

CPMS User Guide

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1. Welcome to the CPMS

Clinical Patient Management System, known as CPMS, is a secure web-based application to support European Reference Networks in the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders.

CPMS Made for ERN

European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly **specialised** treatment and concentrated knowledge and resources. The first ERNs were launched in March 2017, involving more than 900 highly-**specialised** healthcare units from over 370 hospitals in 26 Member States. 24 ERNs are working on a wide range of disease areas such as rare and complex epilepsies, neurological disease, transplantation in children, etc.



2. Getting Started

2.1. Access to CPMS

Access to the Clinical Patient Management System (CPMS) is strictly regulated to protect the data privacy rights of the patients. Only authenticated users (ECAS) can request **authorisation** (SAAS) from the ERN to use the CPMS. Each ERN has member Healthcare Provider **centres** (HCP) and it is envisaged that the users of CPMS are Health Professionals (HP) within these Healthcare Provider **centres** (HCPs). Guest accounts can be created at the direct request of the ERN Coordinators.

2.2. Request Access to CPMS

This document explains how to request access to **CPMS**. To be able to start, the first requirement is an **EU login**. In order to register for one first go to <https://cpms.ern-net.eu/login/> and click on the link **to create an EU login**.

Secure Login

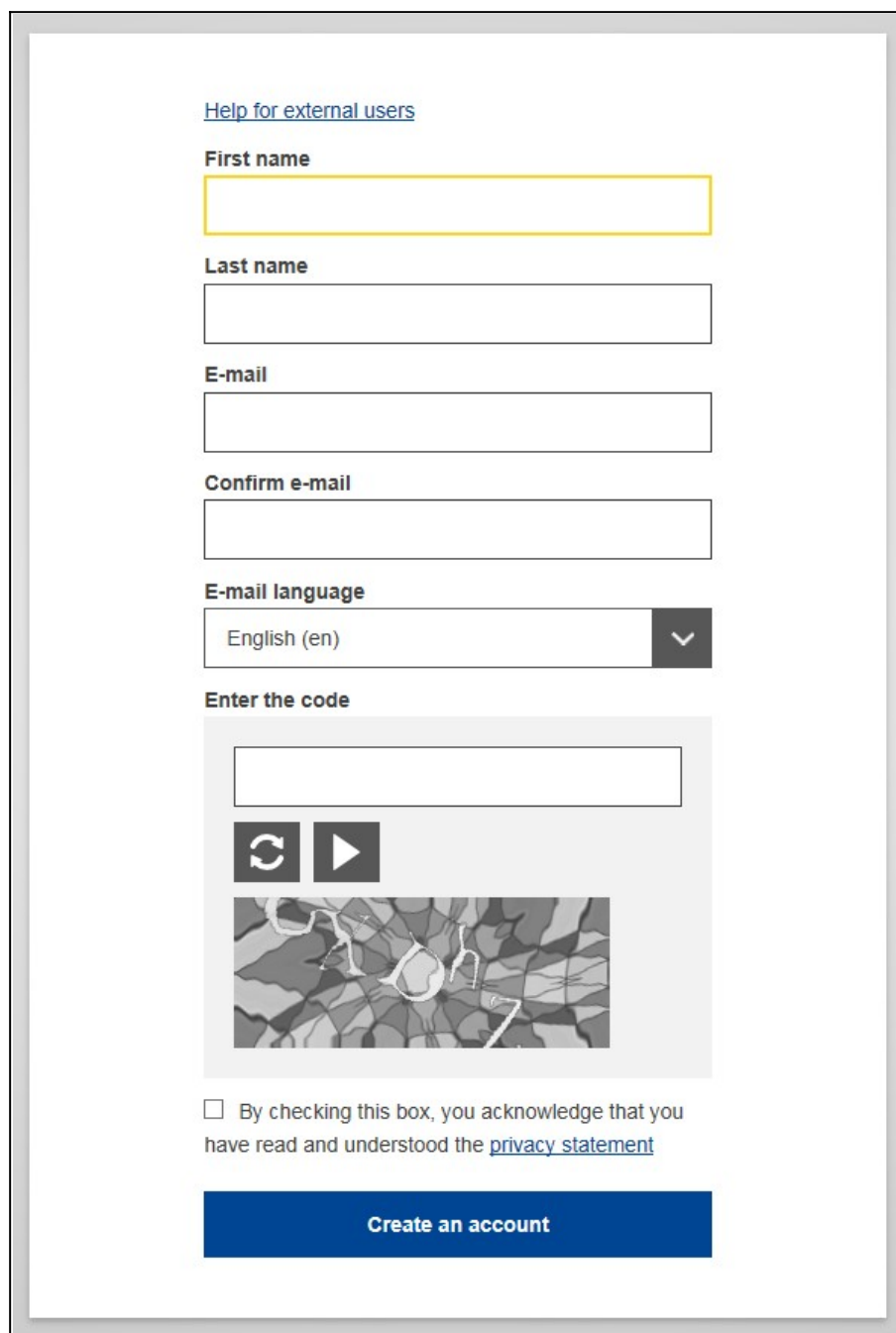
You can Login to the CPMS ERN through the EU Login Authentication Service.

[➔ Login via EU Login](#)

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

- Only authenticated users (EU Login) can access or request access to CPMS. To create an EU Login [click here](#).
- Only authorised users (SAAS) can access CPMS. To request authorisation to use CPMS [click here](#).
- To access or request access to the ERN Collaborative Platform (ECP) [click here](#).
- For more information about the European Reference Networks for Rare Disease, please visit ec.europa.eu.

Once you arrive at the site, fill in the information in each of the boxes and click on **Create an account** at the end.



The screenshot shows a web form for creating an account. At the top left is a link: [Help for external users](#). The form fields are: 'First name' (a text box with a yellow border), 'Last name' (a text box), 'E-mail' (a text box), 'Confirm e-mail' (a text box), 'E-mail language' (a dropdown menu showing 'English (en)' with a downward arrow), and 'Enter the code' (a text box). Below the code box are two icons: a refresh icon and a play button icon. Underneath these is a CAPTCHA image showing the word 'FOUR' in a stylized font. Below the CAPTCHA is a checkbox with the text: 'By checking this box, you acknowledge that you have read and understood the [privacy statement](#)'. At the bottom of the form is a blue button labeled 'Create an account'.

Fill in the provided form with your personal details:

- First name – Your first name cannot be empty and can contain letters in any alphabet;
- Last name – Your last name cannot be empty and can contain letters in any alphabet;
- E-mail – An e-mail address that you have access to;
- Confirm e-mail – Type your e-mail address again to make sure it is correct;

- E-mail language – The language used when EU login sends you e-mails regardless of the language used in the interface. It guarantees that you are able to understand these e-mails even if they were triggered mistakenly. EU login only sends you e-mails for validating your identity or for notifying you about security events affecting your account;

-
- Enter the code – By entering the letter and numbers in the picture, you demonstrate that you are a human being who is legitimately creating an account. If the code is too difficult to read, click on the button with two arrows to generate a new one;
 - Check the privacy statement by clicking on the link and tick the box to accept the conditions;
 - Click on "Create an account" to proceed.

If the form is correctly filled in, an e-mail is sent to the address you provided in order to verify that you have access to it. After a couple of seconds, you should receive an e-mail in your mailbox. If you cannot find the e-mail, check your spam or junk folder.

Dear ...,

You have been registered in EU Login.

Your email address is ...@... .

To create your password, follow the link below:

[this link](#)

You have a maximum of 5 min, starting from the time that this message was sent, to create your password, but you are encouraged to do so immediately if possible. After this time, you can make another request by following the same link: you will then need to re-enter your username and confirm your request.

If the above link does not work, you can copy the following address (make sure the complete address is copied!) and paste it into your browser's address bar:
<https://ecas.ec.europa.eu/cas/init/initialisePasswordLogin.cgi?xxx...>

Instead of replying to this message, if you have a problem, please follow the help or contact information on the site where you were trying to register.

Note that it may take up to 5 minutes after reception of this mail before the above-mentioned site will recognize your registration.

Sent to you by EU Login


Click the link in the e-mail or copy/paste it in the address bar of your browser.

You are invited to select a password and to confirm it to make sure you did not mistype it.

The E-mail field is pre-filled and cannot be changed.

It should contain the e-mail address you provided previously.

New password

 Please choose your new password.

n...

(External)

New password

Confirm new password

Submit

Passwords cannot include your username and must contain at least 8 characters chosen from at least three of the following four character groups (white space permitted):

- Upper Case: A to Z
- Lower Case: a to z
- Numeric: 0 to 9
- Special Characters: !"#\$%&'()*+,-./:;<=>?@[\\]^_`{|}~

Examples: SEN5RbaW GwOzMg9m U(nuCuwh

[\[Generate other sample passwords\]](#)

Type the password you want to use in the "New password" field.

It must contain at least 10 characters and a combination of:

- upper case letters,
- lower case letters,
- numbers and
- Special characters.

Select a password as long and as complex as you can in order to make your account more secure but keep in mind that you will have to remember it.

Type your password again in the "Confirm new password" and click on "**Submit**".

You are now authenticated.
Click on "**Proceed**" in order to do so.

Sign in with an EU Login account

Once your EU Login account is created, you can use it to access CPMS. While accessing these services, the EU login screen will display when authentication is needed.

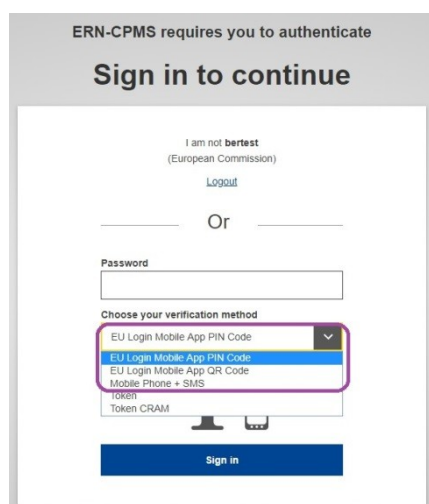


Enter the e-mail address you provided when creating your EU login account in the "Use your e-mail address" field and click on "**Next**".

Your e-mail address will automatically be remembered so that you can skip this step next time you use the same browser on the same PC.

Choose your verification method

EU login supports a variety of verification methods. Using a password is the simplest one. But CPMS uses an additional verification method. It involves using an additional device which can provide more security. This is your cellphone. The 3 different methods here below are the one used to login to CPMS.



Several verification methods require using the ECAS Mobile App. The ECAS Mobile App is an application that you can install on your mobile device from the Google Play Store (Android), the App Store (iOS) or the Windows Store (Windows Phone). You first need to initialize the application. Using the ECAS Mobile App in combination with the password provides additional security.

Please note that some verification methods might not be available while accessing some specific services.

1) **ECAS Mobile App PIN code** – If the mobile device where your ECAS Mobile App is installed has internet connectivity then you can use the "ECAS Mobile App PIN Code" verification method. You will have to enter a 4 digits PIN code into the ECAS Mobile App in order to connect to EU login. This is the PIN code that you have chosen while registering your mobile device into EU login.

2) **ECAS Mobile App PIN code** – If the mobile device where your ECAS Mobile App is installed has internet connectivity then you can use the "ECAS Mobile App PIN Code" verification method. You will have to enter a 4 digits PIN code into the ECAS Mobile App in order to connect to EU login. This is the PIN code that you have chosen while registering your mobile device into EU login.

3) **ECAS Mobile App QR code** – If the mobile device where your ECAS Mobile App is installed does not have internet connectivity then you can use the "ECAS Mobile App QR Code" verification method. You will need to scan a QR code using the ECAS Mobile App in order to get a one-time password, which you then introduce while connecting from your PC.

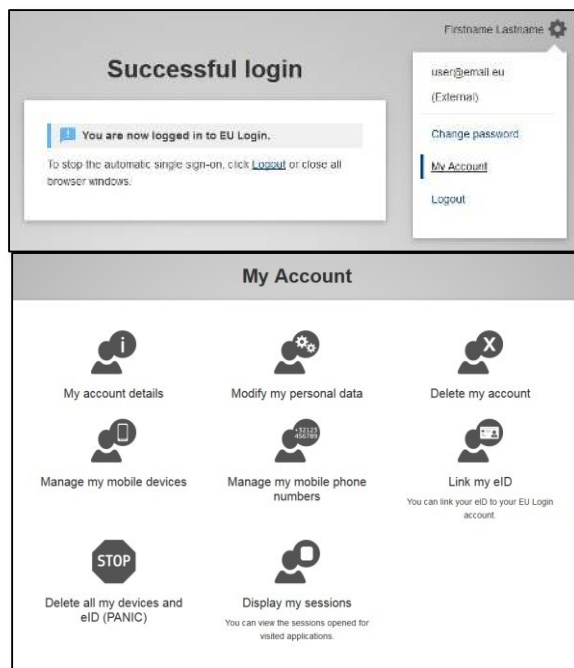
4) **Mobile phone + SMS** – Your mobile phone allows you to connect to EU login by receiving an SMS, if your number is registered in your EU login account. In some countries, you might not receive the SMS and should rather use another verification method.

You then have to register your phone number in your EU login account:

Register a mobile phone number for receiving verification SMS

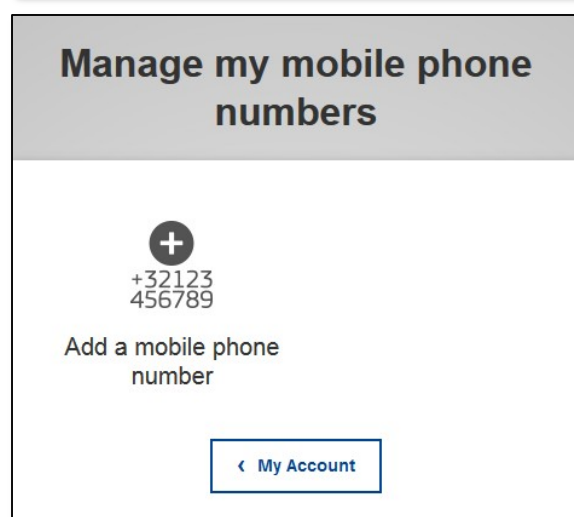
Your mobile phone number needs to be registered in your EU login account in order to receive SMS to authenticate.

In order to register your mobile phone number, open a browser and **go to the following URL:** <https://ecas.ec.europa.eu/cas>

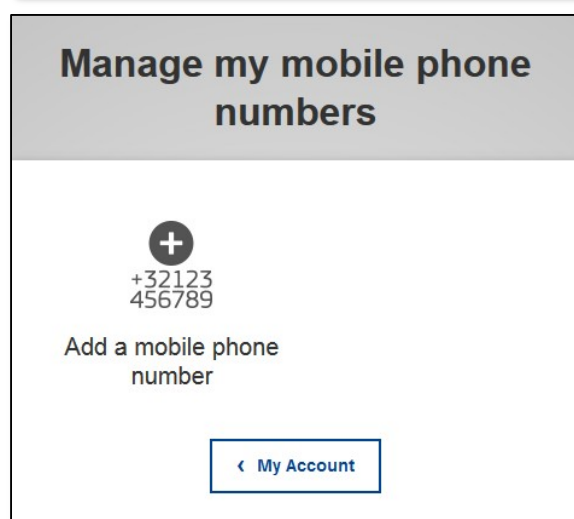


Once successfully authenticated, move the mouse over the gear at the top right corner to display the menu and select "My Account".

Click on "Manage my mobile phone numbers".



Click on "Add a mobile phone number".



Click on "Add a mobile phone number".

Add a mobile phone number

Mobile phone number

International format including country code,
e.g. for Belgium: +32 123 45 67 89

Add Cancel

Enter your mobile phone number in the "Mobile phone number" field, starting with a plus sign and with the country code.

Do not include dots, parenthesis or hyphens.

When clicking "Add", a SMS is sent to your mobile device.

The SMS contains a challenge code made of eight characters separated with a hyphen (minus sign).

Challenge code for adding a mobile phone number, sent by text message

Please enter the *challenge code* that was texted to your mobile phone.

It might take up to 8 minutes for the message to reach your mobile phone.

Mobile phone number

Text message challenge code


 -

Finalise Cancel

Type the challenge code you received in the "Text message challenge code" fields and click on **"Finalise"**.


Manage my mobile phone numbers

✓ Your mobile phone number +321234567890 was added successfully.



+32123
456789

Add a mobile phone number



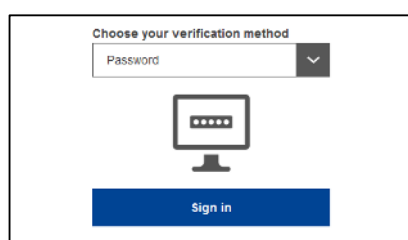
+32123
456789

Delete a mobile phone number

[< My Account](#)

Your mobile phone number is successfully registered and can now be used for authenticating.

Sign in with an EU login account using a password



Select "**Password**" as the verification method, **enter your password** in the "Password" field and click on "**Sign in**" to proceed to the service you requested to use.

Sign in with an EU login account using the ECAS Mobile App PIN code

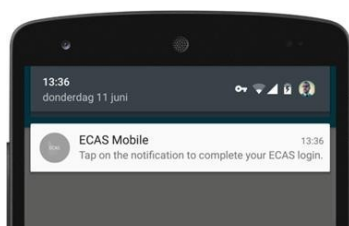


Select "**ECAS Mobile App PIN Code**" as the verification method, **enter your password** in the "Password" field and click on "**Sign in**".

If you have more than one device with an initialised ECAS Mobile App, you are asked to select the one you would like to use.

This left screen does not display if you have only **initialised** one device.

Click on **the device** using the name you provided.



EU login sends a **notification** to your mobile device.

Tapping on the notification triggers the launch of the ECAS Mobile App.

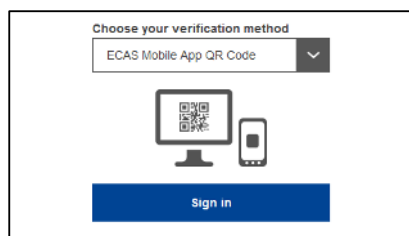


The ECAS Mobile App prompts you to enter your PIN code.

Enter your PIN code and tap on "**Authenticate**".

This automatically completes the process on your PC that proceeds to the service you requested to use.

Sign in with an EU login account using the ECAS Mobile App QR code



Select "ECAS Mobile App QR Code" as the verification method.

Enter your password in the "Password" field and click on "**Sign in**".

