The ERN IT platform:
How the ERN Clinical Patient Management System (CPMS) works.

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Directive 2011/24/EU

Provide additional tools to Member States to:

- Facilitate greater interoperability of ICT systems in the healthcare field
- Support patient access to eHealth applications
- Avoid duplication of effort
- Mutual recognition or adaptation of [...] standards
- Provide a better evidence base for optimal use of new technologies
- Practical facilitating of cross-border provision of healthcare by health professionals
ERN Public Web
https://ec.europa.eu/health/ern_en
ERN shared info Links to ERN websites

ERN Collaborative Platform (ECP)
https://webgate.ec.europa.eu/ern/
ERN working spaces (restricted access)
• Latest news, activities, events
• Publications, discussions, documents,
• Agendas, polls, forums
CIRCABC
Video-conferencing

Clinical Patient Management System (CPMS)
https://cpms.ern-net.eu/login/

Patient registries
(JRC Rare Disease Platform; population registries; links with registries)

Performance Indicators (together with ERN Working Groups):
Activities
Key indicators

Released In development Out of scope
CPMS Users

Health professionals defined by Article 3(f) of Directive 2011/24/EU

- ERN Members
- EU Guest

Beneficiaries:
- Patients
- ERN healthcare professionals
- Other healthcare professionals
- Researchers
Clinical Patient Management System (CPMS)

**CPMS Version 1:**
- Released 20 November 2017
- [https://cpms.ern-net.eu/login/](https://cpms.ern-net.eu/login/)
- One glossary of terms for processes
- Set of generic common data elements
- Single referral and workflow
CPMS Workflow

Part I: Patient enrolled and consent registered
Identifying data, enrolled at patient’s treatment Centre

Part II: Consultation/Assessment/Conclusions
Sharing pseudonymised data to arrive at conclusion

Part III: Close/Patient Register/Research
Transfer de-identified, anonymised data
CPMS Key Functionalities (1/2)

- Secure exchange of data
- Crossover between ERNs
- Database/Reporting
- KPIs
- Customised datasets
- Data transfer for research
- IHE – data transfer from hospitals
CPMS Key functionalities (2/2)

- Medical Image Viewer
- Real-time & off-line communication
CPMS- 4 Steps before using CPMS

1- Use a verified log in
   • authenticated by EU Login

2- Request access to use CPMS
   • authorised by ERN Coordinator

3- Train in CPMS Training (No patient Data)
   • [https://cpms-training.ern-net.eu/login/](https://cpms-training.ern-net.eu/login/)
   • Use training accounts

4- Consult CPMS documentation and videos
   • CPMS start page (webinars, user manuals)
CPMS major improvements since launch

- Workflow flexibility: back and forward options
- Activity report for Coordinators
- Priority flagging urgent clinical cases
- Request for additional data box
- Copy a panel (for same patient)
- Customised data sets (e.g. ERN-EYE, TRANSPLANT-CHILD)

https://cpms.ern-net.eu/login
CPMS major changes planned

- **December 2018:**
  - Medical Viewer improvements

- **February 2019:**
  - PDF Generation of consultation form
  - Panel manager role
  - Usefulness metrics
  - Scheduling and agenda Setting

- **2019:**
  - Viewer ERN Histopathology Task Force (viewer, standards)
  - Working with hospitals for data exchange
    - IHE
    - DICOM
  - Customised datasets for ERNs under analysis
    - EuroBloodNet, EURACAN, eUROGEN
Report on CPMS Activity:
Users
End October 2018

- **1085 Registered users**
- **674 Active users since Nov. 2017**
  (A user who have logged at least once in CPMS)

<table>
<thead>
<tr>
<th>Country</th>
<th>Registered users</th>
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<tbody>
<tr>
<td>Austria</td>
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<tr>
<td>United Kingdom</td>
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</table>
Report on CPMS Activity: Panels
End October 2018

- 267 Panels created (at various phases of aborted, deleted, open, panel selection, assessment, sign-off, closed and archived)
- 89 Panels closed or archived
CPMS Useful Links

Learn!  CPMS Training (see videos after log in):
https://cpms-training.ern-net.eu

Use!  CPMS Production:
https://cpms.ern-net.eu/login/

Inform!  CPMS Overview Video:
https://webgate.ec.europa.eu/ern/imgs/cpms%20overview.mp4

Ask!  CPMS Support:
SANTE-ERN-CPMS-ITSupport@ec.europa.eu
Conclusions & A Coordinator's view

- CPMS is an excellent tool and opportunity with high potential once further tailored to respective needs

- **ERN PaedCan Mission:**
  NO child dies of cancer in Europe!

- **ERN PaedCan Vision:**
  Every Child with Cancer in Europe will be presented to a tumour board: local or virtual via CPMS!
Conclusions & A Coordinator's view

- All patients in Europe with rare disease
  - have access to **early and correct diagnosis** supported by experts on CPMS
  - are guided early to therapeutic interventions based on **European guidelines to secure better quality of life and improved survival!**
  - Have **access to therapeutic standard of care and innovation** as indicated by expert panels
  - Have essential disease and therapeutic data captured in **adequately linked registries with CPMS being a resource to create evidence** and reach oversight on progress being made in Europe
Needs and steps ahead!

Member States

- to fully embrace the powerful ERN concept allowing information to travel rather than patients
- to recognise virtual advise as a high quality and state of the art health care intervention across Europe requiring personnel resources at HCP level
- to agree in an act of solidarity this patient centric approach and to integrate virtual care interventions in already existing CBHC compensation schemes between MS (enlarge the current scope of S2!)
- to realise that early and correct interventions based on CPMS including access to innovation are cost saving and prevent later higher costs in NHS when based on expertise as provided by ERNs!