



ERN Conference
21 November 2018



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

EC, DG SANTE Web

Institutional
Information

Clinical Patient Management System (CPMS)

<https://cpms.ern-net.eu/login/>

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

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

Training and e-Learning tools, e.g.
Webinars

Research tools: clinical trials, etc.

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/>
- One glossary of terms for processes
- Set of generic common data elements
- Single referral and workflow

CONSULTATION FORM

- Consultation Request ●
- Patient Information ●
- Episode Description ●
- Rare Disease Diagnosis ●
- Comorbidities
- Phenotype/Genetic Features and Biobanks
- Family History ●
- Health Behaviours
- Allergies and Other Adverse Reactions
- History of Past Illness and Disorders
- Special Treatment Intervention
- Surgical Procedures
- Transplantation History
- Medication Summary
- Others
- Medical Documents ●

European Reference Networks | ERN | DE01 - Charité Universitätsmed... | Centres ▾ ERN ▾ Map ⓘ ⚙️ 👤

Patient ID: ERN-de01-014 S, D DOB: 24/10/2014 (F) Enrolled: 15/Nov/2018

#922 Lucky luck

Centre DE01 - Charité Universitätsmedizin Berlin
Lead ERN RITA - Immunodeficiency, Autoinflammatory and Autoimmune Diseases

Open Panel Selection Data Completion Assessment Outcome Sign-off Closed

▲ If meeting "test" has finished please ensure meeting status is changed to finished and meeting summary is recorded. 🗨️

[Invite Members](#) [Schedule Meeting](#) [Request Additional Data](#)

CONSULTATION FORM RECORDED: 15/NOV/2018 14:03 (EUROPE/BERLIN) BY: MR. PAUL BURNS
EDITED: 15/NOV/2018 14:19 (EUROPE/BERLIN) BY: MR. PAUL BURNS

CONSULTATION REQUEST

- * Nickname: Lucky luck
- Is urgency required for this panel? No
- * Is this a repeat of a previous panel for the same patient but a different episode? No
- * Consultation request description short: Potential Noonan or Turner Syndrome in a 4-year-old female. History consistent but unusual fever and rash.
- * Consultation request reason: Diagnosis, Treatment
- * Consultation request reason description: ok
- Healthcare provider: DE01 - Charité Universitätsmedizin Berlin
- Point of care specialist: Nick
- * ERN: RITA - Immunodeficiency, Autoinflammatory and Autoimmune Diseases

TIMELINE

- 15/Nov/2018: Panel was copied by Mr. Paul Burns.
- 15/Nov/2018: The Panel is now in state "Panel Selection"
- 15/Nov/2018: The Panel is now in state "Data Completion"

Patient Documents

Created	Last Update
Document	15/Nov/2018

Additional data requested by	Created Date	Completed Date
Mr. Paul Burns	15/Nov/2018	15/Nov/2018
Mr. Paul Burns	15/Nov/2018	15/Nov/2018

Patient documents are being completed

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

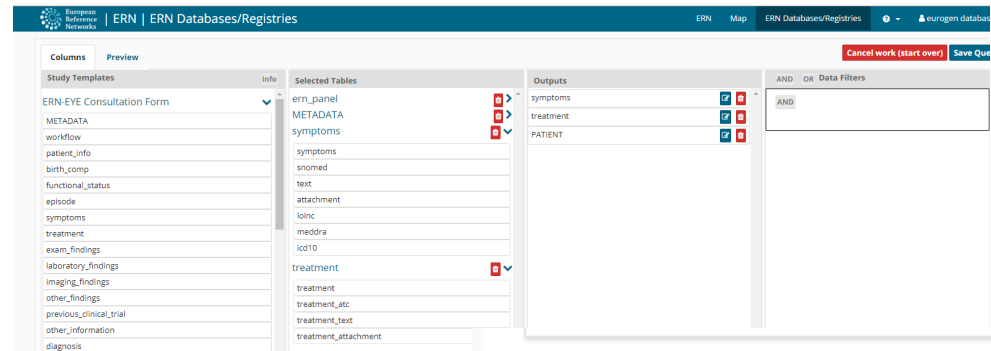
Part III: Close/Patient Register/Research

Transfer de-identified, anonymised data

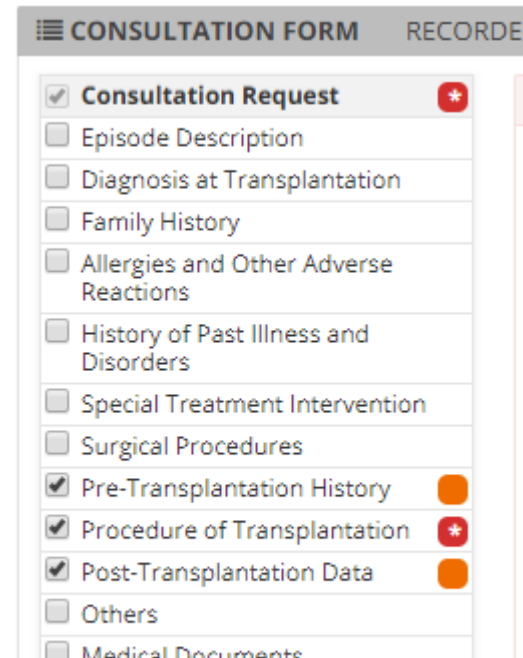


CPMS Key Functionalities (1/2)