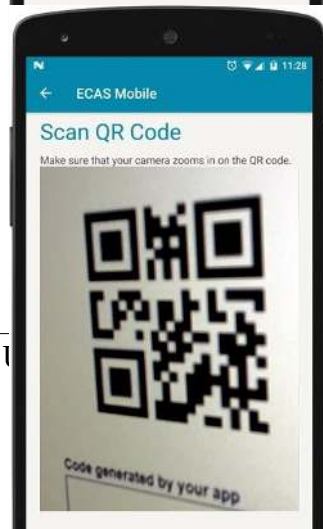


A QR code is displayed on screen.



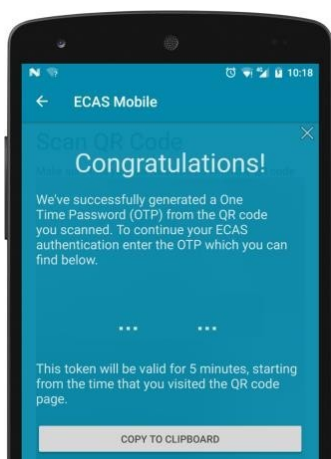
Start the ECAS Mobile App on a mobile device where it has been previously **initialised**.

Tap on "**Scan QR Code**".

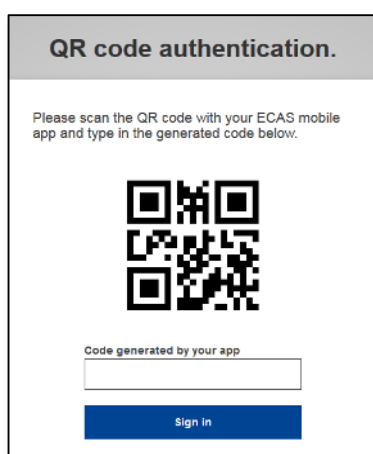


The QR code scanner starts on your mobile device.

Point the camera of your mobile phone to your PC screen until the QR code is **recognised**.



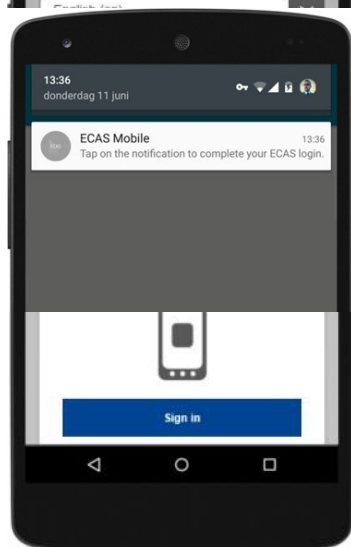
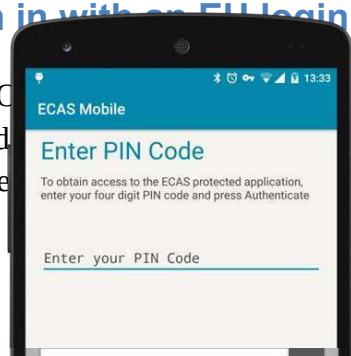
The ECAS Mobile App displays a **one-time password** composed of 8 digits.



Type the one-time password in the "code generated by your app" field and click "**Sign in**" to proceed to the service you requested to use.

Sign in with an EU login account using On Mobile authentication

The "On Mobile" authentication method is only available when browsing on a mobile device and the ECAS Mobile App has been previously installed and **initialised** on that device.



Select "**On Mobile Authentication**" as the verification method and tap on "**Sign in**".

The ECAS Mobile App opens automatically and prompts you to enter your **PIN code**.

Enter your PIN code and tap on "**Authenticate**".


ECAS sends a **notification** to your mobile device.

Tapping on the notification sends you back to your browser that proceeds to the service you requested to use.

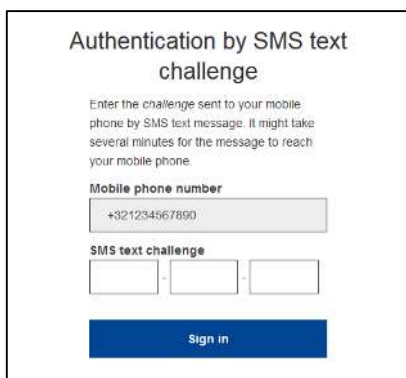
Sign in with an EU login account using Mobile Phone + SMS



Password

[Lost your password?](#)
 Choose your verification method
 Mobile Phone + SMS

 Mobile phone

International format including country code, e.g. for Belgium: +32 123 45 67 89
 Sign in



Authentication by SMS text challenge
 Enter the challenge sent to your mobile phone by SMS text message. It might take several minutes for the message to reach your mobile phone.
 Mobile phone number

 SMS text challenge
 - -
 Sign in

Select **"Mobile Phone + SMS"** as the verification method.

Enter your password in the "Password" field and enter a previously registered mobile phone number in the "Mobile phone" field, starting with a plus sign and with the country code. Do not include dots, parenthesis or hyphens.

When clicking **"Sign in"**, an SMS is sent to your mobile device. The SMS contains a challenge code made of nine characters separated with hyphens (minus sign).

Type the challenge you received in the "SMS text challenge" fields and click on **"Sign in"** to proceed to the service you requested to use.

02042020UG-CPMS

Once the EU login has been created you are ready to request access to the CPMS. Go back to the login page for CPMS on <https://cpms.ern-net.eu/login/>. This time click on the link to request **authorisation** to use CPMS.

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).

- Only authenticated users (EU Login) can access or request access to CPMS. To create an EU Login [click here](#).
- Only authorised users (SAAS) can access CPMS. To request authorisation to use CPMS [click here](#).
- To access or request access to the ERN Collaborative Platform (ECP) [click here](#).
- For more information about the European Reference Networks for Rare Disease, please visit ec.europa.eu.

Once you arrive at the site click on the **Request access** button:



Saas - Authorization System

[Privacy Statement](#) [Support](#)

European Commission > DG Health and Food Safety > Saas

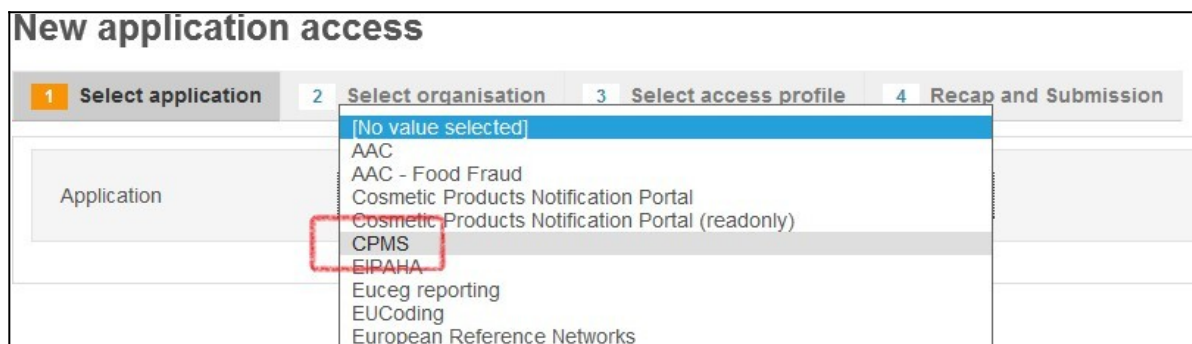
Home

Request access

User Data details

Select an application ▼

On the page, that appears select **CPMS** in the Application box:



New application access

1 Select application 2 Select organisation 3 Select access profile 4 Recap and Submission

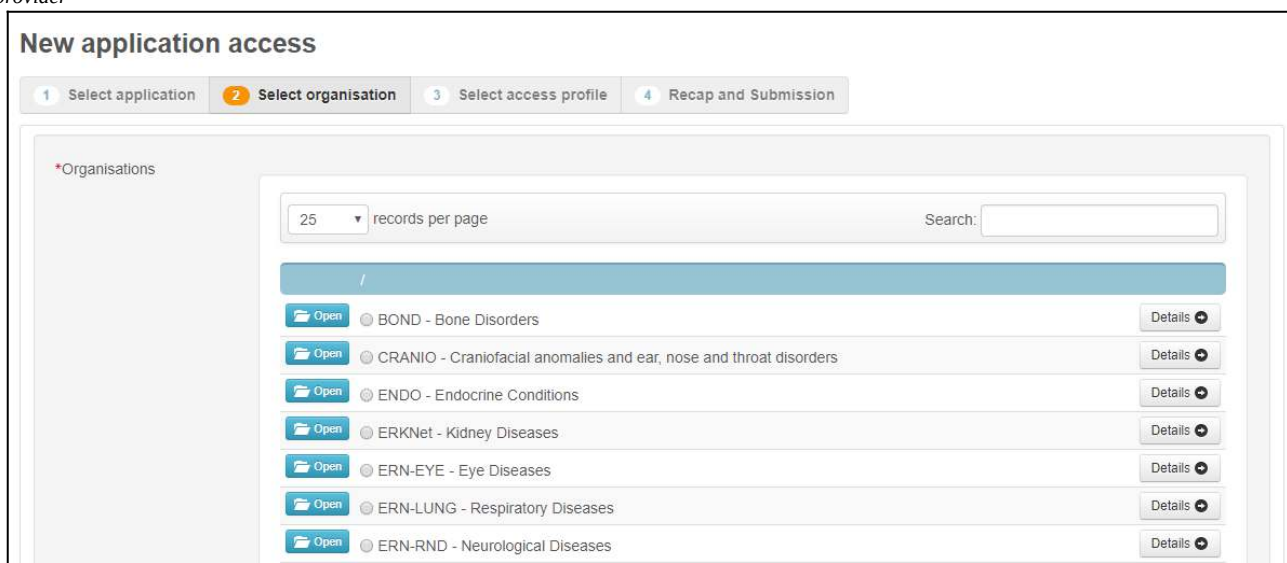
Application

- [No value selected]
- AAC
- AAC - Food Fraud
- Cosmetic Products Notification Portal
- Cosmetic Products Notification Portal (readonly)
- CPMS**
- EIPAH
- Euceg reporting
- EUCoding
- European Reference Networks

Once selected click on **Step 2: Select an organisation**, to proceed

Step 2 : select an organisation →

On the **Select Organization** page you need to select which ERN you wish to request access for by clicking on **Open** next to it. **You do not need to click in the circle until the very last step when you select your healthcare provider*



New application access

1 Select application 2 Select organisation 3 Select access profile 4 Recap and Submission

*Organisations

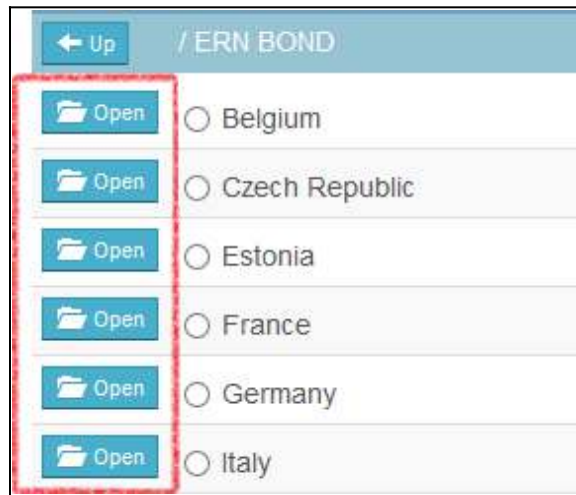
25 records per page Search: []

Open	BOND - Bone Disorders	Details
Open	CRANIO - Craniofacial anomalies and ear, nose and throat disorders	Details
Open	ENDO - Endocrine Conditions	Details
Open	ERKNet - Kidney Diseases	Details
Open	ERN-EYE - Eye Diseases	Details
Open	ERN-LUNG - Respiratory Diseases	Details
Open	ERN-RND - Neurological Diseases	Details

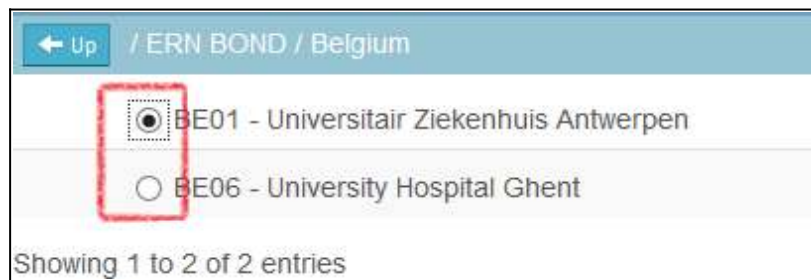
It is technically possible to proceed to step 3 after just selecting the ERN.

Please note that doing this will result in the request being rejected. No account can be activated without selecting the Country and Healthcare Provider. Please see below:

After clicking **Open**, you need to select which country your Healthcare Provider is located in. Again, you select this by clicking **Open**



Finally, you select your Healthcare provider by clicking in the small circle next to its name



Once selected you click on **Step 3: select an access profile** to continue

On the Select access profile page you need to select which type of access profile you are requesting. You do this by clicking in small circle next to it:

New application access

1 Select application 2 Select organisation 3 **Select access profile** 4 Recap and Submission

*Access Profile

Name	Status	Description
<input type="radio"/> Coordinator		handles requests for assistance from ERN and has access to KPIs
<input type="radio"/> Database Manager		can create or consult queries or reports on the anonymised data from the ERN
<input type="radio"/> Dispatcher		handles requests for assistance on behalf of Coordinator
<input type="radio"/> HP		healthcare professional available to participate in or lead panels

When done you click on **Step 4**: You can type a comment to continue

Step 4 : type a comment →

On the final page, you will see a summary of what you have selected in previous steps. You can write a comment to the person who is going to validate the access request. *This is not mandatory*

New application access

1 Select application 2 Select organisation 3 Select access profile 4 **Recap and Submission**

Summary

Application	CPMS
Organisation	BE01 - Universitair Ziekenhuis Antwerpen
Access Profile	user

Comments

Before submitting
A request to get access to an application will be validated by the administrators, this is a manual process and can take a few days.

When you are ready click on **Submit request access**:

Submit request access

Clicking the Submit request access button will notify the coordinator of the ERN you requested access to and he or she will either accept or reject the request.

Once the access has been accepted you can access CPMS by going to <https://cpms.ern-net.eu/login/> and selecting **Login via EU login**.


The acceptance process may require a few days and is manually managed. Once accepted, The Help desk will create your user and will be automatically notified by mail when your user is created and ready for use.

2.3. Logging In

The application can be accessed through web-browsers. For best experience, make sure you are using a supported browser. CPMS is supported to its full potentials on **Google Chrome, Mozilla Firefox or Safari** preferably latest version.

Please note that users on unsupported browsers, will NOT be able to benefit from the video conference facility in CPMS.

Note:

- Cameras and microphones have to be enabled to be accessed through the browser.
- User on **Safari** browser can **NOT** share their screen as a limitation of Safari with the video technology in CPMS
- Users should **NOT** use private browsing modes such as “**incognito**” on chrome whilst using the CPMS.
- Also, in your settings, turn on: JavaScript.  To be modified or explained (procedure to activate Java in each supported browser).

To access CPMS Live system where only real, and authentic data are supposed to be recorded, please go to page on the web:

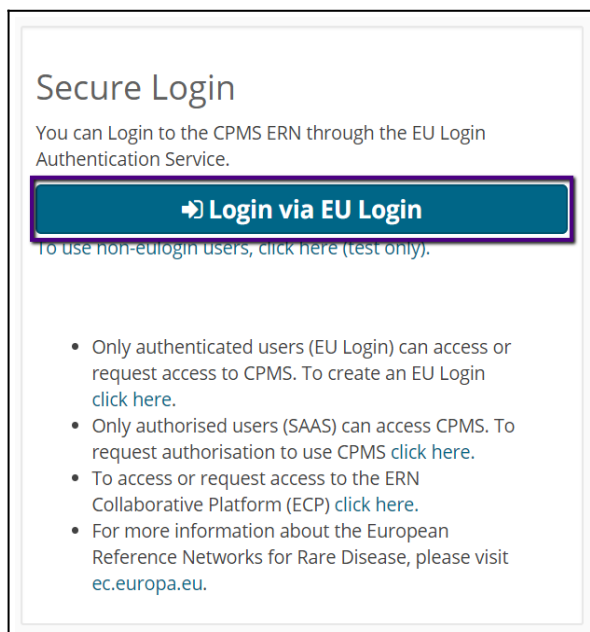
<https://cpms.ern-net.eu>

It is strongly advised to have the very last browser version available installed for a better performance and avoid any issues..

Potential users should already have or create an EU login account (which allows CPMS to validate the authenticity of the user without having access to the user passwords). When you have an EU login account (which can be used to access multiple EU information systems), click on the button “Login via EU login” to request authorisation to use CPMS and follow the instructions, this **authorisation** is granted at ERN level.

1. Click '**Login via EU login**', to access the EU login authentication page:

Figure 1: EU login Link



2. The user should enter their registered email, then choose a verification method that is typically a password and another method of authentication from the drop-down menu. Please refer to the different methods above.

Figure 2: EU login

2.4. CPMS Support Desk

In case you have any technical difficulty logging into the CPMS or using any of its services, please contact the support team via email sante-ern-cpms-itsupport@ec.europa.eu. Please send your feedback, suggestions, or complaints to the support team.

