



European
Reference
Network

for rare or low prevalence
complex diseases

Network

Craniofacial anomalies
and ear, nose and throat
disorders (ERN CRANIO)

ERN CRANIO CPMS panel-creation protocol

Contents

| | |
|--------------------------------------|-----------|
| 1. Patient UPLOAD | 2 |
| 1.1. Aim..... | 2 |
| 2. FIRST LOGIN | 2 |
| 3. CPMS HOMESCREEN | 2 |
| 4. CREATING A PANEL | 3 |
| 4.2. Opening a panel | 5 |
| 4.3. Editing your panel | 7 |
| 4.4. Attachments | 8 |
| 4.5. Panel members..... | 9 |
| 4.6. Requesting additional data..... | 9 |
| 4.7. Meetings | 10 |
| 4.7.1 Opening a meeting..... | 11 |
| 4.8. Contributions & outcomes | 11 |
| 4.8.1 Contributions | 11 |
| 4.8.2 Outcome | 12 |
| 5. CLOSING THE PANEL | 12 |

1. Patient UPLOAD

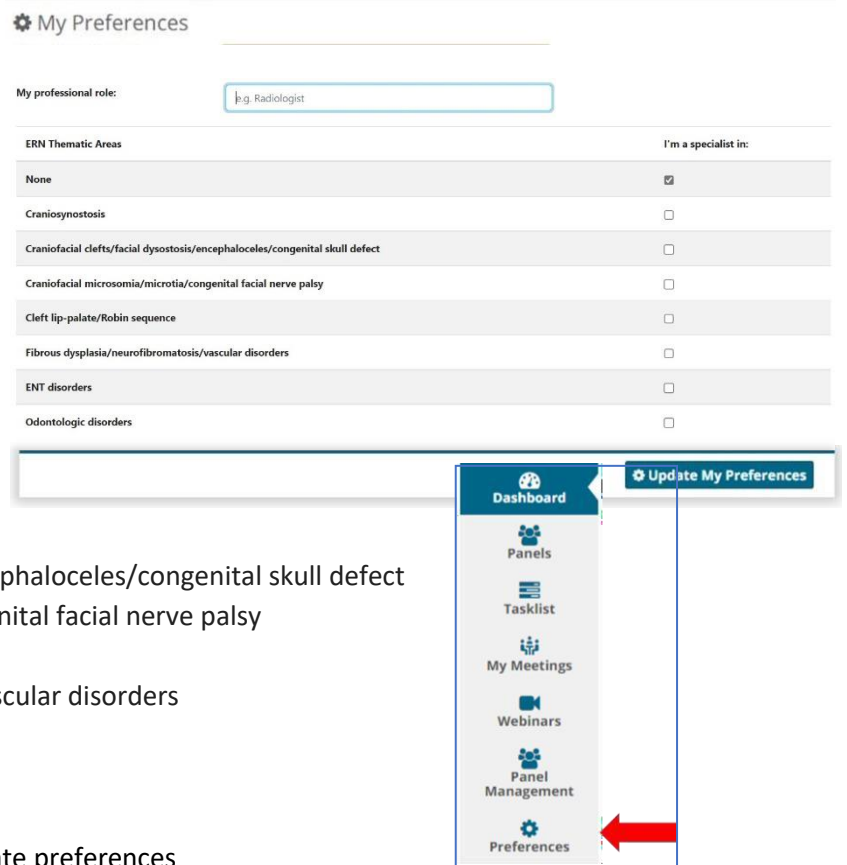
1.1. Aim

This document describes the steps required to both enrol a patient and create a panel in CPMS as a support for the CPMS users of ERN CRANIO.

