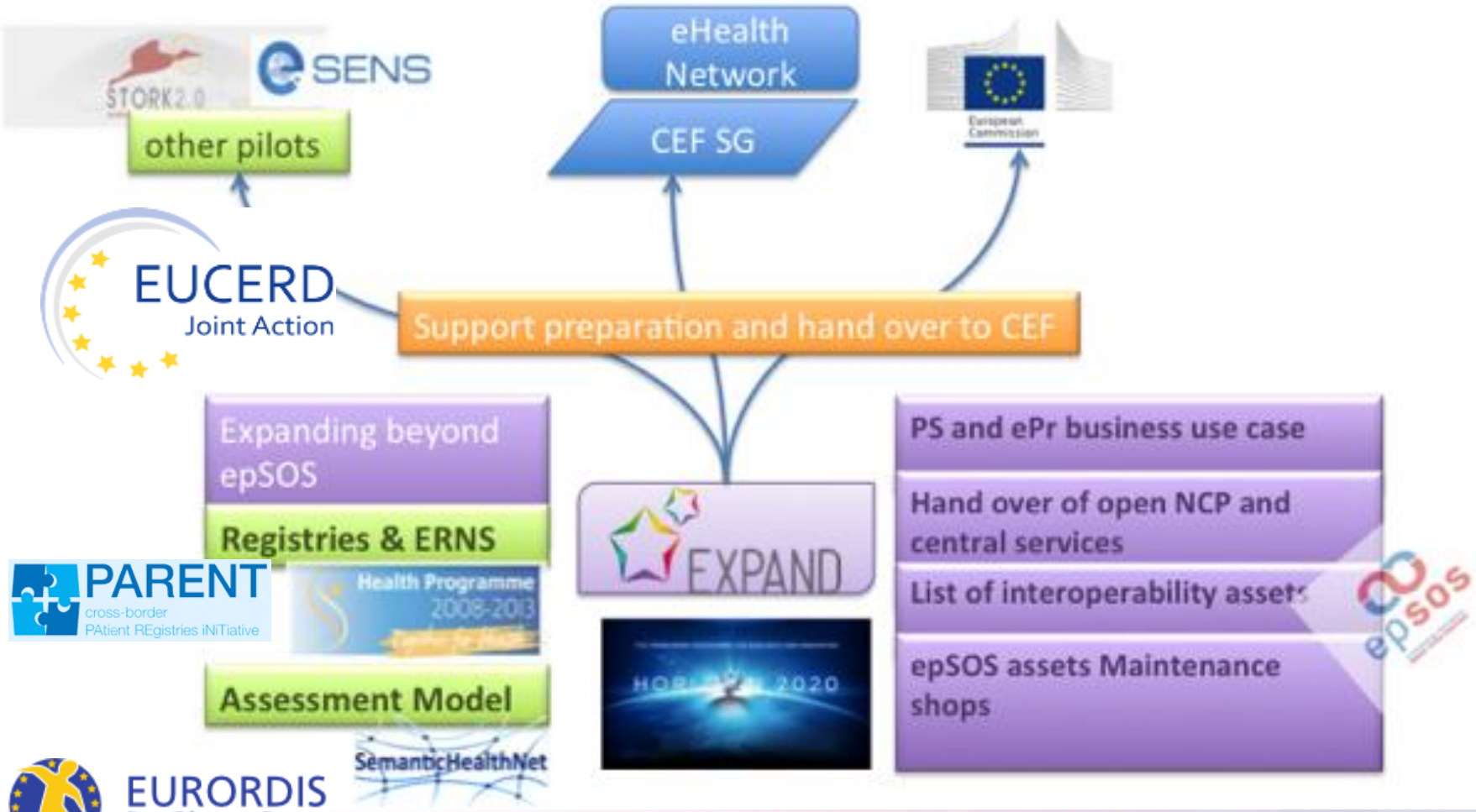
STORK 2.0
eSENS
other pilots
eHealth Network
CEF SG
European Commission
EUCERD
Joint Action
Support preparation and hand over to CEF
Expanding beyond epSOS
Registries & ERNS
Assessment Model
SemanticHealthNet
PARENT
cross-border
PAtient REgistries iNiTiative
Health Programme
2008-2013
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HORIZON 2020
PS and ePr business use case
Hand over of open NCP and central services
List of interoperability assets
epSOS assets Maintenance shops
epSOS
EURORDIS
Rare Diseases Europe
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Beyond cross border Patient Summary and ePrescription services

- Improve emergency care for RD patients, for example..

"RD specificities in the European Patient Summary may be envisaged as an extension of the current data set to include data elements necessary for identifying RD patients and for adequately conveying core information on rare conditions and treatments."

- From emergency care to planned care, supporting ERNs, for example..

"Supporting planned care through shared care records may be envisaged as an evolution of the Patient Summary service to address the needs of planned care, starting from selected diseases."

- Linking health care to research, for example..

"**Extending eID services** provided for Patient Summary and ePrescription needs, **to include the Global Unique Identifier for patients/research participants** which could allow clinicians and researchers to 'link' genome sequencing data with essential phenotypic information gathered in shared care EHRs. "

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Building on eHealth Digital Service Infrastructure for PS and ePr

It is sensible to assume that extensions of cross border eHealth DSIs will **need to demonstrate** that:

- there is a clear ***policy priority under Directive 2011/24/EU***;
- there exists an infrastructural need at a European level that addresses an ***important integration gap*** and will ***deliver real added value*** to the implementation of this policy if it is met;
- this integration functionality will **not** be provided through the services that the CEF already plans to deliver, and
- the additional interoperability services can draw on ***mature specifications and standards*** that have consensus acceptance within the user community.

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Open issues

- Current projects and Joint Actions
  - Will continue to support a certain level of co- operation e.g. joint workshops,
  - Will validate and publish an Exploratory paper
- New (homeless) needs
  - Identify appropriate candidate use cases for a possible extension of eHealth in the CEF 2016 programme,
  - if eHealth extensions will be included in the CEF 2016 work programme, ***a supplementary activity*** to prepare assets for these extended CEF services ***will become urgent,***
  - reflect on and deliver ***a proposal for a Roadmap of use cases and associated work elements*** necessary to address in a stepwise and prioritized approach the full span of cross border eHealth needs implicit in the Directive

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Thank you for your attention