3. Accessing Your Applications within the CPMS

Successfully logging in to the CPMS, it will direct the user to the **Global Dashboard** Page as displayed below:

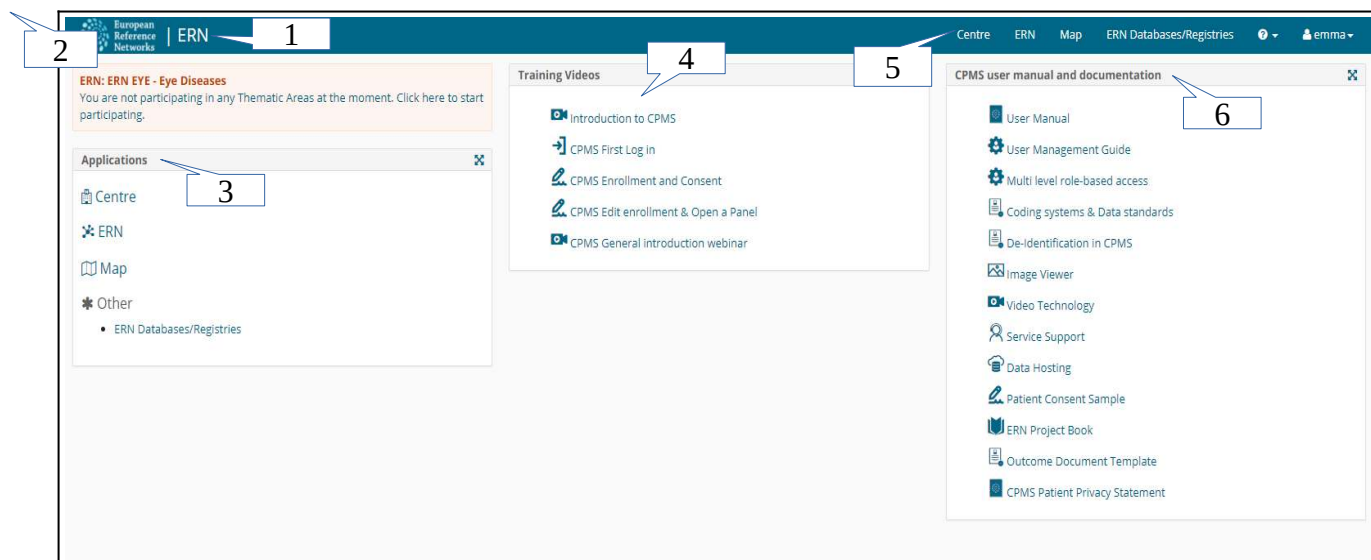


Figure 3: Home Page

1. Clicking here will always direct the user to the Global Dashboard from anywhere in the system.
2. There will always be a notification message appearing the top corner on the left hand side until users select their preferences in a number of thematic areas of their ERN.
3. The 'Applications' section lists and links the applications (ERN's, medical centres etc.) so that the user can access within the system.
4. The box in the middle of the Global Dashboard lists all the training materials and webinars produced for the CPMS users
5. The top menu contains links to the user's applications allowing for quick and easy navigation of the CPMS.
6. The documentation section contains various training materials and documents detailing the different parts of the system.

4. CPMS system navigation

4.1. Medical Centre (Hospital) Dashboard

By clicking on a link to one of their medical **centres** as detailed in Section 2(4.2. ERN Dashboard), the user can navigate to their dashboard for that **centre**. An example of such a dashboard is shown in Figure 4 below:

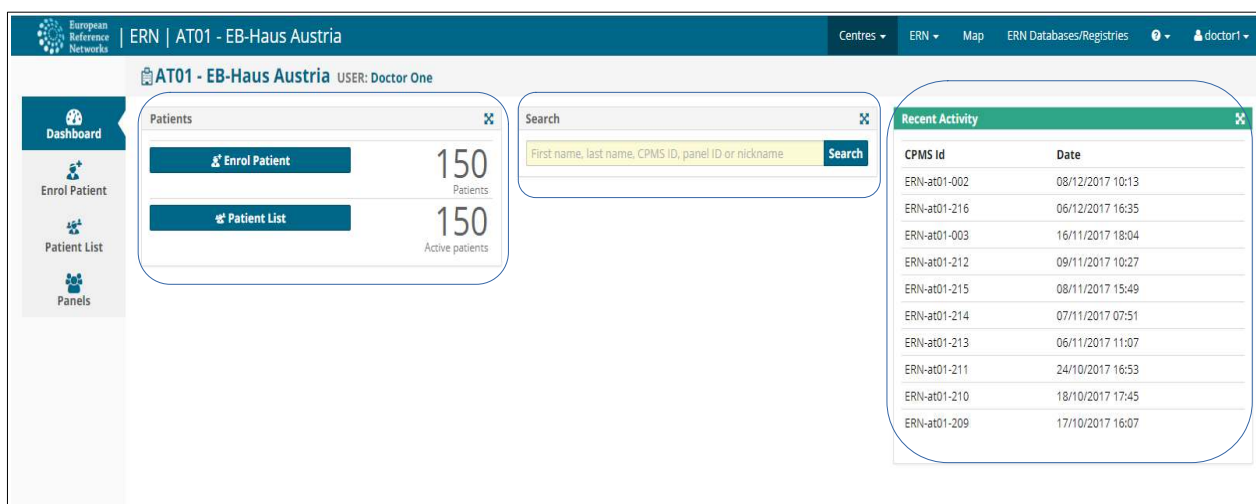


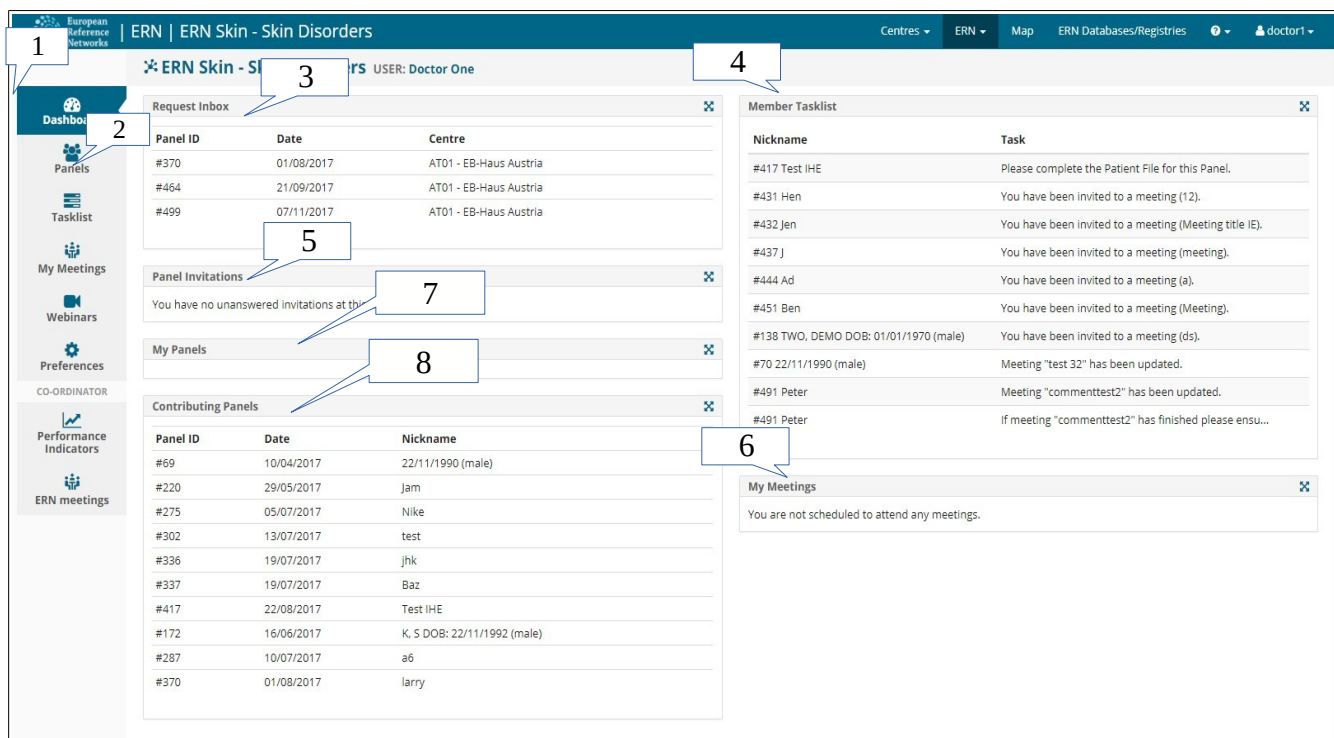
Figure 4: Medical Centre Dashboard

1. The side menu facilitates quick navigation of the CPMS's features, based on the user's role.
2. The 'Patients' box contains links for the user to **enrol** a new patient to the system and to view current patients in their **centre**.
3. The search feature allows the user to quickly find a particular patient, based on their first name, last name, CPMS ID, panel ID and nickname.
4. The 'Recent Activity' section lists the latest patients to have been enrolled or to have had their data updated. Clicking on the patient ID will direct the user to that patient's page.

4.2. ERN Dashboard

ERNs can be accessed in a similar manner to the medical **centres** by clicking on the appropriate link either from the top menu or from the applications page. Doing so will direct the user to their dashboard for that ERN. An example of an ERN dashboard is shown in Figure 5 below:

Figure 5: ERN Dashboard



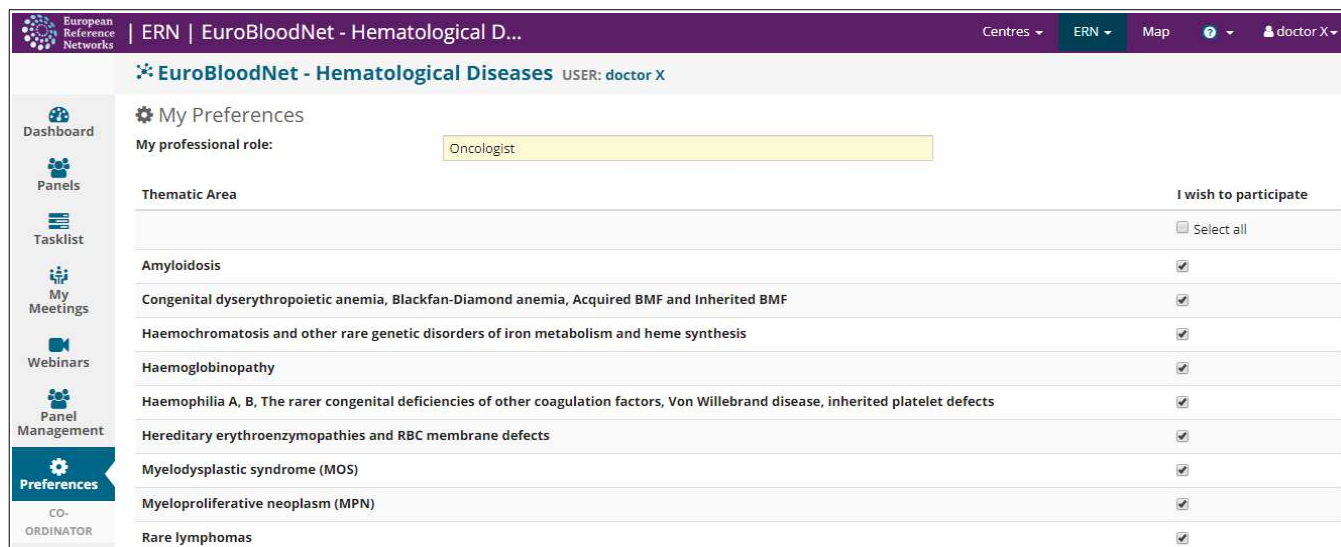
The screenshot shows the ERN Skin - Skin Disorders dashboard for a user named Doctor One. The dashboard is divided into several sections:

- 1. Side Menu:** A vertical menu on the left containing links to Dashboard, Panels, Tasklist, My Meetings, Webinars, Preferences, CO-ORDINATOR, Performance Indicators, and ERN meetings.
- 2. Panels:** A section showing a list of panels the user is involved in, including Panel ID, Date, and Centre.
- 3. Request Inbox:** A section showing a list of requests for assistance, including Panel ID, Date, and Centre.
- 4. Member Tasklist:** A section showing a list of pending tasks awaiting the user's interaction, including Nickname and Task.
- 5. Panel Invitations:** A section showing a list of invitations the user has to join different panels.
- 6. My Meetings:** A section showing a list of meetings the user is scheduled to participate in.
- 7. Contributing panels:** A section showing a list of panels the user is contributing to, including Panel ID, Date, and Nickname.
- 8. My Panels:** A section showing a list of panels the user is leading, including Panel ID, Date, and Centre.

- 1. Side Menu:** Contains links to the features of the ERN to allow for quick and easy navigation.
- 2. Panels:** Contains links to the panels on which the user is the Panel Lead and links to the panels that user contributes to, but does not lead.
- 3. Request Inbox:** Contains the requests for assistance sent to the user (as ERN Coordinator or Dispatcher only). Discussed further below.
- 4. Member Task list:** Contains a list of pending tasks awaiting the user's interaction.
- 5. Panel Invitations:** Lists the invitations the user has to join different panels. The invitations can be accepted or declined by clicking on the link.
- 6. My Meetings:** Lists the meetings the user is scheduled to participate in.
- 7. Contributing panels:** Lists the panels you are contributing to. Selecting a panel will immediately open it.

4.3. Preferences

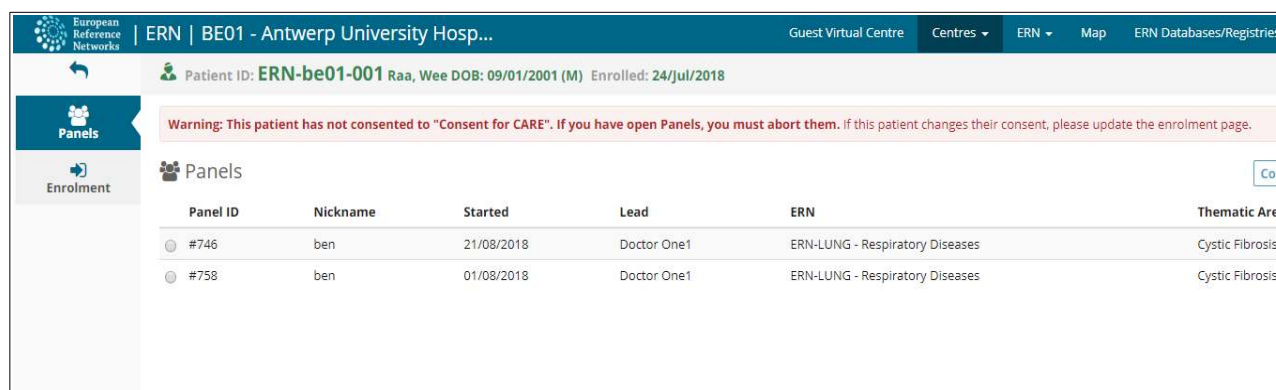
In the 'Preferences' tab, Health Professionals must specify the thematic areas they are interested in within the ERN. It is **mandatory** in the ERN application that all active users set their preferences; if the user does not set their preferences then they will not be able to access any of the CPMS components until their preferences are selected. This is an important step to ensure that the user is listed as an available Health Professionals during the Panel Selection phase (discussed below). Figure 6 below shows an example of a preference list.



My Preferences

My professional role:

Thematic Area	I wish to participate
	<input type="checkbox"/> Select all
Amyloidosis	<input checked="" type="checkbox"/>
Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF	<input checked="" type="checkbox"/>
Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis	<input checked="" type="checkbox"/>
Haemoglobinopathy	<input checked="" type="checkbox"/>
Haemophilia A, B, The rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects	<input checked="" type="checkbox"/>
Hereditary erythroenzymopathies and RBC membrane defects	<input checked="" type="checkbox"/>
Myelodysplastic syndrome (MOS)	<input checked="" type="checkbox"/>
Myeloproliferative neoplasm (MPN)	<input checked="" type="checkbox"/>
Rare lymphomas	<input checked="" type="checkbox"/>



Panels

Warning: This patient has not consented to "Consent for CARE". If you have open Panels, you must abort them. If this patient changes their consent, please update the enrolment page.

Panel ID	Nickname	Started	Lead	ERN	Thematic Area
#746	ben	21/08/2018	Doctor One1	ERN-LUNG - Respiratory Diseases	Cystic Fibrosis
#758	ben	01/08/2018	Doctor One1	ERN-LUNG - Respiratory Diseases	Cystic Fibrosis

4.4. Guest Dashboard

As an uncommon user, Guest or an external Health Professional may be given access to **enrol** patients and seek assistance from an ERN. Unlike typical users in CPMS, Guest HP will be assigned to a “Guest Virtual Centre” as virtual **centre**.

The “guest” Dashboard allows guest **users** to enrol their patients and participate in panels they create themselves.

When the ERN Coordinator accepts the guest’s invitation, they assign a lead and grant them access to the ERN dashboard as a guest. The guest will not have access to an actual Healthcare Provider (Centre) inside CPMS. Instead they will be given access to a Virtual Centre inside the ERN they requested access to. They can enrol Patients, see a list of already enrolled patients and also any open Panels.

The Guest user can open a panel and will be part of it. Note that it is not possible for a guest user to act as the lead of a panel. When any of Enrolling Guest in GVC or Expert Guest in ERN are added to an ERN, CPMS allows to record the HCP name in which the clinician works in the Preference page in the ERN dashboard. This is to provide more information to be visible on Guest user to other ERN members when forming a panel and collaborating on patient.

Note: A guest user is a member of CPMS for 90 days. Then if he/she is not participating to a panel, the account will be deactivated.

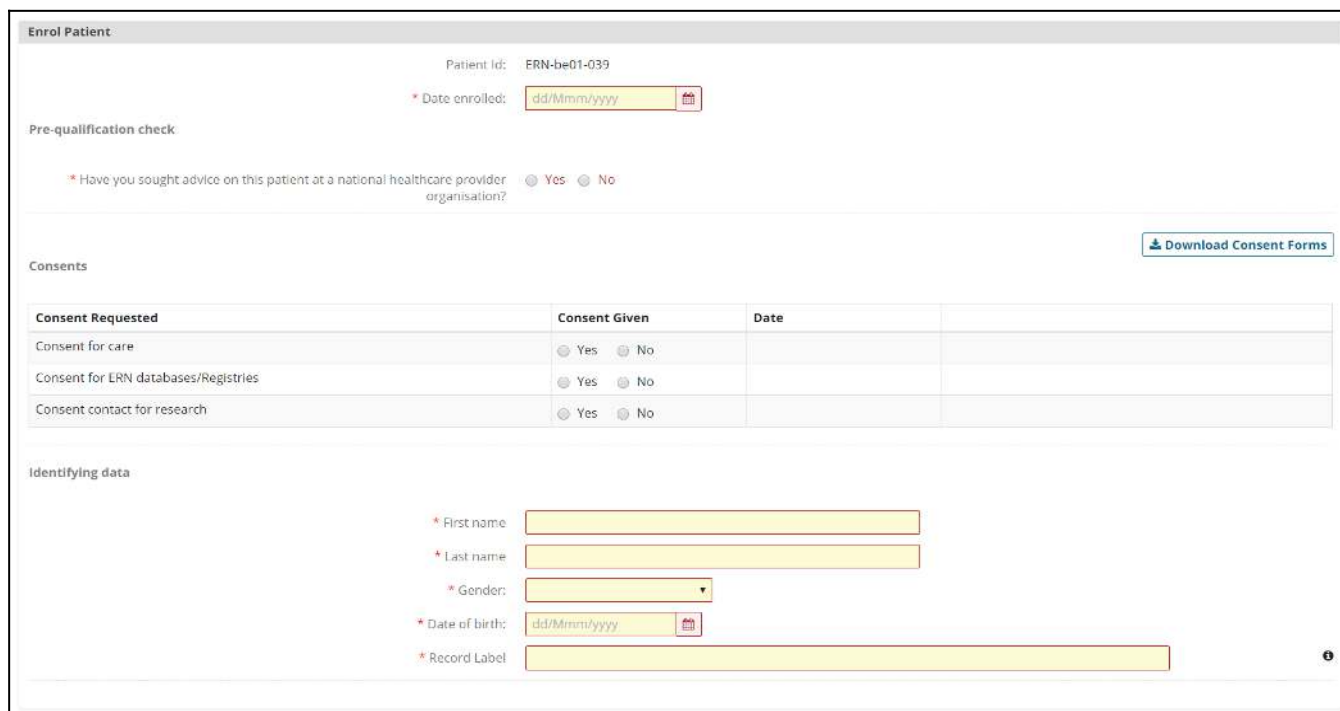
5. Patient Enrolment

In order to **enrol** a new patient for a certain medical **centre**, the enrolling Health Professional can click on either of the ‘**Enrol Patient**’ buttons on their dashboard for the medical **centre** in question.