2. FIRST LOGIN

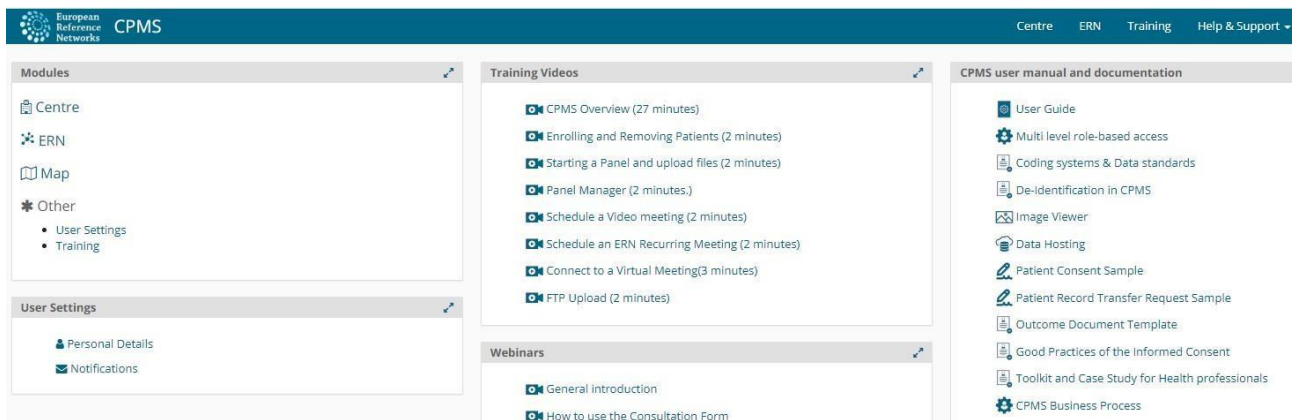
Before trying to access CPMS, you will need to create an EU login and make a CPMS access request. This process is described in a separate document (For more info see: [Clinical Patient Management System \(CPMS\) \(ern-cranio.eu\)](https://ern-cranio.eu/clinical-patient-management-system-cpms)). Once this is completed and authorized, you will receive a confirmation email that your access was approved after which you can login for the first time in CPMS.

- When logging in for the first time your personal preferences are requested, namely your role and thematic area.
- Type in your professional role (this will be shown beside your name in panels)
- Choose one or more of the ERN CRANIO thematic areas that best describes your expertise:
 - Craniosynostosis
 - Craniofacial clefts/facial dysostosis/encephaloceles/congenital skull defect
 - Craniofacial microsomia/microtia/congenital facial nerve palsy
 - Cleft lip-palate/Robin sequence
 - Fibrous dysplasia/neurofibromatosis/vascular disorders
 - ENT disorders
 - Odontologic disorders
- To save these preferences please click Update preferences
- To update your preferences at any time, simply click on the ERN tab at the top screen
- Then click on Preferences in the left bar
- This will open the Preference tab again



3. CPMS HOMESCREEN

After logging in to CPMS, you will see the home screen



- Modules: contains the Centre, ERN and Map tab
- User settings: Here you can change your personal details and preferences regarding notifications (**We recommend viewing these settings**)
- Training videos: Useful video for when using CPMS for the first time, some important videos are the **CPMS overview, Enrolling and removing patients, and Starting a panel and upload files**
- Webinars: Here are several explanatory videos where recent new functions are also explained
- CPMS user manual and documentation: Contains documents concerning several CPMS functionalities

4. CREATING A PANEL

Workflow Overview

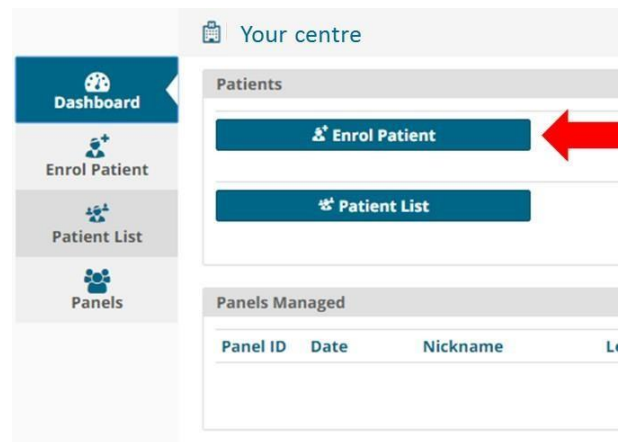


4.1. The Centre Tab

This tab contains the information of patients that were input both within your centre (Healthcare Provider) and within ERN CRANIO. From this tab, these local patients can be enlisted and managed. The most important difference with the ERN tab is that patient data is not anonymous in this section.

4.1.1 Enrolling a patient

- In the Centre tab, click on **Enrol Patient**
- This will open a tab where you can input the patient's data



Enrol Patient

Note: All authorised users from this centre can see all patients enrolled within this centre regardless of enrolling user.