- Secure exchange of data
- Crossover between ERNs
- Database/Reporting
- KPIs
- Customised datasets
- Data transfer for research
- IHE – data transfer from hospitals



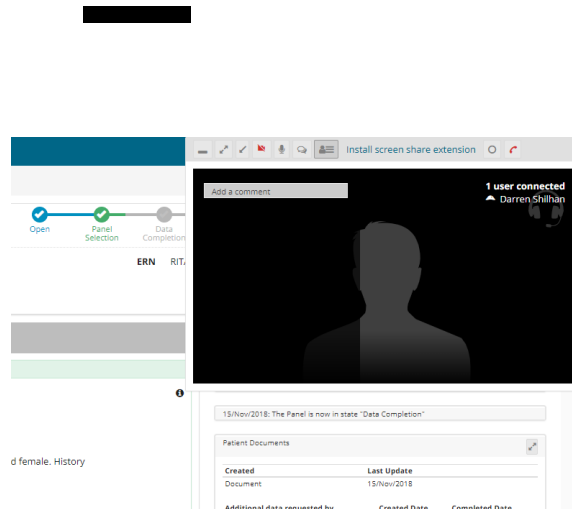
The screenshot shows the CPMS interface with the 'Columns' and 'Preview' tabs. The 'Columns' tab is active, displaying a list of study templates and selected tables. The 'Preview' tab shows a table with columns for symptoms, treatment, and patient information.



The screenshot shows the CPMS interface with the 'CONSULTATION FORM' section. The form is titled 'CONSULTATION FORM' and 'RECORDED'. It contains a list of checkboxes for various consultation request items, including 'Consultation Request', 'Episode Description', 'Diagnosis at Transplantation', 'Family History', 'Allergies and Other Adverse Reactions', 'History of Past Illness and Disorders', 'Special Treatment Intervention', 'Surgical Procedures', 'Pre-Transplantation History', 'Procedure of Transplantation', 'Post-Transplantation Data', 'Others', and 'Medical Documents'.

CPMS Key functionalities (2/2)

- Medical Image Viewer
- Real-time & off-line communication



TIMELINE

- 06/Nov/2018: A new Panel was started by Francesco Rotolo.
- 06/Nov/2018: The Panel is now in state "Panel Selection"
- 06/Nov/2018: The Panel is now in state "Data Completion"
- 06/Nov/2018: The Panel is now in state "Panel Selection"
- 06/Nov/2018: The Panel is now in state "Data Completion"
- 06/Nov/2018: The Panel is now in state "Assessment"
- 06/Nov/2018: The Panel is now in state "Outcome"
- 06/Nov/2018: The Panel is now in state "Assessment"
- 06/Nov/2018: The Panel is now in state "Outcome"

Panel Members

Member	Status	Actions
Mr. Paul Burns	Lead	Invited: 06/Nov/2018
Magdalena Drozyńska-Duklas	Accepted	Invited: 06/Nov/2018 Accepted: 06/Nov/2018

Patient Documents

Created	Last Update
Document	06/Nov/2018

Contributions

Member	Status
Mr. Paul Burns	No contribution
Magdalena Drozyńska-Duklas	No contribution

06/Nov/2018: The Panel is now in state "Outcome"

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/>
- **Use training accounts**

4- *Consult CPMS documentation and videos*

- **CPMS start page (webinars, user manuals)**

Secure Login

You can Login to the CPMS ERN through the EU Login Authentication Service.

[Login via EU Login](#)

To use non-eulogin users, [click here](#) (test only).

- Video: Getting Set-Up and Logged In to CPMS
- Only ERN members and ERN guest users can be authorised users of the CPMS.
- To access the CPMS you need to have an EU login. To create an EU login, [click here](#).
- To request authorisation to use the CPMS, [click here](#).
- To request access to the ERN Collaborative Platform (ECP) to exchange non clinical data with the other members of your ERN, [click here](#).
- For more information on the European Reference Networks, please visit ec.europa.eu.