The “**Enrol Patient**” button will allow the Health Professional to **enrol** a new patient the “Patient List” button will show the list of the existing patients

Figure 8: **Enrol Patient Buttons**

Clicking on either of these buttons will bring the user to the ‘**Enrol Patient**’ form shown in Figure 9. Required fields are indicated by a red field or a ‘required’ tag. These **must** be filled out in order for the patient to be successfully enrolled.



Enrol Patient

Patient Id: ERN-be01-039

* Date enrolled:

Pre-qualification check:

* Have you sought advice on this patient at a national healthcare provider organisation? ☐ Yes ☐ No

Consents

[Download 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:

Figure 9: **Enrol Patient Form**

5.1. Consent

In order to be enrolled in the system, the patient **must** give consent. As can be seen in Figure 9 above, there is a checkbox, which the enrolling Health Professional must use to indicate that consent has been given. The consent forms are available in the local language for all Member States taking part in the ERN project. User can download the consent by clicking the ‘Download Consent Model Forms’ button located on the right hand side of the consent section. Three types of consents are available on the CPMS:

- Consent for care pathway: This consent is the minimum required consent for successful enrolment and having consultation panels on a particular patient.
- Consent for ERN databases and registries: This consent is linked directly to authorize Panel Leads to make the Pseudonymised clinical data available in low accessibility databases for authorized users after panels have been closed and an outcome has been signed off.
- Consent to be contacted for research: This consent outlines that patients are interested to be contacted for specific research projects outside the CPMS.

Download Consent Forms

Download Consent Forms (pdf format)

- BG (20/11/2017)
- CS (04/05/2018)
- DA (20/11/2017)
- DE (05/03/2018)
- EL (20/11/2017)
- EN (20/11/2017)
- ES (04/05/2018)
- ET (20/11/2017)
- FI (20/11/2017)
- FR (04/05/2018)
- GA (20/11/2017)
- HR (20/11/2017)
- HU (20/11/2017)
- IT (04/05/2018)
- LT (20/11/2017)
- LV (21/11/2017)
- MT (20/11/2017)
- NL (20/04/2018)
- NO (05/12/2017)
- PL (04/05/2018)
- PT (20/11/2017)
- RO (20/11/2017)
- SK (20/11/2017)
- SL (20/11/2017)
- SV (04/05/2018)

Reference

Guidelines Toolkit Case Study

Good Practices Informed Consent Data Management

If a patient revokes their consent for care, all open panels for that patient must be cancelled. An error message to this effect will be displayed on the patient's page to remind Health Professionals from the enrolment **centre** to cancel any on-going or future consultation requests for this particular patient, as shown below in Figure 10:

Figure 10: Error Message to remind the user to cancel any open panels for a patient who has revoked consent for care.

5.2. Wipe Patient Record

When the consent for care is revoked or any other reason that may require patient removal from CPMS, HP from the enrolment centre can wipe the patient record that from CPMS. The patient records contains patient identifying data, clinical data in panels and also any attachment. To wipe the patient record, users are request to visit the enrolment page on the patient record and scroll down and click on **Wipe this Patient's data**. CPMS will record a reason why a HP is removing a patient from CPMS for audit and security purposes.

Wipe Patient's Data

If a patient withdraws consent for sharing their information with the ERN, you must remove their data from the system. Please note that this is a full wipe of the patient's data. The data cannot be re-constituted. If you want to work with this patient again, you will have to re-enter the data.

Wipe this patient's data

Wipe Patient's Data

☒ Please confirm that you understand that it is your responsibility to notify the patient that their data has been cleared down.

Has a request from the Patient to delete file been received:
 ☐ Yes
 ☒ No

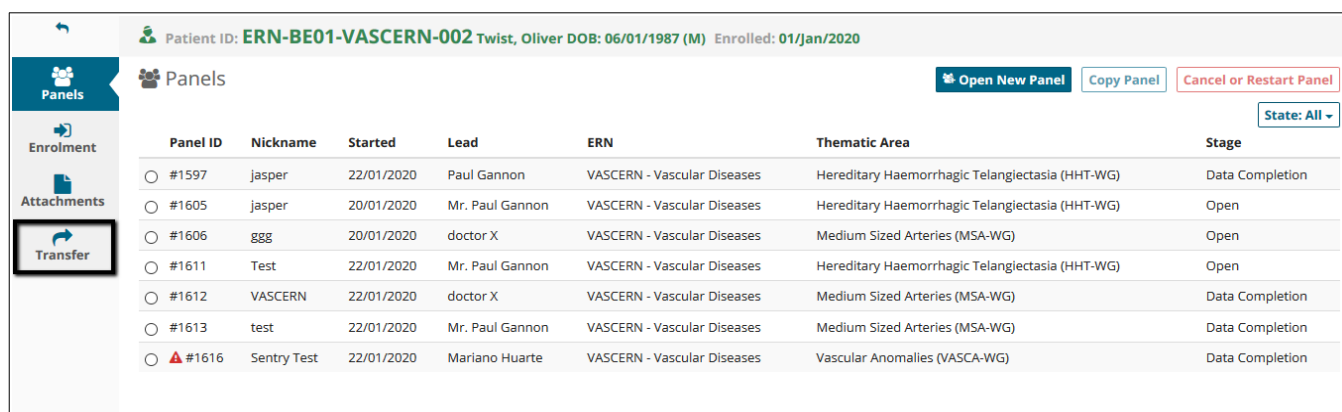
Reason for Deletion:

6. Record Transfer

This functionality is meant to serve users with temporary access into CPMS (i.e. HP Guest in Guest Virtual Centre -GVC-) or those who are assigned to HCP that might be deactivated/removed from the ERN in future occasions. The feature enables users to trigger a request to the ERN Coordinator to transfer patient record(s) before their access to CPMS is expired so that the data controllership is switched from a HCP/GVC to the ERN Coordinator Centre.

ERN Coordinators shall be nominated and managed by DG SANTE so that a definitive list of 24 users -one per each network- shall deal with such requests.

HP in GVC or HCP can access this feature by going to Patient List in the Centre dashboard then access any of the Patient Records wherein a TRANSFER tab is show in the left hand-side menu.



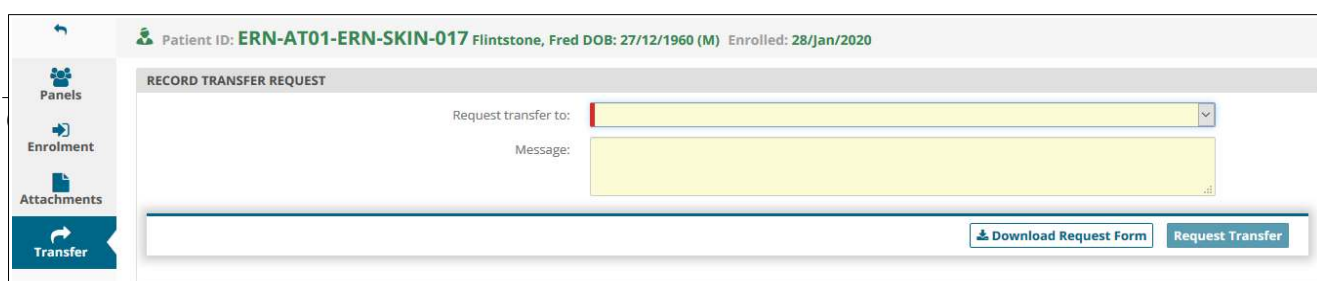
Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage
#1597	jasper	22/01/2020	Paul Gannon	VASCERN - Vascular Diseases	Hereditary Haemorrhagic Telangiectasia (HHT-WG)	Data Completion
#1605	jasper	20/01/2020	Mr. Paul Gannon	VASCERN - Vascular Diseases	Hereditary Haemorrhagic Telangiectasia (HHT-WG)	Open
#1606	ggg	20/01/2020	doctor X	VASCERN - Vascular Diseases	Medium Sized Arteries (MSA-WG)	Open
#1611	Test	22/01/2020	Mr. Paul Gannon	VASCERN - Vascular Diseases	Hereditary Haemorrhagic Telangiectasia (HHT-WG)	Open
#1612	VASCERN	22/01/2020	doctor X	VASCERN - Vascular Diseases	Medium Sized Arteries (MSA-WG)	Data Completion
#1613	test	22/01/2020	Mr. Paul Gannon	VASCERN - Vascular Diseases	Medium Sized Arteries (MSA-WG)	Data Completion
#1616	Sentry Test	22/01/2020	Mariano Huarte	VASCERN - Vascular Diseases	Vascular Anomalies (VASCA-WG)	Data Completion

Upon clicking on **Transfer** users can select the Centre of the ERN Coordinator to whom the request shall be initiated and upon accepting the request, this HCP shall be the destination of the patient record.

Please note that in the event of ERN Coordinator decline the Request for transferring the record into their HCP, the patient record shall be deleted automatically from CPMS when all active panels are closed.

For offline process to document this request, users are able to download the transfer request form by clicking on **Download Request form** which is available in various languages to server all Member States whose Centres are part of ERNs.

Users also can use the dialogue box in the **Transfer** functionality to record a short description of the reasons why a patient transfer request is submitted to the ERN Coordinator (e.g. User access is expiring or HCP is no longer active member in an ERN.)



Patient ID: ERN-AT01-ERN-SKIN-017 Flintstone, Fred DOB: 27/12/1960 (M) Enrolled: 28/Jan/2020

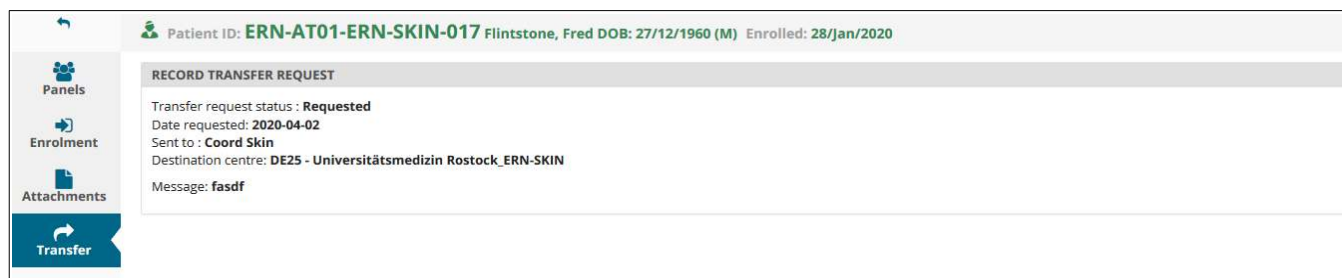
RECORD TRANSFER REQUEST

Request transfer to:

Message:

[Download Request Form](#) [Request Transfer](#)

Upon submitting the record transfer request, users shall be able to see the current status of the **Request Submitted**.

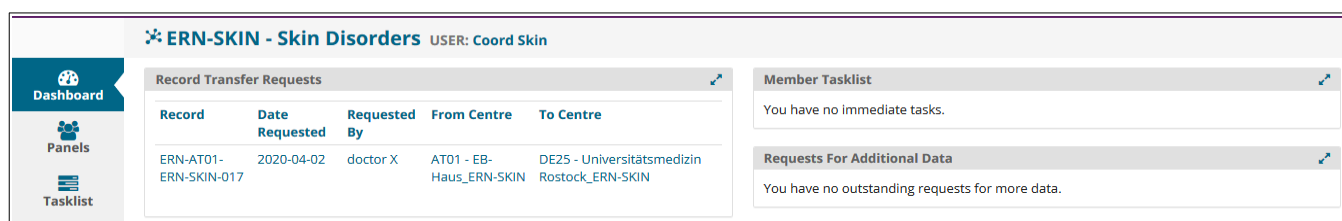


Patient ID: **ERN-AT01-ERN-SKIN-017** Flintstone, Fred DOB: 27/12/1960 (M) Enrolled: 28/Jan/2020

RECORD TRANSFER REQUEST

Transfer request status : **Requested**
 Date requested: **2020-04-02**
 Sent to : **Coord Skin**
 Destination centre: **DE25 - Universitätsmedizin Rostock_ERN-SKIN**
 Message: **fasdf**

ERN Coordinators shall receive the **Request** through the ERN Dashboard and also notified by email about a pending request.



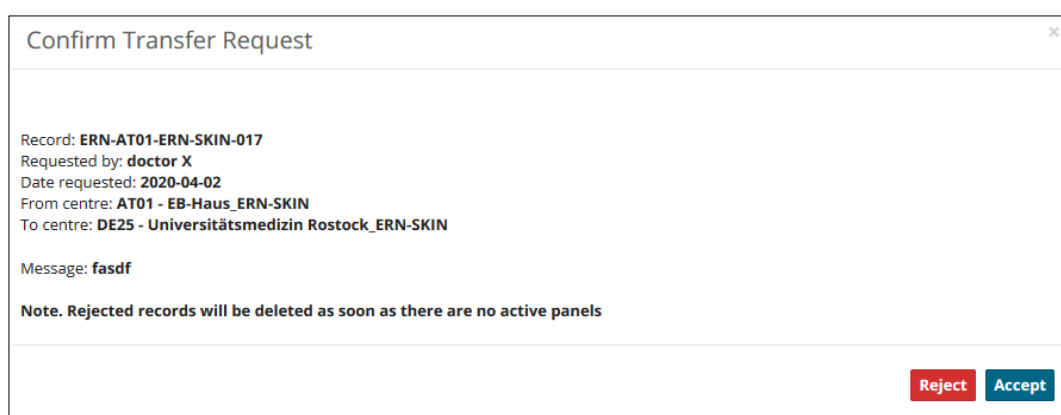
ERN-SKIN - Skin Disorders USER: **Coord Skin**

Record	Date Requested	Requested By	From Centre	To Centre
ERN-AT01-ERN-SKIN-017	2020-04-02	doctor X	AT01 - EB-Haus_ERN-SKIN	DE25 - Universitätsmedizin Rostock_ERN-SKIN

Member Tasklist
You have no immediate tasks.

Requests For Additional Data
You have no outstanding requests for more data.

When clicking on the **Queued Request** on the dashboard, ERN Coordinator shall decide on accepting the request to transfer the patient record to their HCP or decline the request which shall trigger a process in the background to delete the record permanently from the CPMS system and can not be retrieved.



Confirm Transfer Request

Record: **ERN-AT01-ERN-SKIN-017**
 Requested by: **doctor X**
 Date requested: **2020-04-02**
 From centre: **AT01 - EB-Haus_ERN-SKIN**
 To centre: **DE25 - Universitätsmedizin Rostock_ERN-SKIN**
 Message: **fasdf**

Note. Rejected records will be deleted as soon as there are no active panels

Reject **Accept**

When Accepting the **Transfer request**, the patient record shall be migrated into the HCP of the ERN Coordinator as the new destination and as specified at the time of submitting the request.

Thereafter, the ERN Coordinator shall review the **Patient Consent** to make sure the enrolment form of the patient in the new centre is up-to-date. This appears on the Centre dashboard as seen in the screenshot below.

DE38 - Universitätsklinikum Freiburg_ERN-SKIN USER: Ms. Natalia Lepinski

Dashboard

Enrol Patient

Patient List

Panels

Patients

Enrol Patient 10

Patient List 10

Patients to be reviewed

ERN-DE38-ERN-SKIN-001, QWDW, FF DOB: 30/12/1980 (F) View

Search

First name, last name, CPMS ID, panel ID or nick Search

Recent Activity

CPMS Id	Date
ERN-DE38-ERN-SKIN-003	20/mar/2020 18:02 (Europe/Dublin)
ERN-DE38-ERN-SKIN-002	20/mar/2020 17:56 (Europe/Dublin)
ERN-IE01-ERN-SKIN-007	19/mar/2020 15:14 (Europe/Dublin)
ERN-DE38-ERN-SKIN-001	19/mar/2020 14:41 (Europe/Dublin)
ERN-IE01-ERN-SKIN-006	19/mar/2020 14:35 (Europe/Dublin)

7. Covid-19 Patient Transfer

As part of the effort to assist with the global pandemic of Covid-19, a special section of the CPMS application is dedicated to the process of dealing with patients that need to be transferred between HCPs (Centres) within and across international borders. Much of the functionality as described already in this document remains the same with some small changes that are local only to this section of the application. These will be explained here.

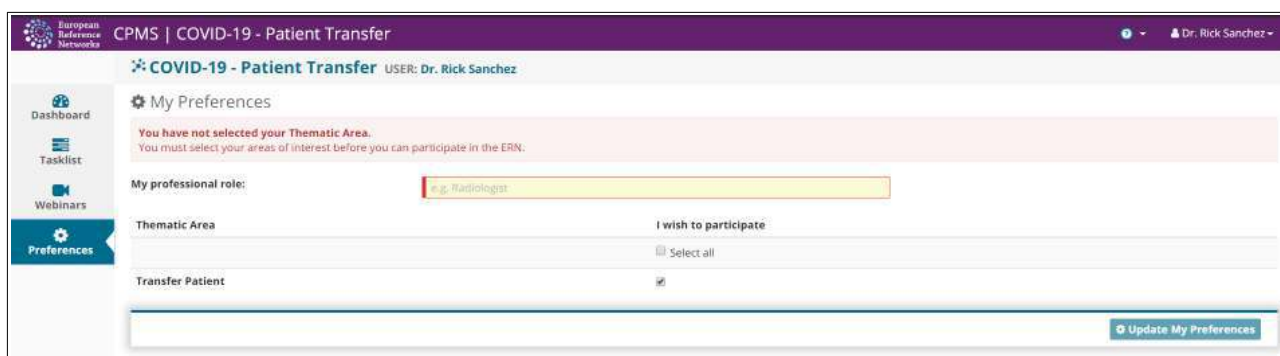
The purpose of the Covid-19 ERN is to contain Centres dedicated to enrolling patients in order to Transfer them from one Centre to another Centre. There are no collaborations, meetings, Panels or Guest users. The standard procedure of having a Coordinator role for an ERN and a single Transfer Coordinator per ERN is not required, as this would complicate the intended functionality.