ENROL PATIENT

* Patient id: **Automatically created**

* Date enrolled:

[Download Model Consent Forms](#)

| Consent Requested | Consent Given | Date |
|--|--|------|
| * Consent for care | <input type="radio"/> Yes <input type="radio"/> No | |
| * Consent for ERN databases/Registries | <input type="radio"/> Yes <input type="radio"/> No | |
| * Consent contact for research | <input type="radio"/> Yes <input type="radio"/> No | |

Identifying data

* First name:

* Last name:

* Gender:

* Date of birth:

* Record Label:

- A patient ID is automatically created
- The consent forms can be downloaded by clicking on **Download model consent forms**
- The consent forms are not uploaded in CPMS but locally stored
 - o please make sure they are saved with the patients' file and can be found again (e.g. if patient removes consent)
- Fill out the required fields to complete the enrolment
 - o No specific medical information is required here
 - o The record label is automatically created but can be adjusted if desired
- Once finished, click on **Enrol patient**
- The next screen will give you the option to **Open a new panel**

4.2. Opening a panel

- After enrolling a patient, you will automatically continue to the option to open a new panel
- You can also access this option for previously enrolled patients by clicking on Centre > Patient list > and select the patient where you want to open a panel
- Click on **Open a new panel**

CONSULTATION REQUEST

Do not use any nicknames liable to identify the patient, including his/her first name or last name.

* Nickname:

Is urgency required for this panel?

* Is this a repeat of a previous panel for the same patient but a different episode? Yes No Don't know

* Consultation request description:

* Consultation request reason: Diagnosis Treatment Other

* Healthcare provider:

* Point of care specialist:

* ERN: ERN CRANIO

* Panel lead:

Panel Manager:

* Primary Thematic Area: Cleft Lip-Palate
 Robin Sequence
 Craniofacial clefts
 Facial dysostosis
 Encephaloceles
 Aplasia cutis skull
 Craniofacial Microsomia
 Microtia
 Congenital Facial nerve palsy
 Craniosynostosis
 Genetic and isolated hearing loss
 Laryngotracheal stenosis
 Laryngotracheo-oesophageal cleft
 Congenital nasal anomalies
 Congenital anomalies of the neck
 Fibrous dysplasia
 Neurofibromatosis
 Vascular disorders
 Amelogenesis imperfecta
 Hypodontia
 Oligodontia
 Supernumeracy teeth
 Dentinogenesis imperfecta
 Dentine dysplasia
 Eruption/resorption/early loss teeth
 Solitary median maxillary central incisor syndrome

* Diagnosis Provider: ERN member Affiliated ERN Member Non-ERN member

* Treatment Healthcare Provider: ERN member Affiliated ERN Member Non-ERN member

- As the panel is anonymised, the patient data, including the patient name, cannot be used to identify the panel. Therefore, a nickname is required:
 - Centres using an electronic patient file often use local patient numbers which are different from social security numbers. An option is to use the local patient number as a nickname because it can only be connected to the patient at the local centre by authorised personnel
- Fill out the required fields to complete the form:
 - At the point of care specialist, the name of the main treating physician of the patient is mentioned
 - note that initially, the Panel Lead can only be set to be someone in your Centre, but this can be changed later on. Guest users will not have the option to choose a Panel Lead
 - Select the panel lead from a list of locally registered CPMS users
 - If available, select a local panel manager
- Once all fields are completed, click on **Create panel** to complete this form

4.3. Editing your panel

- You will now see the panel overview screen like the example below

#4255 CPMS tryout **PANEL IN PROGRESS**

| | | | |
|----------------|--|----------------------|------------------|
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN | ERN CRANIO |
| Lead | ERN CRANIO testuser | Thematic Area | Craniosynostosis |
| Manager | ERN CRANIO testuser | Date created | 08/Mar/2021 |

Consultation Form Attachments Panel Members Meetings Contributions & Outcome

Consultation Form Recorded: 08/Mar/2021 12:56 (Europe/Paris) by: .hpuser1 testuser Download Edit

CONSULTATION REQUEST

Nickname: CPMS tryout

* Is this a repeat of a previous panel for the same patient but a different episode? No

* Consultation request description: Advice for further treatment

* Consultation request reason: Treatment

- In the consultation request you will find the data you just entered
- To provide medical information regarding your case click on **Edit**
- On the left you will find a column with specific medical subject, check the box next to it top open this heading and provide the information
- You can provide the patient information that you find essential to each specific section and click on **Save** to finish editing the patient data
- The newly added information will be shown after saving in the panel overview, here you can check for correctness and completeness

4.4. Attachments

- Alternatively, rather than adding patient information to each of the predefined sections, a graphical patient abstract can also be made and uploaded to CPMS as a PDF file
 - When using PowerPoint to create a case overview with inclusion of essential media files we would like to **emphasize the importance of saving the file as PDF** to prevent further editing
 - When using screenshots in your abstract, please remove all patient identifying data
- To upload a graphical patient abstract or medical documents click on the “**Attachments**” section. Be aware that attachments can only be uploaded in the ‘ERN’ environment of the system and only be deleted in de ‘Center’ environment of the system (see below).

