ERN IT Platform – delivering the virtual link for the Networks

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Presentation will highlight

• Objectives of the ERN IT platform
• Where are we at with each of the components?
• Planning of the next steps?
Presentation focuses on
1) ERN Collaborative Platform
2) ERN Clinical Patient Management System
3) ERN Public Website
To support ERN collaboration activities:

- online communication
- document management
- event organisation.

~ NOT to exchange clinical patient data ~
- Ready for use
  - Welcome page
  - Members’ area for all ERNs
  - Specific area for each 24 ERNs

- User support
  - Demos, training manual online

- Secure access
  - User authentication (EU Login)
  - User authorisation to join Specific ERNs
• Introduce users to the platform
• ERNs to add content and develop the concept how to use the platform in the best way
• Promote use and collaboration
• Future releases: add necessary features
Clinical Patient Management System is critical for:
- patient care, diagnosis and treatment; and
- future clinical research.

The focus is first on diagnosis and treatment for patients by providing tools for collaboration, virtual consultations.
Building the ERN Clinical Patient Management System is a huge challenge.

No such multi-country clinical system exists yet.

We can expect many organisational, semantic and technical challenges.
Software as a Service – key parameters

- Planned delivery of the first version in July 2017
- Proven, working, existing software
- Sharing of clinical data, including medical imagery
- All the ERNs use the same system
- Commission will pay for active use (pay per use)
  - Monthly reports on actual use generate the invoice
  - Could stop paying for the service for non-use
1. Register the patient enrolled into an ERN consultation
   Confirm and record the patients’ consent
2. Share clinical, pseudonymised data on the patient
   Consultation process to arrive at clinical conclusions on diagnosis and treatment
3. Archive the patient case data, forming the ERN patient register
   Optionally transfer data to research projects
Each user needs an account in ERN Patient System
- The authorisation (right to access) is controlled by the ERNs
- Commission will technically implement the authorisation
- EU Login used, as for the Collaborative Platform

Support for users (help desk) in the Commission (DG SANTE)
• Working with ERN Coordinators' IT Advisory Group on elements common for all ERNs, such as
  • Referrals and patient workflow
  • One minimum standard patient dataset
  • Glossary of terms for the processes – communication

• Tight governance to focus on the essentials
  • All communication to the service provider of the ERN Patient System routed through the Commission
• The ERN Patient System is the priority of the development: to get it functional by mid-2017.
• 2 year period to test current solution, make an improvement plan and decide on iterative next steps
• Develop a strategy for patient data and registries to guide future development.
• Raise awareness of ERNs and their outcomes
  • Information about all the ERNs
  • Share knowledge with general public, patients and healthcare professionals
    • members, characteristics, evaluation, activity, etc.
  • Publish public deliverables of the ERNs
    • clinical guidelines, patient guidance, etc.
• Europa.eu website
  • Maintain the official ERN information
  • Links to all relevant websites

• ERN website(s)
  • Support for ERNs from the Commission through software tools and a possibility for hosting free of charge
  • Commission will provide visual elements and standard multilingual content