In the CPMS Covid-19 application, Transfer Coordinators are assigned to a Centre and there may be multiple Transfer Coordinators per Centre. The only roles required at the Covid-19 ERN level is a HP. The only roles required at a Centre level are HP and Transfer Coordinator. Enrolling Patients and Requesting Transfers operate in the same manner, however Accepting Transfers will occur at the receiving Centre's Dashboard, not the ERN Dashboard.

What follows next is a step by step operation of logging into the system, enrolling a patient, requesting a transfer, accepting a transfer and confirming the consent of a transferred patient.

7.1. Logging In for the First Time

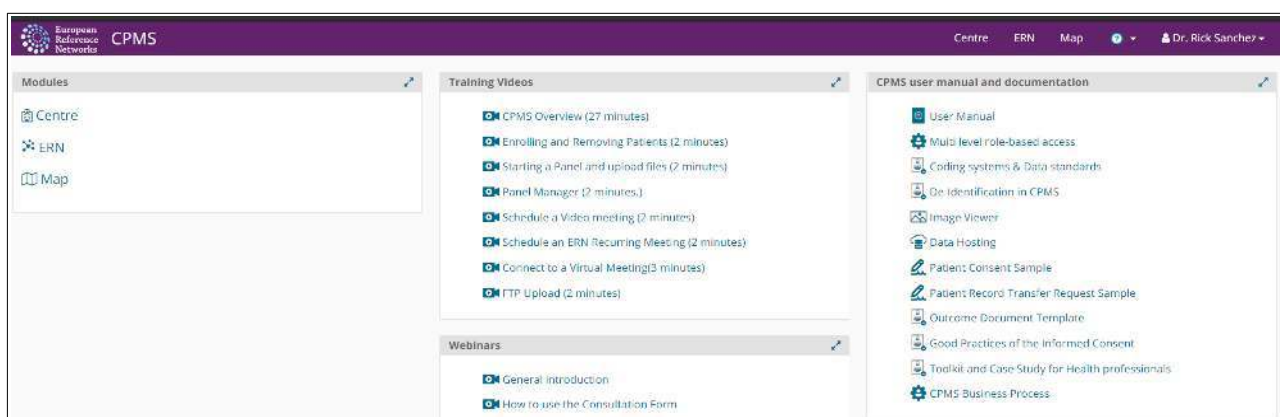
Upon logging into the system for the first time, the user will be greeted with a screen requesting to confirm their understanding of the usage of the system and their Professional code of conduct. Once the screen is confirmed the User Preferences screen will be displayed.



- Enter in your Professional Role.
- Select 'Transfer Patient' as the area you wish to participate in.
- Click on 'Update My Preferences'.
- In the top menu bar select the 'Centre' button, this will bring you to your Centre Dashboard.

7.2. Standard Log In

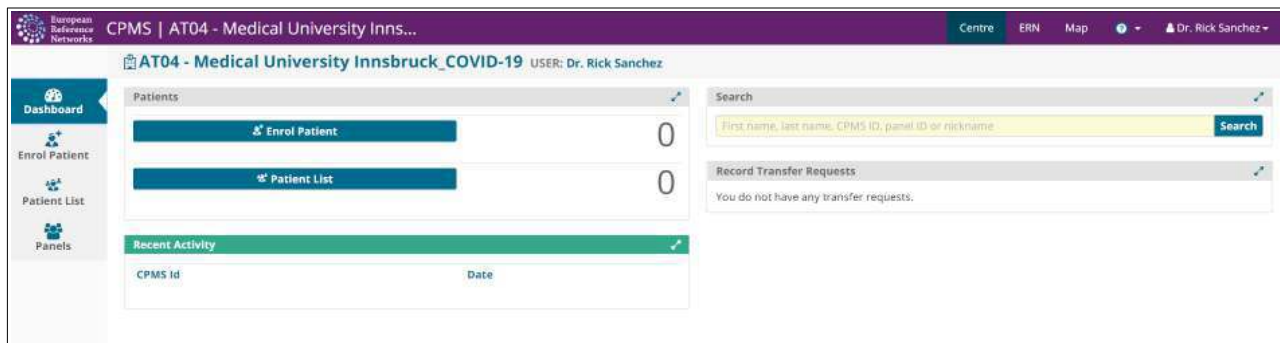
After logging in to the system as described in this document the first screen shown is the CPMS Dashboard:



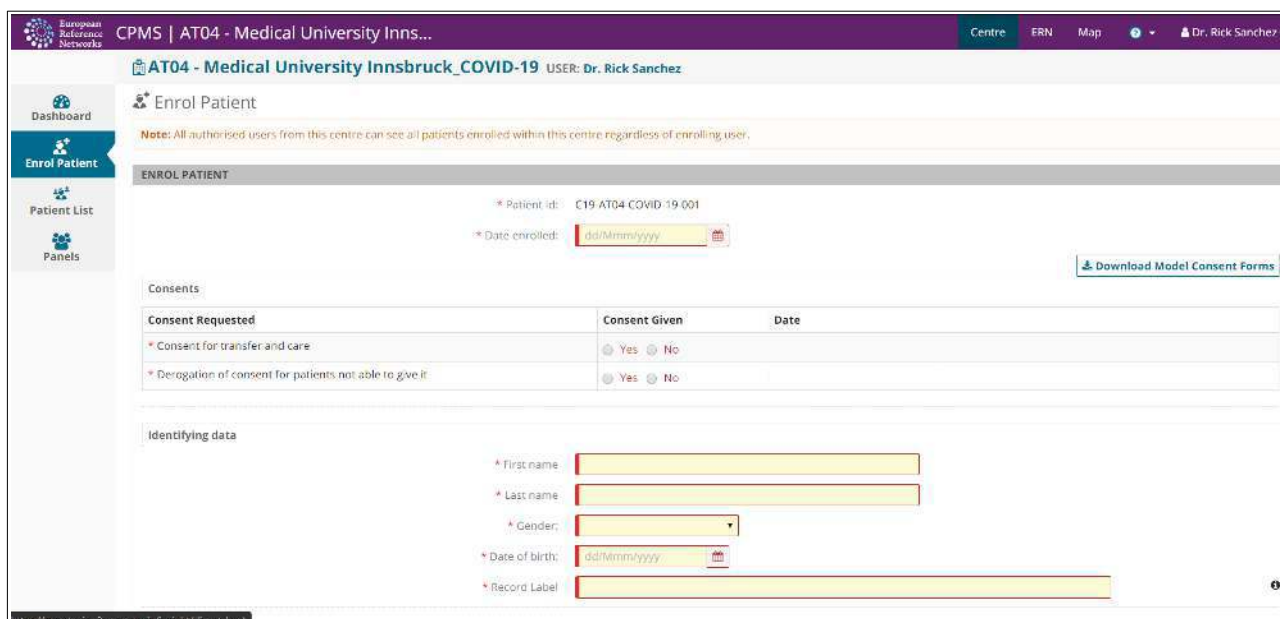
- Click on the Centre button in the top menu bar, or click on the Centre link in the Modules widget on the left hand side of the Dashboard.
- In order to return to this dashboard at any time, click on the ERN Icon and CPMS link on the left hand side of the top menu bar.

7.3. Enrolling a Patient

All operations in the CPMS Covid-19 application are accessed from the Centre Dashboard. The Centre Dashboard displays the same information as the standard Centre Dashboard, with the addition of a widget for Record Transfer Requests.



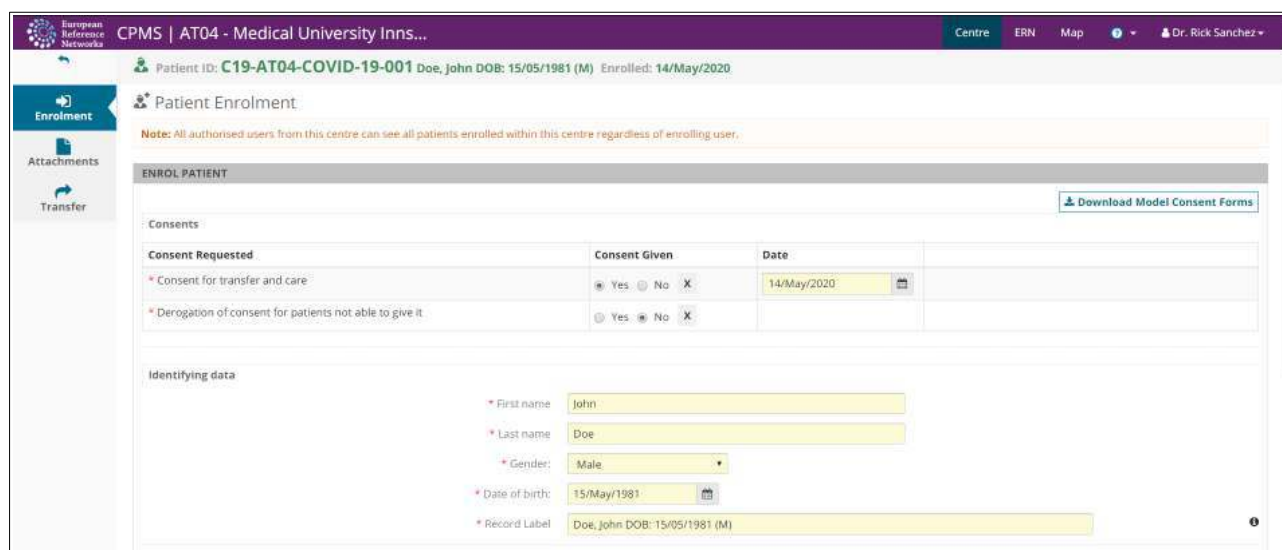
- In Centre Dashboard, click on the Enrol Patient button in the Dashboard or click the tab Enrol Patient on the left hand side of the screen.
- The Patient Enrolment screen is displayed:



- Enter the enrolment date for this patient. The calendar will default to the current date.
- Click on the Download Modal Consent Forms button to show a screen that will allow you to download and manually fill in the Consent for Transfer and Care Form in your chosen language.
- Fill in Consent details on screen.
 - "Consent for transfer and care" is the overall consent, given or not given.
 - "Derogation of consent for patients not able to give it" is the type of consent given, either from the patient or from someone else.
 - If the option **Yes** is selected, it means that someone else **other** than the patient gave consent.

- If the option **No** is selected, it means that the **patient** themselves gave the consent.
- Fill in patient identifying data.
- Click Enrol Patient.
- Confirm the understanding of data sharing responsibilities by ticking the checkbox and clicking I Confirm.

The patient information screen with all the patient data filled in is shown:



CPMS | AT04 - Medical University Inns...

Centre ERN Map Dr. Rick Sanchez

Patient ID: C19-AT04-COVID-19-001 Doe, John DOB: 15/05/1981 (M) Enrolled: 14/May/2020

Patient Enrolment

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

ENROL PATIENT

Download Model Consent Forms

Consents

Consent Requested	Consent Given	Date
* Consent for transfer and care	<input checked="" type="radio"/> Yes <input type="radio"/> No X	14/May/2020
* Derogation of consent for patients not able to give it	<input checked="" type="radio"/> Yes <input type="radio"/> No X	

Identifying data

* First name: John

* Last name: Doe

* Gender: Male

* Date of birth: 15/May/1981

* Record Label: Doe, John DOB: 15/05/1981 (M)

7.4. Adding Attachments to a Patient

- From the Centre Dashboard click on the Patient List button in the Dashboard or on the Patient List tab on the left hand side.



CPMS | AT04 - Medical University Inns...

Centre ERN Map Dr. Rick Sanchez

AT04 - Medical University Innsbruck COVID-19 USER: Dr. Rick Sanchez

Patient List

Last Name	First Name	Record Label	CPMS Id	Enrolled	Gender	Frozen	Date Of Birth
Doe	John	Doe, John DOB: 15/05/1...	C19-AT04-COVID-19-001	14/May/2020	M	false	15/May/1981

Enrol Patient

- From the list of patients, select the patient of interest by clicking on their row.
- The Patient information screen will be displayed.
- In the Patient Information screen, click the Attachments tab to the left of the screen.
- The Patient Attachments screen will be displayed.

CPMS | AT04 - Medical University Inns...

Centre ERN Map Dr. Rick Sanchez

Patient ID: C19-AT04-COVID-19-001 Doe, John DOB: 15/05/1981 (M) Enrolled: 14/May/2020

Attachments (Files / Images) [Attach file / image](#)

Viewer	Attachment name	Uploaded	Date	Size	Usage
--------	-----------------	----------	------	------	-------

- Click the Attach File/Image button in the top right of the page.
- Confirm the understanding about sharing personal data.
- Click the grey area of the modal to open the windows explorer and find a file to attach.
- Click the Attach button.
- Repeat for each file to be attached for a patient.
- To attach multiple files at once, please create a **zip** folder containing all the files to be uploaded together.

CPMS | AT04 - Medical University Inns...

Centre ERN Map Dr. Rick Sanchez

Patient ID: C19-AT04-COVID-19-001 Doe, John DOB: 15/05/1981 (M) Enrolled: 14/May/2020

Attachments (Files / Images) [Attach file / image](#)

Viewer	Attachment name	Uploaded	Date	Size	Usage
pdf	Patient Files	Dr. Rick Sanchez	14/May/2020	8.0 kB	

7.5. Request a Patient Transfer

- From the Centre Dashboard click on the Patient List button on the dashboard or on the Patient List tab on the left hand side
- From the list of patients, select the patient of interest by clicking on their row.
- Click the Transfer tab to the left of the screen

CPMS | AT04 - Medical University Inns...

Centre ERN Map Dr. Rick Sanchez

Patient ID: C19-AT04-COVID-19-001 Doe, John DOB: 15/05/1981 (M) Enrolled: 14/May/2020

RECORD TRANSFER REQUEST

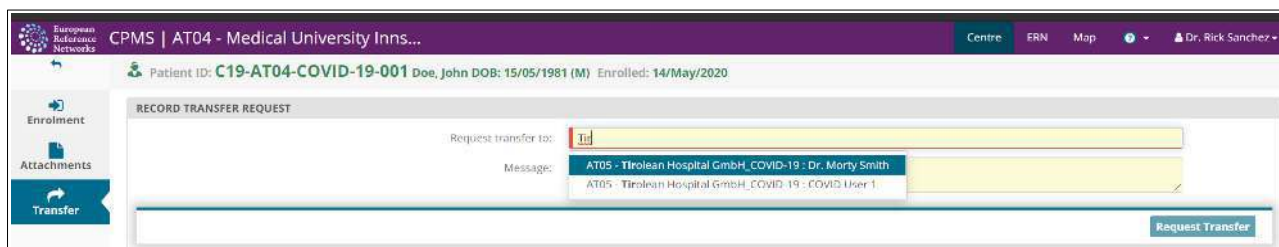
Request transfer to:

Message:

[Request Transfer](#)

- In the Request Transfer To dialogue box, begin typing the code for the centre (hospital/department) that the patient is to be transferred to.
- The list of centres will be filtered and the correct centre can be selected.

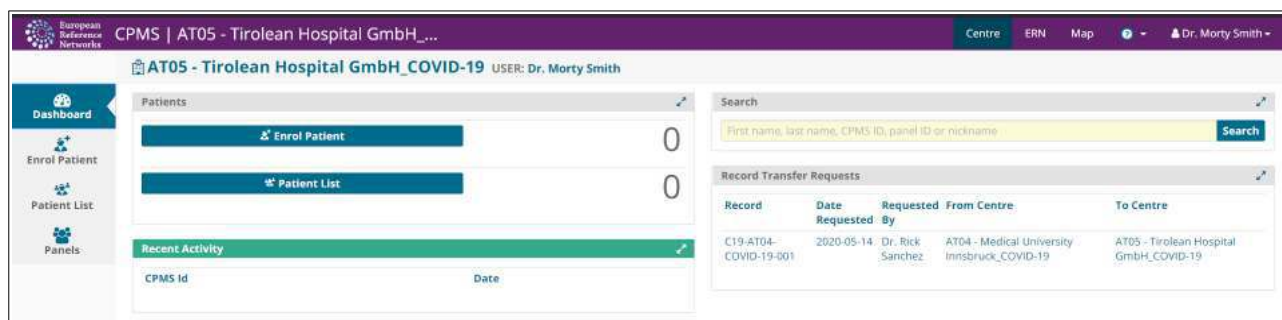
- If there are more than one Transfer Coordinators for a centre, the centre will be listed for each Transfer Coordinator. In this case, select the Transfer Coordinator you wish to send the Transfer Request to.
- Only one Transfer Request can be made at a time for a patient.



- Enter any optional text as part of a message to the Transfer Coordinator.
- Click Request Transfer
- In the following Confirmation modal, click Request Transfer
- A Site message will appear to state the Transfer request has been created. Click OK.
- Click on either the Centre name or the Centre button in the top bar to return to the Centre Dashboard

7.6. Accepting a Patient Transfer Request

- In the Centre Dashboard, there is a Record Transfer Requests widget on the right hand side of the dashboard
- For each Transfer Request made to you, there will be a new entry in the list.



Record	Date Requested	Requested By	From Centre	To Centre
C19-AT04-COVID-19-001	2020-05-14	Dr. Rick Sanchez	AT04 - Medical University Innsbruck_COVID-19	AT05 - Tirolean Hospital GmbH_COVID-19

- Click on the Transfer Request for a patient

Confirm Transfer Request

Record: **C19-AT04-COVID-19-001**
 Requested by: **Dr. Rick Sanchez**
 Date requested: **2020-05-14**
 From centre: **AT04 - Medical University Innsbruck_COVID-19**
 To centre: **AT05 - Tirolean Hospital GmbH_COVID-19**

Message: **Please accept this patient**

Note. Rejected records will be deleted as soon as there are no active panels

Reject

Accept

- In the Confirm Transfer Request modal choose to Accept or Reject this Transfer Request.
 - If you choose to Reject, the patient record will be immediately removed from the system as there are no panels in this part of the application.
 - If you choose to Accept, the patient record will be added to your Centre's patient list
- Click OK in the site message to say the Transfer Request has been approved.
- From the Centre Dashboard, click on the Patient List button on the dashboard or on the Patient List tab on the left hand side to see the newly added patient to your Centre.

7.7. Reviewing Transferred Patients

- In the Centre Dashboard, in the Patients widget under the Patient List button is a list called 'Patients to be reviewed'.
- This is a list of the recently transferred patients to this Centre.