#4255 CPMS tryout **PANEL IN PROGRESS**

| | | | |
|---------------------|--|----------------------|------------------|
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN | ERN CRANIO |
| Lead Manager | ERN CRANIO testuser | Thematic Area | Craniosynostosis |
| | ERN CRANIO testuser | Date created | 08/Mar/2021 |

Consultation Form **Attachments** Panel Members Meetings Contributions & Outcome

Attach Image or File

Drop Documents, Images, Videos, or other files here or click to upload.

Cancel Attach

- Click Save to finish the uploading of files

Removing attachments

If you have uploaded the wrong document, you can remove it by returning to the ‘centre’ section of CPMS:

- In ‘panels managed you can find the panel you are leading (red), click on the panel id (green) to move to the panel.
- In the left corner you can click on Patient Documents (red)
- By clicking on de three vertical dots, you can delete the document (red)

Patients

Enrol Patient

Patient List

Panels Managed

| Panel ID | Date | Nickname |
|----------|-------------|----------|
| #2257 | 06/jul/2021 | |
| #2264 | 08/jul/2021 | |

Panels

Enrolment

Patient Documents

Transfer Request

#2257

Attach file / image

| Usage | |
|----------|-------------|
| 845.5 kB | Panel #2257 |

View

Rename

Delete

Download

4.5. Panel members

- When viewing the panel overview after editing of the data, you can click the Panel Members button

#4255 CPMS tryout **PANEL IN PROGRESS**

| | | | |
|---------------------|--|----------------------|------------------|
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN | ERN CRANIO |
| Lead Manager | ERN CRANIO testuser | Thematic Area | Craniosynostosis |
| | ERN CRANIO testuser | Date created | 08/Mar/2021 |

Consultation Form Attachments **Panel Members** Meetings Contributions & Outcome

- Under Panel Members, there will appear four tabs to choose from

Accept / Refuse Invited Available Co-ordinator Assistance

- Accept / Refuse:** here you can accept or refuse a panel invitation you received
- Invited:** this tab shows the currently invited panelist and their status
- Available:** here you can select per workstream which panelist you would like to invite
- Coordinator Assistance:** use this tab if you would like **help from the ERN coordinator** appointing your panel or if you would like to request panel members from other ERNs (**cross-ERN panel members**)
 - Be specific about your question and which expertise you require
 - Provide member names If you have specific members of another ERN you want to invite

4.6. Requesting additional data

- Once participants have accepted your invitation, they can also request additional information
- When this is done you will receive an automated email that additional data has been requested
- If you login to CPMS and go to ERN > Dashboard > Requests for additional data

| Additional Data Requested By | Created Date | Completed Date |
|------------------------------|--------------|----------------|
| ERNCRANIOpuser2testuser | 04/08/2020 | |

- This shows the data request, click on it to go the panel overview
- In the timeline column on the right side, the request is shown
- Click on the **Action** button to add the additional data
- In this screen you can respond to the panel member
- If additional data is still needed, click on **Mark as pending** to let the panel know you have read the request
- Once you have provided the additional data click on **Mark as Complete** to sign off the data request
- Your response will appear in the timeline column on the left

testuser agreed to join the panel 04/Aug/2020 13:56

Requested: testuser
Please provide the reports of previous surgeries 04/Aug/2020 14:00

Action

Add a comment

Additional Request ✕

Status: **Requested**

Responsible: **testuser**

user2 testuser 04/Aug/2020 14:00

Please provide the reports of previous surgeries

Additional request text response

[Add Comment](#)

[« Summary](#)
[Set to Requested](#)
[Mark as Pending](#)
[Put on hold](#)
[Mark as Complete](#)

4.7. Meetings

Once enough panel members have accepted a meeting can be scheduled. In the panel overview click on **Meetings**

#4255 CPMS tryout PANEL IN PROGRESS

| | | | |
|----------------|--|----------------------|--------------------------------|
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN | ERN CRANIO |
| Lead | ERN CRANIO testuser | Thematic Area | ERN CRANIO Craniosynostosis |
| Manager | ERN CRANIO testuser | Date created | 08/Mar/2021 |

[Consultation Form](#)
[Attachments](#)
[Panel Members](#)
[Meetings](#)
[Contributions & Outcome](#)

This will show you the upcoming and past meetings. Click on **Schedule meeting** to plan a new meeting

- A single meeting at a specific time and date
 1. Click on Individual meeting
 2. Fill out the required fields and click on Schedule meeting