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)**

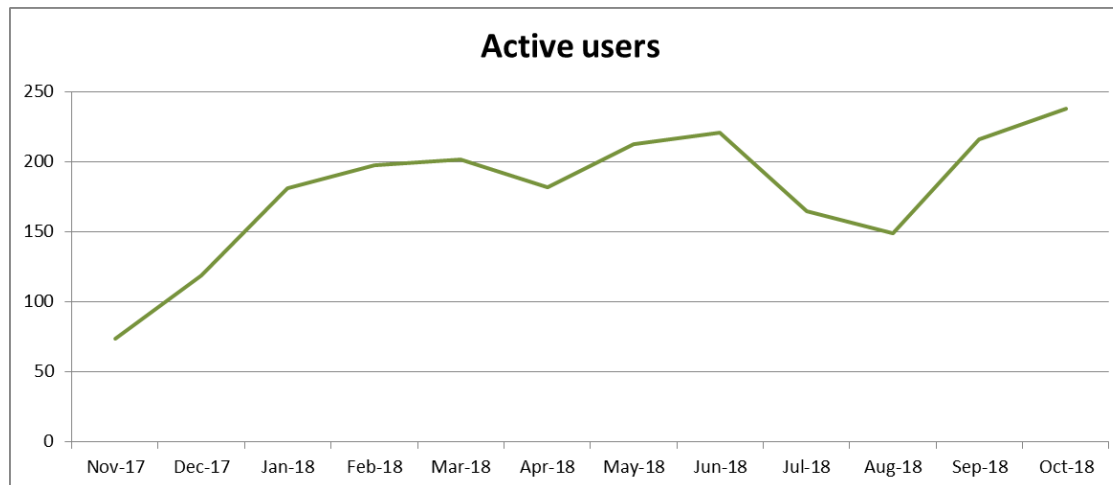
CPMS major changes planned

- **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)



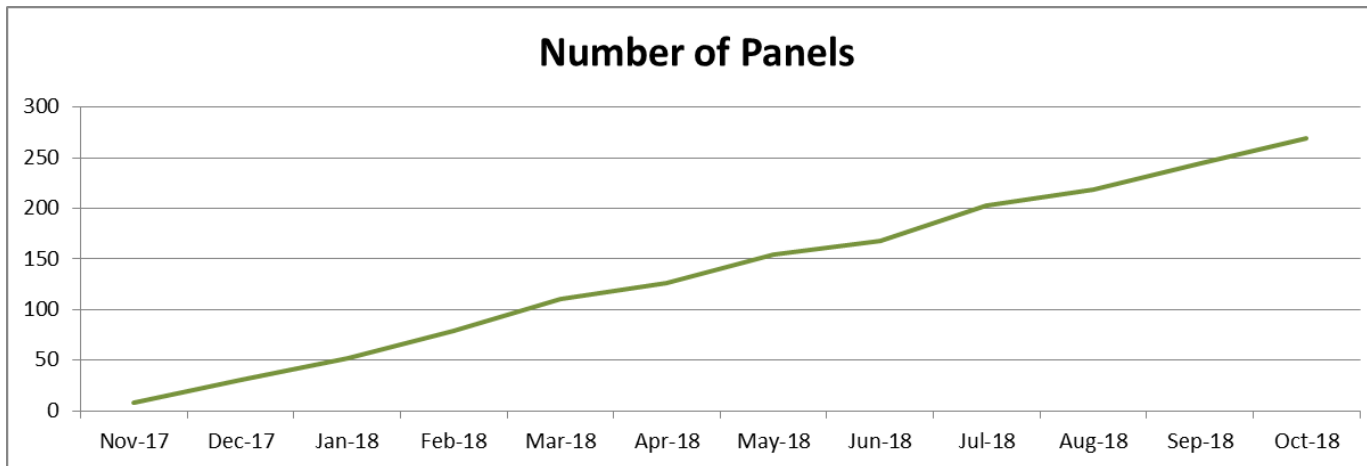
Country	Registered users
Austria	13
Belgium	82
Bulgaria	7
Croatia	2
Cyprus	2
Czech Republic	31
Denmark	14
Estonia	2
Finland	16
France	116
Germany	153
Hungary	17
Ireland	3
Italy	188
Latvia	3
Lithuania	17
Luxembourg	1
Netherlands	131
Norway	5
Poland	28
Portugal	41
Romania	10
Slovenia	9
Spain	67
Sweden	38
United Kingdom	117



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**



ERN	Panels
BOND	7
CRANIO	11
ERKNet	5
ERN-EYE	5
ERN-LUNG	6
ERN-RND	37
ERN-SKIN	3
ERNICA	7
EURACAN	5
EURO-NMD	3
Endo-ERN	15
EpiCARE	7
EuroBloodNet	10
GENTURIS	14
GUARD-HEART	5
ITHACA	25
MetabERN	11
PaedCAN	12
RARE-LIVER	15
RITA	2
ReCONNET	4
TRANSPLANTCHILD	16
VASCERN	11
eUROGEN	31



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%20overvieuw.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!