European Reference Networks

CPMS | AT05 - Tirolean Hospital GmbH_...

Centre ERN Map Dr. Morty Smith

AT05 - Tirolean Hospital GmbH_COVID-19 USER: Dr. Morty Smith

Dashboard

Enrol Patient

Patient List

Panels

Enrol Patient 1

Patient List 1

Patients to be reviewed

C19-AT04-COVID-19-001, Doe, John DOB: 15/05/1981 (M) View

Recent Activity

CPMS Id	Date
C19-AT04-COVID-19-001	14/may/2020 20:15 (Europe/Vienna)

Search

First name, last name, CPMS ID, panel ID or nickname Search

Record Transfer Requests

You do not have any transfer requests.

- Click on the View button for each patient in the list.
- The patient details screen is displayed with a notification stating that the consent for this patient must be confirmed.

CPMS | AT05 - Tirolean Hospital GmbH...

Centre ERN Map Dr. Morty Smith

Patient ID: C19-AT04-COVID-19-001 Doe, John DOB: 15/05/1981 (M) Enrolled: 14/May/2020

This patient data has either been recently transferred to this centre or it has been 15 years since their last consent. Please review the need to retain this patient data and delete it or obtain updated consent to retain it.

[Update patient consent](#) [Wipe patient data](#)

Patient Enrolment

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

ENROL PATIENT

[Download Model Consent Forms](#)

Consent Requested	Consent Given	Date
* Consent for transfer and care	<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="button" value="X"/>	14/May/2020
* Derogation of consent for patients not able to give it	<input type="radio"/> Yes <input checked="" type="radio"/> No <input type="button" value="X"/>	

Identifying data

* First name: John

* Last name: Doe

- Click on the Update Patient Consent button at the top of the patient data screen

Update Patient Consent

[Download Consent Forms](#)

Consent Requested	Consent Given	Date
* Consent for transfer and care	<input checked="" type="radio"/> Yes <input type="radio"/> No <input type="button" value="X"/>	14/May/2020
* Derogation of consent for patients not able to give it	<input type="radio"/> Yes <input checked="" type="radio"/> No <input type="button" value="X"/>	

☐ I confirm that I have reviewed the need to retain this data and obtained updated consent to retain it.

[Cancel](#) [Update consent](#)

- In the Update Patient Consent modal, ensure that the patient consent details are correct.
 - If the patient consent form has been transferred physically with the patient, ensure the dates and consent given match the details in the modal and tick the "I confirm ..." check box
 - If new consent forms are required to be signed, they can be downloaded from the Download Consent Form button in this modal.
 - If the patient consent form has been attached to the patient record, this can be viewed and downloaded to confirm the details in the modal are correct.
- To view any attached consent forms, cancel the Update Patient Consent modal by clicking on the Cancel button. This will not affect the patient data.

- Click on the Attachments tab on the left menu of the page.
- If the consent form is there, click on the 3 dots button at the end of the attachment row and choose to either view or download the attachment.
- Once you are satisfied with the contents of the consent form, you can access the Update Patient Consent by again clicking on the Update Patient Consent button at the top of the screen.
- Tick the "I confirm ..." check box and click on Update Consent.
- Click OK in the site message box that tells you the consent has been updated.

7.8. Automatic Patient Removal.

Patients that are enrolled into a Covid-19 Centre in the Covid-19 ERN are subject to an automatic removal policy from the system. All record of the patient and all attachments belonging to the patient will be automatically deleted from the system on the night of their 30th day after enrolment. That means that a patient enrolled into the system on 1st April 2020, will be automatically deleted from the system on the 1st May 2020.

This automatic patient removal is only for Covid-19 patients and does not affect patients enrolled in other Centres of other ERNs in the system.

8. Consultation Form

The consultation form is the heart of the consultation process on which experts and specialists can collaborate to reach a consensus for diagnosis and treatment. The Panel lead or the enrolling clinician can fill in patient's data and attach documents, thereafter, panel members will be invited to review the consultation request and decide whether or not they can participate or request more information and procedure results to be provided for making better informed decisions.

The consultation form is composed of multiple sections where a Panel Lead or Panel Admin from the enrolment **centre**, can type in information and record findings relevant to the type of the consultation request.

For each section, when it is selected, either a red or an orange dot appears on the right of the title. When it is fully filled in or that the mandatory fields are filled in, it turns to green. When on red, mandatory fields are not filled in.

When in orange, some fields are not filled in but they are not mandatory.

Sometimes an orange status can turn to red because a field requires another mandatory when filled in.

The form can be only edited in the “Edit view” to allow doctors to record patient data into the form at two stages in the workflow namely: “Open” and “Data Completion”. Whilst, during the assessment process and the later stages of the workflow, the form will be displayed in view mode only beside to the timeline.

All ERNs will be using one generic data set known as Basic Data Set in the CPMS. Then, further in the development process of the CPMS, an Extended Data Set will be developed based on the customized need of each ERN. It is highly expected that each ERN will have unique requirements for some conditions or specific thematic disease area.



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

The following coding and terminology systems have been used to build the Basic Data-Set in the consultation form:

- ICD
- Orphanet Rare Disease Ontology (ORDO)
- ICCC-3 based on ICD-O-3
- Human Phenotype Ontology (HPO)
- LOINC
- MedDRA
- UCUM Codes
- ISO 3166-1
- HGNC
- EDQM Standard Terms
- NCBI genomic nucleotide RefSeq Id/LRG Id
- Eurostar classification for self-defined current economic status
- ISCED classification
- ATC (Anatomical Therapeutic Chemical)

Persistent editable fields: In the rare diagnosis section, users can choose one of two options; Current or Working diagnosis. When selecting “Working Diagnosis”, multiple differential diagnoses can be added underneath this option. Working diagnosis is the only section within the form that can be added during the assessment stage of the workflow in order to eliminate or update diagnoses during the panel life-cycle.

Rare Disease Diagnosis

Update

Working Diagnosis

Diagnosis Coding System:	ICD-10, Orphanet
ICD-10 classification:	A00.9: Cholera, unspecified
Orphanet nomenclature:	58: Alexander disease
Date of working diagnosis:	07/Feb/2018

When clicking on “Update” button, a pop up will be displayed on the screen to enable users to edit this section.

Update Diagnosis

Consultation Form

Recorded: 10/Jan/2018 10:20 (Europe/London) by: Doctor One
Edited: 07/Feb/2018 12:31 (Europe/London) by: Doctor One

Rare Disease Diagnosis

Working Diagnosis

Search All Coding Systems:

Type value for auto-complete...

Diagnosis Coding System:

☒ ICD-10
☐ ICC-3
☒ Orphanet
☐ Other

ICD-10 classification:

A00.9: Cholera, unspecified

Q

Orphanet nomenclature:

58: Alexander disease

Q

Date of working diagnosis:

07/Feb/2018

Result:

Click here to attach file

Add Differential Diagnosis

Cancel

Save

NOTE: After any update, it is needed to click on the Save button to keep the changes!

Search widget: Please note that a search widget is provided in some sections of the consultation form to help Health Professionals select a medical condition without prior knowledge to the coding systems such as ICD-10, Orphanet and ICC-3 in the diagnosis section.

Search All Coding Systems:

Type value for auto-complete...

Diagnosis Coding System:

☐ ICD-10
☐ ICC-3
☐ Orphanet
☐ Other

Multi-check coding systems: Health professionals can pick one or more of the coding systems that are available in the CPMS to enter data on specific condition or procedure such as ICD-10, Orphanet and ICC-3 in the diagnosis section or MedDRA and LONIC in the surgical procedures.

Furthermore, Help text occasionally can be seen above or next to some data fields to indicate structure or type in information in a certain format e.g. RNA Nucleotide variant description. Additionally, general attachments can be uploaded in some sections or particularly the medical document section; those documents need to be viewed in the radiology or pathology viewer.

For more information about the data-set and the coding systems (versioning, etc.), please visit the documentation section in the CPMS.

The screenshot shows a form section for coding systems. It includes a search bar labeled 'Search All Coding Systems:' with a placeholder 'Type value for auto-complete...'. Below it, the 'Diagnosis Coding System:' is selected with radio buttons for 'ICD-10', 'ICCC-3', 'Orphanet', and 'Other'. There are also date fields for 'Date of first symptoms onset:' and 'Date of current Diagnosis:', both with a calendar icon. A red box highlights a tooltip that appears over the search bar, containing the text: 'Information on the coding standards and versions used is available from the documentation section' and a link labeled 'Documentation'.

For more information about the data-set and the coding systems, please visit the documentation section in the CPMS. (The right pane on the Global Dashboard page)

8.1. File Upload

Files can be uploaded into the consultation form up to, and including, the data completion stage of the consult process (see Section 7). The upload feature is located either as an attachment field in a form section or in the 'Medical Documents' section of the form, as shown in Figure 11 below:

The screenshot shows a section titled 'MEDICAL DOCUMENTS' in orange. It contains a text block explaining the feature: 'Use this feature to share Files and DICOM images with this Panel. The server can remove identifying data from DICOM images and CDA standard documents. You must remove all identifying data from all other file types before uploading. The sharing rules for these Files and DICOM images are the same as for this form. When you share this form with a Panel all attached files and DICOM images are also visible to the Panel.' Below the text are two buttons: 'Attach file / image' with a paper plane icon and 'Attach Using FTP'.

Figure 11: Attaching Files in the Consultation Form

After clicking on ‘**Attach File/Image**’, the user will be prompted to acknowledge that there is “no identifiable personal data in the uploaded file”. This checkbox must be ticked if the user wants to proceed. The user will then have the opportunity to upload file by clicking on **Single File** or **Dicom Study**.

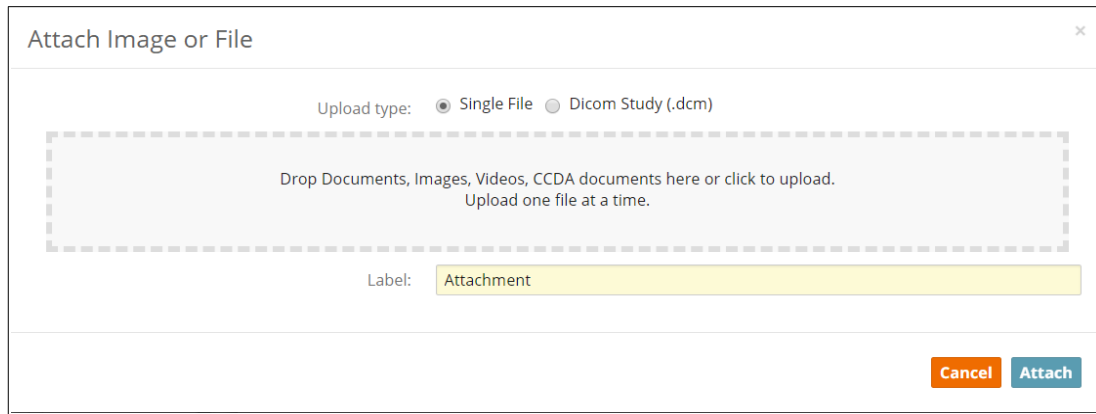
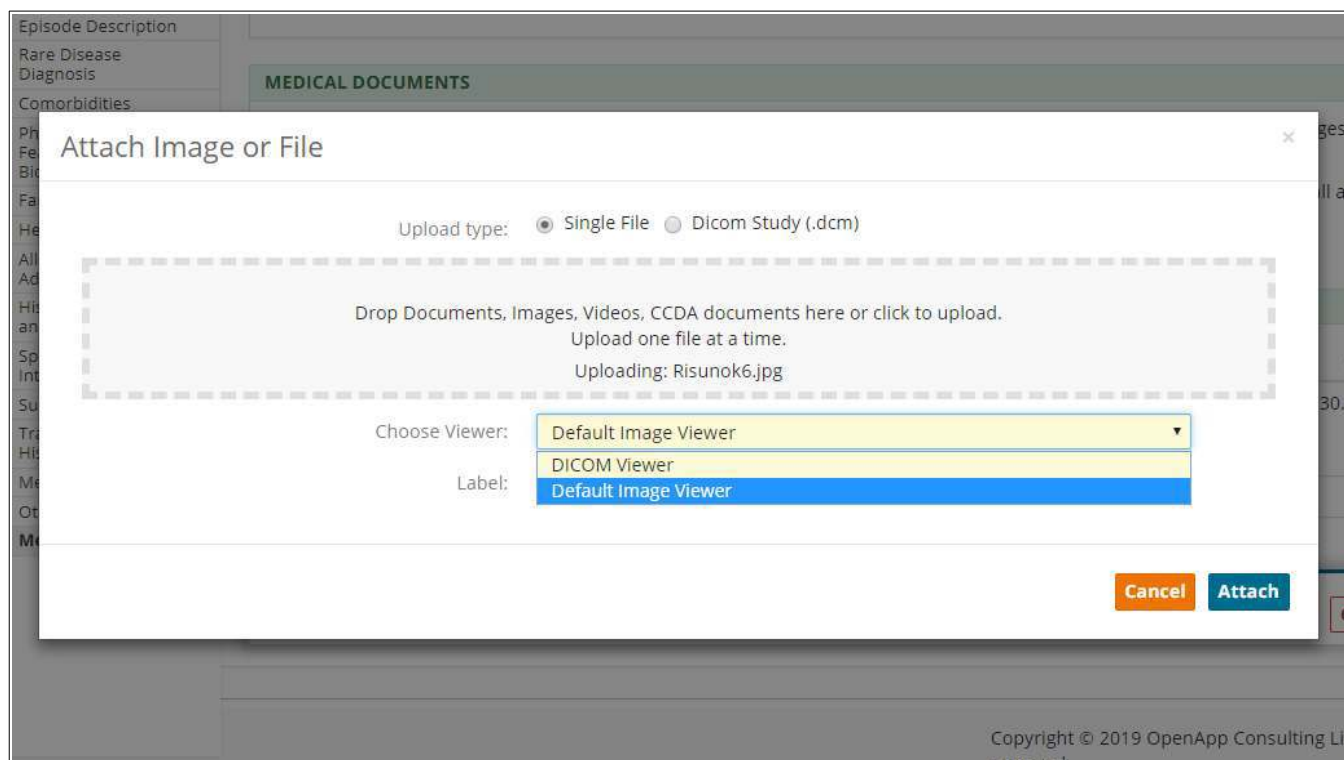


Figure 12: Drag or Browse Files to Upload

The upload modal allows for single file upload with an option to upload DICOM study that comprises typically several studies. The user is given the option to choose between Single file or DICOM study.

The upload mechanism in CPMS is empowered with a sniffing mechanism to assign a specific viewing tool to view the uploaded materials when appropriate. For example, dicom and pathology images (.tif, .tiff, .svs, .ndpi) are viewed in the Medical DICOM viewer and pathology viewer retrospectively whereas .pdf documents will be viewed within a PDF document viewer. Users can also manually change the viewing tool in some cases to another type, for instance to view jpg in the Medical Viewer rather than the default image viewer which is non diagnostic tool.



The table below contains a complete list of the supported file formats:

PDF	pdf							
Excel	xml	csv	xls	xlsx	xlsm			
Power Point	ppt		pptx		pptm			
Word	doc		docx		docm			
Open Doc	odt	ods	odp	odc	odi			
Image	dcm	jpg	jpeg	bmp	Tiff,tif	png	svs	ndpi
Video	avi	flv	wmv	mov	mp4			
Sound	pcm	wav	ogg	flac	mp3			

Note: Currently, the formats mentioned above in the table are case sensitive. For example pdf files have to be *.pdf not *.PDF.

Files can easily be deleted by clicking 'delete' next to the unwanted files in the 'Remove Files' tab.

Note: When a file is deleted, you cannot upload it again unless you change its name!

Attach file / image
Attach Using FTP

Files / Images

Viewer	Document	Upload	Date	Size	
pdf	radiology-report-sample	Diana Well	22/Feb/2019	230.8 kB	⋮
ccda	problems-and-medications	Diana Well	22/Feb/2019		⋮
video	SampleVideo_360x240_2mb	Diana Well	22/Feb/2019		⋮
dicom	CMU-1-Small-Region	Diana Well	22/Feb/2019		⋮
dicom	MRBRAIN	Diana Well	22/Feb/2019	514.0 kB	⋮

Patient ID: **ERN-de16-003** Smith, Kerry DOB: 06/02/2019 (M) Enrolled: 16/Feb/2019

[Open in new tab](#)
[Close](#)

pdf (2)
 ccda (1)
 video (1)
 dicom (2)

radiology-report-sample

Uploaded by: Diana Well Date: 22/Feb/2019 Size: 230.8 kB
[Download](#)

IDEXX Telemedicine Consultants
radiology | cardiology | specialty services

Radiology Report

Patient Name: Tinkerbelle

Requesting Doctor:

Gender:	Female, Spayed	Species:	Cat	Age:	13Yr 0Mo
		Breed:	Burmese	Weight:	5.00

HISTORY: hx of dyspnea for 2 days, rdvm drained 100cc of serosanguinous fluid off right side. NO heart murmur. Right lateral and vd thorax

THORAX 12/06/10: Two views are provided.

FINDINGS: There is moderate bilateral pneumothorax and mild pleural effusion, more pronounced on the right. There is a round soft tissue mass within the right dorsal thorax. There is widening and increased soft tissue opacity of the cranial mediastinum, with mild dorsal deviation of the caudal thoracic trachea. There is an additional soft tissue mass within the right cranial lung lobe. The cardiovascular structures are within normal limits. There is mineral opacity in the region of the gallbladder. Multiple sites of spondylosis are considered incidental. No other significant abnormalities are seen.

CONCLUSIONS: Bilateral pneumothorax and scant pleural effusion are consistent with recent thoracocentesis. Suspected soft tissue masses within the right caudal and right cranial lung lobes are strongly concerning for primary or metastatic neoplasia. Cranial mediastinal and/or tracheal bronchial lymphadenopathy is also suspected. Gallbladder mineralization is of unknown clinical significance.