Date & Time
Participants
Summary

Test video Starts in: 4h 26m 9s

Meeting participants

| Name | Invited | Status |
|----------|----------------------------------|--------|
| testuser | 28/sep/2020 12:33 (Europe/Paris) | Host |

Invite the members of your panel

| | |
|-----------------------------------|-------------------------------------|
| <input type="text" value="Name"/> | <input type="text" value="Invite"/> |
|-----------------------------------|-------------------------------------|

3. Do not forget to individually invite the member of the panel in the participants tab.

4.7.1 Opening a meeting

- Under upcoming meetings you can see your scheduled meeting
- At the time of the meeting the countdown button will change to Join Meeting

Upcoming meetings

| | |
|--------------------|--|
| Title | test |
| When | 08/Mar/2021 15:55 (Europe/Paris) |
| Description | None |
| Status | Upcoming |
| | Test video Starts In: 2h 9m 15s |

4.8. Contributions & outcomes

4.8.1 Contributions

- When the panel has been discussed either through a meeting or by comments alone. Click on the tab **Contributions & Outcome** to record your contribution and create a panel outcome

#4255 CPMS tryout **PANEL IN PROGRESS**

| | | | |
|----------------|--|----------------------|------------------|
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN | ERN CRANIO |
| Lead | ERN CRANIO testuser | Thematic Area | Craniosynostosis |
| Manager | ERN CRANIO testuser | Date created | 08/Mar/2021 |

Consultation Form Attachments Panel Members Meetings **Contributions & Outcome**

- Enter your contribution and the relevant outcome/advice
- Provide the time spent on the panel outcome
- If you would like to have the individual contributions of the panellist you can remind them by clicking on the **Request Contributions** button
- Click on **Record Contribution** to save your work

Contributions Request Contributions

eurogenhpuser1 testuser

Record your contribution here

Or attach file: Geen bestand gekozen

How much time did you spend on this Assessment? HRS MINS

Record Contribution

4.8.2 Outcome

- To create a final panel outcome click on the **Edit** button below

Outcome

No outcome drafted

Edit Sign-off

- Record the final outcome of the panel
- Select your opinion on the usefulness and satisfaction of the panel outcome
- Click the **Save** button to register the outcome
- The **Sign-off** button will now become available, click on it to sign-off the panel
- Confirm if you want to sign-off the panel

The panel has been signed off

You can now download the outcome document from the panel banner. If this panel is now complete please close the panel by clicking the **Close Panel** button at the top of the panel banner.

5. CLOSING THE PANEL

- To access the panel outcome click on **Outcome document**

| | | | |
|---------------------|--|--------------------------|--------------------------------|
| #4255 CPMS tryout | PANEL SIGNED OFF | Close Panel | |
| Centre | FR09 - Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades | ERN Thematic Area | ERN CRANIO Craniosynostosis |
| Lead Manager | ERN CRANIO , testuser | Date created | 08/Mar/2021 |
| | | | Outcome Document |

- This will open a new window with a PDF document of the panel case and outcome document
- We recommend that this document is:
 - locally saved and attached to the patient file
 - shared with the patient by the treating clinician and discussed when planning future treatment

- To close the panel, click on the **Close Panel** button
- Fill out the questionnaire
- Click on **Continue to Closed** to finally close the panel

Please note: This action is irrevocable

The panel phase is now switched to Closed

Transition to Closed

You have chosen to transition to a new state, **Closed**.

This is an irrevocable action! When you close this panel it is still visible within the ERN but a closed panel cannot be restarted.

Questionnaire

How much time did you spend on this Panel? HRS MINS

* Was the panel a success? Yes No Not Determined

What was the Outcome? Diagnosis Treatment Clinical Trial Un-diagnosed Other

* Patient Status Alive Dead Lost to follow up Opted out

Cancel **Continue to Closed**

- If your patient has signed consent for the sharing of data for registries (on the initial ERN consent form) then click on **Make Data available for ERN Databases/Registries**
- The Archive Panel option removes the panel from the ERN list and it then only remains available to the local centre
- We recommend that you **do not use** this option unless you are advised to do so either by a member of the ERN CRANIO Helpdesk or at the request of the patient.

| | |
|----------------------|------------------|
| ERN | ERN CRANIO |
| Thematic Area | Craniosynostosis |
| Date created | 08/Mar/2021 |

[Archive Panel](#)
[Make Data Available for ERN Databases/Registries](#)
[Outcome Document](#)



[EN \(ern-cranio.eu\)](http://ern-cranio.eu)

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The ERNs are co-funded by the European Commission. For more information about the ERNs and the EU health strategy, please visit <http://ec.europa.eu/health/ern>