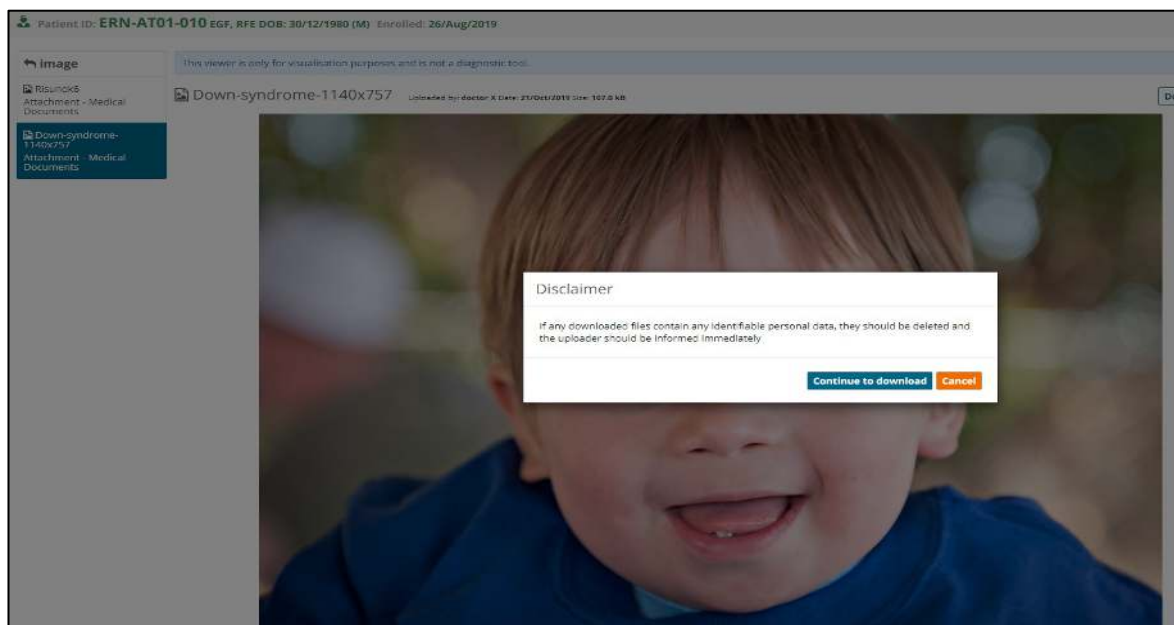
TIMELINE

22/Feb/2019: A new Panel was started by Diana Well.

Patient Documents

Created	Last Update
Panel #457	22/Feb/2019

When downloading any materials from CPMS that does not belong to DICOM studies, user shall be notified with a disclaimer message to delete any downloaded files in case of any identifiable data are found for non-medical purpose.



FTP Upload

Users can also use FTP Batch Upload via the 'Batch Upload' tab, which is particularly useful for large files exceeding one hundred megabytes.

Note:

- Batch upload requires third party software such as FileZilla or WinSCP to be installed.
- Using the FTP functionality may require higher technical competences that require prior experience. Please ask the IT department at your organization if you experience any difficulty in using the FTP client software.

MEDICAL DOCUMENTS

Use this feature to share Files and DICOM images with this Panel. The server can remove identifying data from DICOM images and CDA standard documents. You must remove all identifying data from all other file types before uploading.

The sharing rules for these Files and DICOM images are the same as for this form. When you share this form with a Panel all attached files and DICOM images are also visible to the Panel.

Attach file / image

Attach Using FTP

All the instructions are provided in the pop-up modal to guide users to feed the right information into the FTP client software.

File Picker: Attach Using Secure FTP

This web-interface is suitable for small to medium sized files. If you want to upload large files (> 1 gigabyte), or want more control over your file uploads, e.g. scheduling or throttling internet bandwidth usage, you can use Secure FTP to upload files.

If using WinSCP (available free):

File Protocol:	Secure FTP (ftpes) Explicit mode	Encryption	TLS/SSL Explicit Encryption
Host name:	51.4.136.94	Port number:	2990
User name:	Your login username	Password:	You need an FTP password Set FTP Password

- This FTP interface, uses the Explicit Secure variation of the FTP protocol. You will need to install a program to communicate with it. Third party products such as WinSCP (available free), can upload files via Secure FTP.
- For Security reasons, you can upload to the FTP server, but you cannot download from it.
- You can only attach files to forms which are currently in an editable workflow state.

Close

IHE

CPMS supports IHE integration with hospitals that are compliant with the following IHE profiles and interested to share documents with the CPMS:

- XCPD - Patient Discovery (ITI-5)
- XCA - Retrieve Folder List (ITI-38)
- XCA - Retrieve Document List (ITI-38)
- XCA - Retrieve Document Set (ITI-39)
- IHE ATNA (Audit Trail and Node Authentication)
- IHE-STs (Security Token Service)

Users can use the IHE integration profiles to pull documents stored in the local hospital information system into the CPMS. Users in **Centres** availing of IHE will find an additional 'IHE' tab next to 'FTP Upload' in the Medical Documents section.

For more information on IHE integration, please contact CPMS Support desk.

8.2. Medical Image Viewers

Osimis Pro viewer background

The Osimis zero footprint HTML5 medical imaging viewer features a rich JavaScript API for displaying and working with images within HTML5 elements. It comes as a set of two plugins to the Orthanc core library, which they have been specifically designed for it. The viewer is currently certified with CE-marked as a Class 1 medical device. For more information, please visit <http://www.osimis.io/en/blog/2016/10/14/plugin-osimis-pro-viewer.html>

Uploaded Images

Once DICOM images have been successfully uploaded as detailed above, they can be viewed on the DICOM viewer by all panel members via the consultation form on the panel's home page in the ERN app. Clicking on a link for the images on the consultation form opens the viewer as shown in Figure 13 below:

Series picker

Once the user has selected at least one study, the thumbnails of the series held within the study are shown either in a list or grid format. The user can toggle between the following views. In order to distinguish the series of different studies, they are assigned a colour that is also being used in the viewports. This way, the user can compare 2 or more series of different studies.

The consultation form contains a DICOM (Digital Imaging and Communications in Medicine) viewer for the viewing, editing and sharing of medical images.

1. This section lists the series of images that are available to be viewed.
2. Allows the user to download the series.
3. The top menu bar contains a wide range of features such as:
 - Change the viewport layout
 - Invert colour
 - Zoom & Panning
 - Toggle the windowing tool or apply a preset to the selected viewport.
 - Toggle the magnifying glass tool.
 - Annotations to measure length, area and angles (See Figure 14 below)
 - Pixel probe
 - Elliptical ROI
 - Rectangle ROI.
 - Rotate to the left/right
 - Flip image – vertically and/or horizontally.
 - Synch browsing in multiple ports.

- Reference Lines
 - Cross-hair cursor
 - Export DICOM image in JPG and print out.
4. The user can cycle through the images in the series manually or automatically, at a frame rate of their choosing.

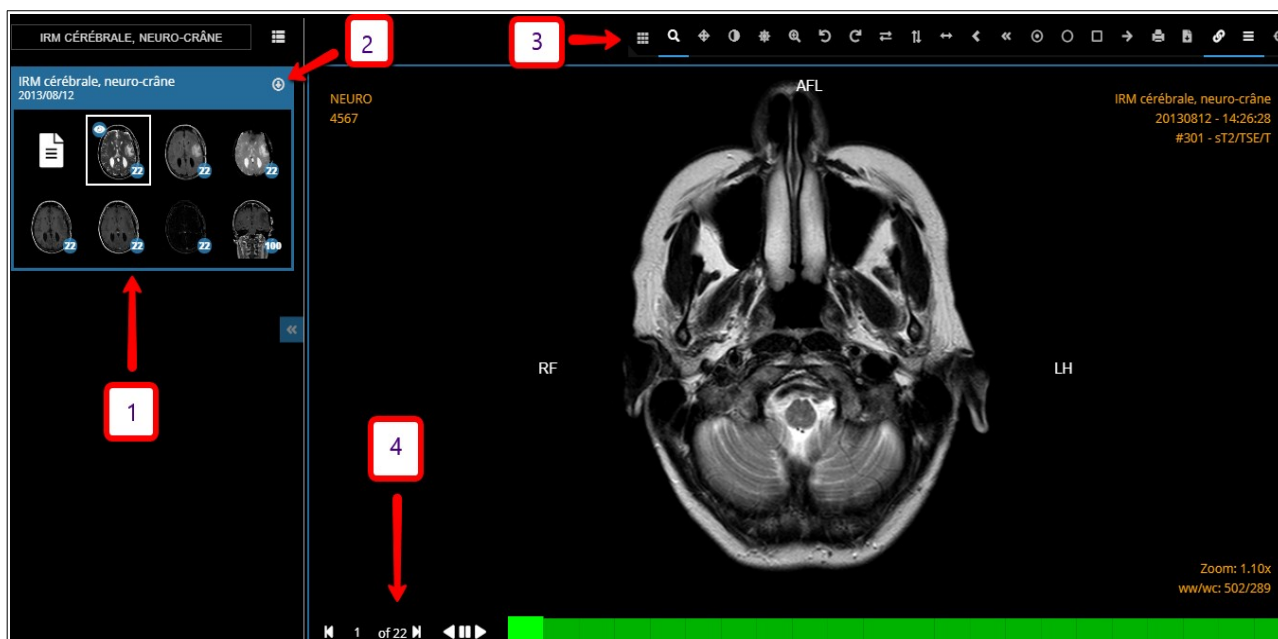


Figure 13: DICOM Viewer

To remove an annotation from the image, simply click and drag it off the image. This will delete that particular annotation.

Study types supported

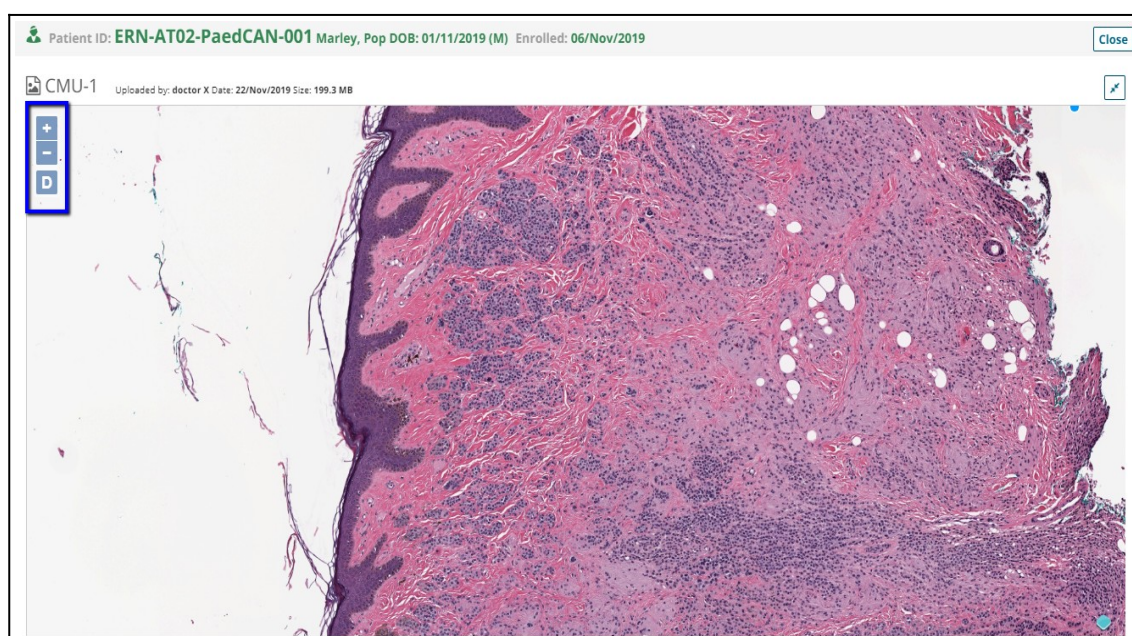
The following types of exams are supported by the viewer:

- CT scans
- MRIs
- PET scans
- Tomography
- Ecographs
- RXs
- Dicomized Static Images
- Endoscopies
- Histopathology

Digital pathology viewer

The digital pathology viewer (also called Whole-Slide Imaging viewer // WSI viewer) comes as a separate viewer. This plugin is based upon OpenLayers, a JavaScript framework to display dynamic maps in any web page.

In case users are dealing with .ndpi formats, we advise you to contact the support team as they will guide you through a conversion process to enable you upload and view this material in the viewer.



8.3. Pedigree

The pedigree tool is located in the Family History section of the Consultation form. It is used to track the patient's ancestry in the form of a family tree, and shows the family members who possess the genetic mutation in question, classified either as 'affected' or as a 'carrier'.

Figure 15 below shows the initial view of the family tree. The icons in the top right corner allow for functions such as zoom (in and out), full-screen view and printing of the pedigree chart. Additionally, users can export the pedigree as an image (i.e. PNG, SVG) or JSON file from the same menu.

Reminder: Currently, the formats mentioned above in the table are case sensitive. For example pdf files have to be *.pdf not *.PDF.

N.B for users of Internet Explorer 11. They can export the pedigree in SVG format to be viewed on the browser.

The text boxes in the top left corner next to 'Affected' and 'Carrier' allow the user to specify the condition in question, if required. This is to avoid confusion in cases where comorbidities have been declared by the patient in addition to the condition of interest.

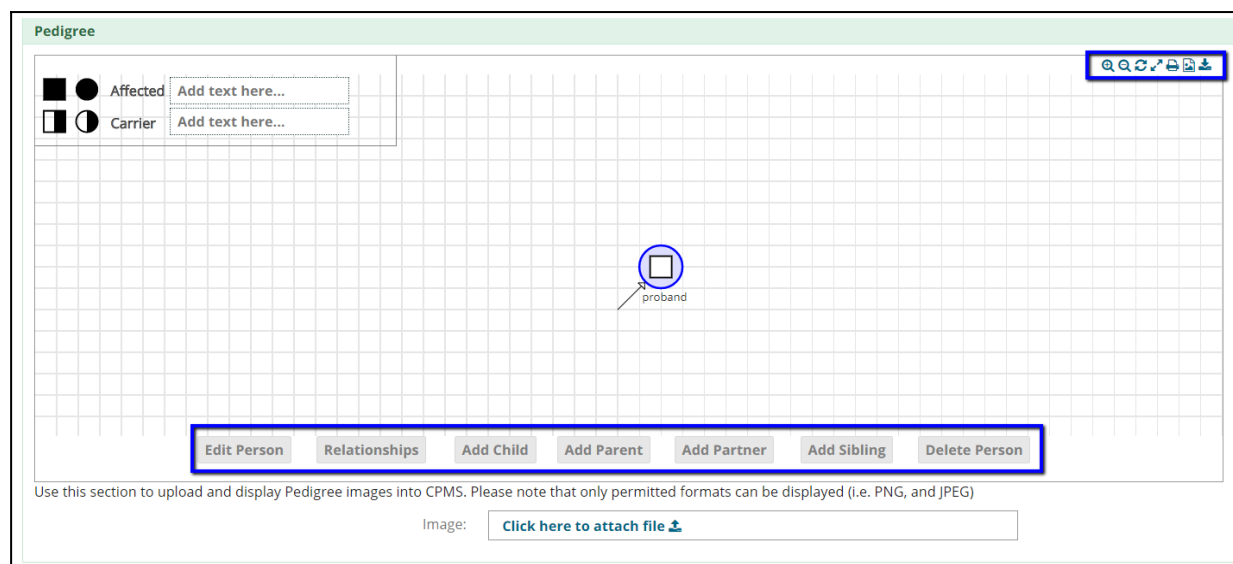


Figure 15: Pedigree Chart

The buttons along the bottom of the screen allow family members of the proband to be added and edited. The 'Edit Person' button allows the user to specify the person's gender, whether or not they are deceased and if they are a carrier, affected or neither. The user can also specify if the person has been tested or not, and the 'Phenotypic Abnormality' they have, if applicable. The 'Relationships' button lets the user set certain relationships (partner, children and parents) between people in the family tree.

Figure 16 below gives an example of a pedigree chart:

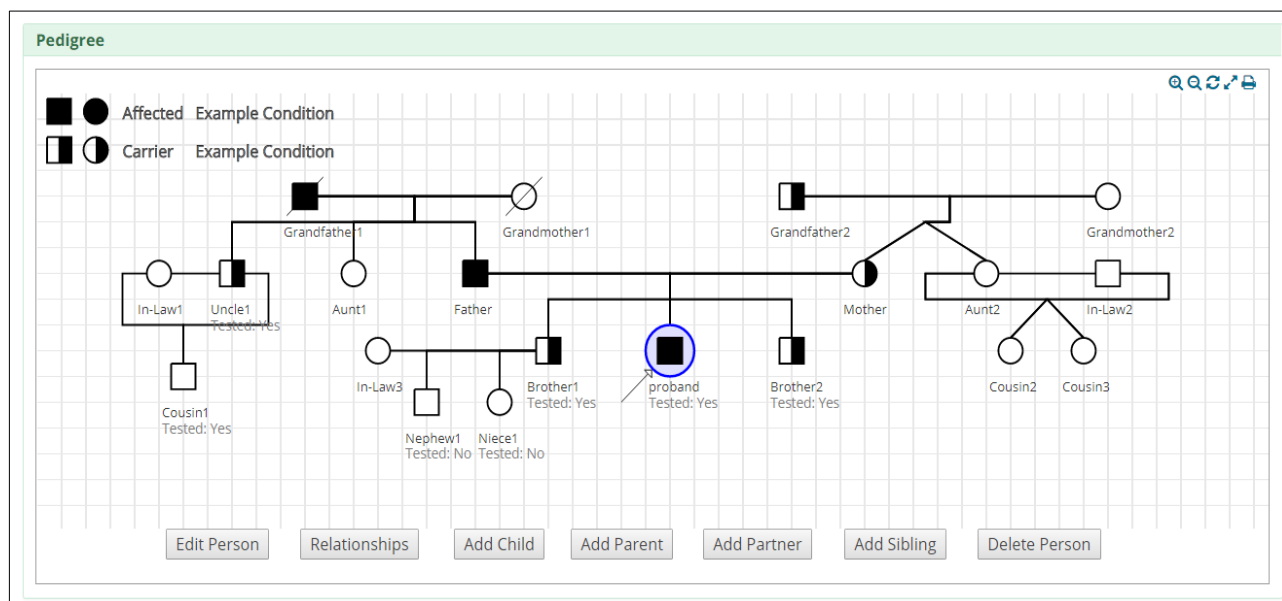


Figure 16: Example of a Pedigree Chart

9. Panel & Form Layout

All interactions and communication happening between Health Professionals on a particular panel can be seen in the Timeline. The panel view shows two main elements; the Consultation Form on the left hand side, in which the user can always see the updated data and the Timeline on the right hand side which shows near-real time transition of the panel based on the actions triggered by a Panel Member or the Panel Lead. The workflow is extremely flexible as it allows the user to transition forward or backwards in case edits or rectification of mistakes need to be made etc.

Please note that Panel Lead/Manager/Members as well as HPs from the enrolling HCP, can print out the consultation form as .PDF at any stage of the workflow for any clinical or administrative purposes.

ERN | DE16 - Universitätsklinikum Ma...

Centre ERN Map Diana Well

Patient ID: ERN-de16-003 smth, Kerry DOB: 06/02/2019 (M) Enrolled: 16/Feb/2019

#457 Peter Pan

« Prev Open Panel Selection Data Completion Assessment Outcome Sign-off Closed Next »

Centre Lead: DE16 - Universitätsklinikum Magdeburg
Diana Well
Harry Potter
Sim Karry (Neurologist)
Mark Lee (Neurologist)

ERN Thematic Area: BOND - Bone Disorders
Fibrodysplasia Ossificans Progressiva

Schedule Meeting Request Additional Data

CONSULTATION FORM Recorded: 22/Feb/2019 12:53 (Europe/Berlin) by: Diana Well
Edited: 22/Feb/2019 13:32 (Europe/Berlin) by: Diana Well

CONSULTATION REQUEST

* Nickname: Peter Pan

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: Test

* Consultation request reason: Diagnosis

* Consultation request reason description: Test

Healthcare provider: DE16 - Universitätsklinikum Magdeburg

Point of care specialist: A

* ERN: BOND

* Panel lead: Diana Well

Panel Manager: Harry Potter

* Primary thematic area: Fibrodysplasia Ossificans Progressiva

MEDICAL DOCUMENTS

The sharing rules for these Files and DICOM images are the same as for this form. When you share this form with a Panel all attached files and DICOM images are also visible to the Panel.

Files / Images

Viewer	Document	Upload	Date	Size
pdf	radiology-report-sample	Diana Well	22/Feb/2019	230.8 kB
ccda	problems-and-medications	Diana Well	22/Feb/2019	35.1 kB
video	SampleVideo_360x240_2mb	Diana Well	22/Feb/2019	2.1 MB
dicom	CMU-1-Small-Region	Diana Well	22/Feb/2019	1.9 MB
dicom	MRBRAIN	Diana Well	22/Feb/2019	514.0 kB

TIMELINE

22/Feb/2019: A new Panel was started by Diana Well.

22/Feb/2019: The Panel is now in state "Panel Selection"

Panel Members:

Member	Status	Actions
Diana Well	Lead	Invited: 22/Feb/2019
Sim Karry	Accepted	Invited: 22/Feb/2019 Accepted: 22/Feb/2019
Mark Lee	Accepted	Invited: 22/Feb/2019 Accepted: 22/Feb/2019

22/Feb/2019: The Panel is now in state "Data Completion"

Patient Documents

Created	Last Update
Panel #457	22/Feb/2019

Patient documents are being completed

Add a comment

Help & Support

If you have any queries, ideas, suggestions, or need help with an issue please contact ERN-CPMS via email at Sante-ERN-CPMS-itsupport@ec.europa.eu.

Co-financed by the European Union
Connecting Europe Facility

Copyright © 2019 OpenApp Consulting Limited. All rights reserved.
Version: insight_ern#dev17.057, created: Wed Feb 20 09:38:43 2019
Browser Information
CPMS Release Notes

Figure 17: Panel Home Page

9.1. Timeline

On the right-hand side of the panel interface, the user can view all of the panel's activity to date via the 'Timeline' feature. Figure 18 gives an example of a timeline, and the accompanying text explains the main features that it incorporates.

1. The double arrow icon allows the user to toggle the order of events between oldest-newest and newest-oldest.
2. The user can view when their meetings for that panel are due to start, and can access the meeting by clicking on the 'Join Meeting' button.*
3. The timeline allows users to leave comments on the timeline, which can be seen by all panel members.
4. Clicking on this icon brings up a bigger screen for that particular feature. The user can then interact with that feature.

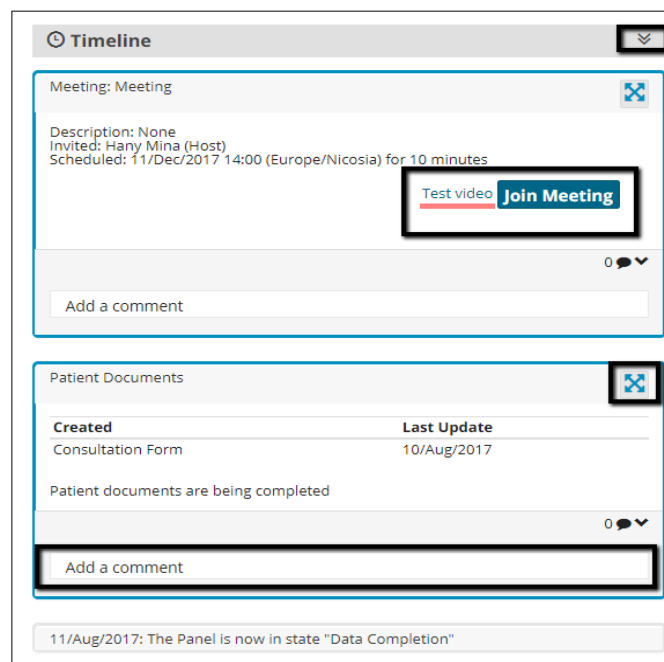


Figure 18: Timeline of Panel

The Timeline is not only a chatting mechanism over the panel but rather a secure approach for exchanging messages in several modal types. It allows panel members to make comments on images, contributions and outcome documents.

*When a video meeting is set at a certain time in the future, the Join Meeting button displays a countdown before the meeting starts. The attendees won't be able to join until the counter goes below 5 minutes.

9.2. Data Entry

Data can be entered using a combination of drop-down lists, check boxes, radio buttons and Date input fields. Here you can see a drop-down list being used. Radio buttons can also be used to select options in lists. The Date input fields (date pickers) allow quick access to the relevant date.

Red asterisks always refer to required data to be filled in a selected section before saving the form.

The screenshot shows a 'Data Picker' window. On the left, there is a list of medical conditions under the heading '280342: Rare rheumatological disease of childhood'. The selected item is '319719: Autoinflammatory syndrome of childhood'. Below it, a list of related conditions is shown: '324933: Mixed autoinflammatory and autoimmune syndrome', '324939: Periodic fever syndrome of childhood', '324942: Pyogenic autoinflammatory syndrome of childhood', '324950: Granulomatous autoinflammatory syndrome of childhood', '324953: Unclassified autoinflammatory syndrome of childhood', and '481671: Type 1 Interferonopathy of childhood'. At the bottom right of the list are 'Cancel' and 'Select' buttons. On the right side of the window, there is a sidebar. The top section is 'Status of current Diagnosis:' with checkboxes for 'Active', 'In Remission', 'Resolved', 'Relapse', and 'Other'. The bottom section is '* Diagnosis Provider:' with radio buttons for 'ERN member', 'Affiliated ERN Member', and 'Non-ERN member'.

Figure 19: Data Picker

Note

Date pickers are used where an exact date is required. However, there are some instances where the month or year are sufficient. For example, the patient records may not hold the exact date for some data fields. So it may be possible to type in the input field and record the month and year, or use the date picker if the exact date is known. When inputting the date manually the date format must be Month/Year, or the year alone is sufficient in some instances.

10. Panel Workflow – Virtual Consult Process

10.1. Open a New Panel

To open a panel for a newly enrolled patient, any authorized Health Professional from the enrolment centre can simply click the 'Open New Panel' button (Figure 20) that they are presented with after filling out successfully the enrolment form.

The screenshot shows a message box with the text 'No Panels have been created for this patient yet.' Below the message is a blue button with a white icon of a person and the text 'Open New Panel'.

Figure 20: New Panel – New Patient

If the user wishes to open a new panel for a previously enrolled patient, they can do so from the patient's page. As discussed in Section 3.1, the user can find a patient by viewing the patient list or by using the search function. The 'Open New Panel' button is located on the right-hand side of the page, as shown in Figure 21 below.

ERN BE01 - Antwerp University Hosp...							
Patient ID: ERN-be01-008 one, Test DOB: 04/02/2011 (female) Enrolled: 03/May/2017							
Panels							
Open New Panel Cancel or Restart Panel							
Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage	
#413	Example	17/08/2017	Doctor Onie	ERN LUNG - Respiratory Diseases	Interstitial Lung Disease	Data Completion	
#245	fg	17/08/2017	Mr. Emma Jackson	ERN LUNG - Respiratory Diseases	Interstitial Lung Disease	Assessment	
#344	Ben	27/07/2017	Mr. Emma Jackson	ERN LUNG - Respiratory Diseases	Alpha-1-Antitrypsin Deficiency	Panel Selection	
#241	test1	02/06/2017	Mr. Emma Jackson	ERN LUNG - Respiratory Diseases	Alpha-1 Antitrypsin Deficiency	Assessment	

Figure 21: New Panel - Existing Patient

The user will also have the option to cancel or restart any panels on which they are the panel lead. This can be done by checking the box next to the Panel ID then the Button “Cancel or Restart Panel” will be activated in red colour.

Panels							
Open New Panel Cancel or Restart Panel							
Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage	
<input checked="" type="checkbox"/> #485	TEST SYMPHTOMS	06/10/2017	Hany Mina	ERN ITHACA - Intellectual Disability and Congenital Malformations	Syndromic eye disorders	Open	

There are eight stages to the virtual consult process, which the user can easily keep track of via the tracker located just under the top menu.

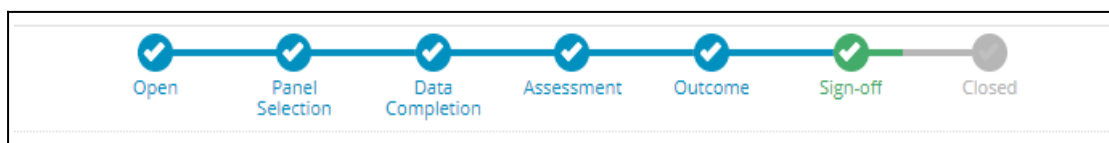


Figure 22: Stages of the consult process

10.2. Open

The panel is considered open as soon as the consultation form has been submitted. This stage allows for the consultation form to be viewed and edited as deemed necessary by any authorized Health Professional in that particular medical **centre**. When opening a panel, users have to enter the minimum required data as it appears in the “Consultation Request” section. Users can also mark the Panel as an urgent or non-urgent request as this determines the level of notifications to the Panel members in later stages of the workflow as well as displaying the urgent panels in a separate section with a red warning triangle symbol.

Consultation Request

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

* Nickname:

Jake

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 Short:

description..

* Consultation Request Reason:

Treatment

* Consultation Request Reason Description:

Reason described

* Healthcare Provider:

EB-Haus Austria

* Point of care specialist:

POC Specialist

* ERN:

☒ ERN-SKIN

* Panel Lead:

Doctor One

* Primary Thematic Area:

☐ ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos

ERN-EYE : Eye Diseases USER: Doctor One

Panel Invitations

You have no unanswered invitations at this time.

Urgent Panels

Panel ID	Date	Nickname
#578	29/01/2018	Vinnie

Contributing Panels

Panel ID	Date	Nickname
#578	29/01/2018	Vinnie
#581	29/01/2018	Nick
#583	29/01/2018	aaa

Member Tasklist

Nickname	Task
#538 Gerry	Please review the data that is provided for this Panel.

My Meetings

You are not scheduled to attend any meetings.

10.3. Panel Selection

#331 dswwd3dw

Open

Panel Selection

Data Completion

Assessment

Outcome

Sign-off

Closed

Next »

Centre BE01 - Antwerp University Hospital

Lead Mr. Emma Jackson

ERN ERN-LUNG - Respiratory Diseases

Thematic Area Interstitial Lung Disease

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

Figure 23: Invite Members and Schedule Meeting

In the 'Panel Selection' stage the Panel Lead, can form the panel by inviting other Health Professionals to join. Meetings can also be scheduled at this stage (see Section 8). Figure 23 above shows the location of the 'Invite Members' and 'Schedule Meetings' buttons.

Panel Selection

Available

Invited

Co-ordinator Assistance

Thematic Area:
6. Cutaneous diseases related to DNA Repair Disorders

Available HPs	Role	
Mr. Emma Jackson	Radiologist	<div>Invite All</div> <div>Invite</div>

Close

Figure 24: Panel Selection

When forming the panel, the Panel Lead at this stage, can invite Health Professionals from a list of those available, sorted by ‘Thematic Area’ (based on ‘Preferences’ as discussed in Section 3.3). If the Panel Lead is unsure of who to invite to the panel, or requires a Health Professional from a different ERN, they can request the assistance of the **co-ordinator** for their ERN in the ‘Co-ordinator Assistance’ tab.


Available

Invited

Co-ordinator Assistance

The ERN Co-ordinator can assist you in recruiting a panel.
If you need assistance of the ERN Co-ordinator in appointing a panel, please use the button below. Generally, the ERN Co-ordinator will invite appropriate Health Care professionals to fill the panel, or provide other guidance.

Can you please help forming my panel on Multiple Sclerosis? and appoint a Panel Lead and Panel Manager?



I would like assistance

Close

Panel lead as well as Panel Managers and HP from the enrolling HP can accept the panel invite on behalf of the invitees to speed up the panel selection step. There is an option to individually accept on behalf of one invitee or all of them in one click.

Panel Selection

Available

Invited

Co-ordinator Assistance

Invited Panel Members

Name	Specialisation	Status	When
Mairsile Hourihane	Ageing specialist	Invited	Invited: 21/Oct/2019
Mr. Emma Jackson	g	Invited	Invited: 21/Oct/2019
Mr. Testo Testo	H	Invited	Invited: 21/Oct/2019
Birmingham Two (Guest)	afaw	Invited	Invited: 21/Oct/2019
A Henry	DJ	Invited	Invited: 21/Oct/2019
Doctor One		Lead	Invited: 21/Oct/2019

Close

Accept all

Setting a Panel Lead

By default, any authorized Health Professional in a given **centre**, who opens a Panel, will be assigned as a Panel Lead unless otherwise, the Panel Lead role has been switched or assigned to another HP from the same/another **centre**.

Below, you can read more about the access rights if either you are a Panel Lead from the enrolling **centre** or you have been assigned to lead a Panel originating from another ERN **centre**.

Use-Case 1

A Panel Lead from the originating/enrolling **centre** (Panel Lead Role NOT assigned to any HP outside the **centre**):

All Users from this **centre** can edit the consultation form and transition the workflow. However, the right to sign-off the outcome document is exclusively given to the Panel Lead.

Use-Case 2

A Panel Lead has been assigned/switched to another expert in a different **centre** within the same ERN:

- Panel Members from the enrolling **centre** and the Panel Lead from the receiving **centre** can ONLY edit the consultation form.
- The Panel Lead from the receiving **centre** can exclusively transition the workflow and sign off the outcome
- No HP from the receiving **centre** can ever edit the consultation form or transition the workflow
- No HP from the originating **centre** is longer able to transition the workflow

10.4. Data Completion

In the 'Data Completion' stage, the clinical data is completed if not previously done so, and is available to be viewed by the whole panel. The consultation form is also made available to be edited if necessary.

10.5. Assessment

During the 'Assessment' stage the Panel can all make contributions to the case, via the 'Record Contribution' button that replaces the 'Invite Members' feature. Text can be entered in the textbox and files can be uploaded via the 'attach file' feature. The Panel Member can also view the other panel members' contributions by clicking on their tab.

Figure 25: Panel Contributions

From the panel selection stage up to the outcome stage, panel members will be able to submit a request for additional test results, data or information. See figure below:

Once
the
request

additional data button has been selected, the data that you want to request must be input into the text box. See example below:

Once the request has been created, it will then show up above the consultation form and also in the timeline. See example below:

The screenshot shows the OpenApp interface for a patient named Jack Smith. The patient ID is ERN-be01-006, and the date of birth is 04/05/2017 (male). The patient is enrolled at BE01 - Antwerp University Hospital. A consultation request titled "#549 Diagnosis Test Update" is shown. The request is from Doctor One at BE01 - Antwerp University Hospital. A warning message indicates that there are requests for additional data. The consultation form shows that it was recorded on 19/Jan/2018 and edited on 08/May/2018 by Doctor One. The consultation request is titled "Diagnosis Test Update".

The information and the status of the request will show up once you click on it. See example below:

The screenshot shows the "Additional Request" dialog box. It contains a table with the following data:

Sender	Date	State	Request
Doctor One	22/May/2018 16:24	Requested	**Doctor One** MRI Scan

A "Close" button is located at the bottom right of the dialog box.

The screenshot shows the "Additional Request" dialog box with detailed information. The status is "Requested" and the responsible person is "Doctor One". The request is titled "Diagnosis Test Update" and was created on 22/May/2018 16:24. There is a text area for "Additional request text response" and an "Add Comment" button. At the bottom, there are several action buttons: "« Summary", "Set to Requested", "Mark as Pending", "Put on hold", and "Mark as Complete".

A panel lead can then mark the request as either pending, on hold or they can mark it as complete. They can also enter some additional request text if they wish. See example below:

Any other additional data requests will also be stored here together. See example below:

Additional Request					
Sender	Date	State	Request		
Doctor One	22/May/2018 16:24	Complete	**Doctor One** MRI Scan		
Doctor One	22/May/2018 16:33	On hold	**Doctor One** hdzxhd		
Doctor One	22/May/2018 16:34	Requested	**Doctor One** X-Ray		
				Close	

10.6. Outcome

After the assessment has been completed and the contributions have been recorded, an outcome for the panel must be considered and decided upon. The Panel Lead also has the option to return to the Assessment stage if he/she deem it necessary, as shown in Figure 26

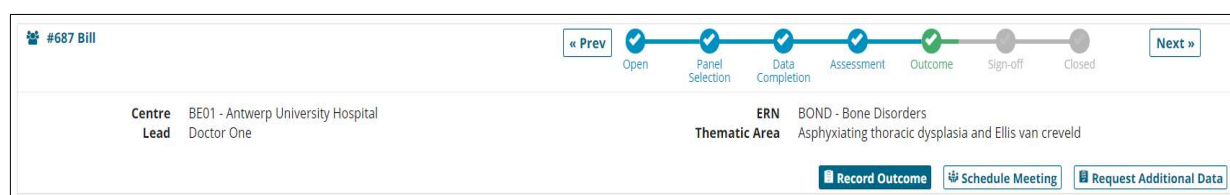


Figure 26: Outcome

The Panel Lead records the outcome at this stage and the rest of the panel have the opportunity to view and comment on it.

In the Appendix of this guide, you can find the initial template of the outcome document as provided by the contracting authority.

10.7. Sign-Off

In the 'Sign-Off' stage, the Panel Lead confirms the outcome of the consult process. Once the outcome is signed-off the panel can be closed, and the outcome can no longer be edited. At this state of the workflow, all Panel Members and the Panel Lead, can export the outcome as a PDF document for personal record or send it over to the POC specialist or patient themselves.

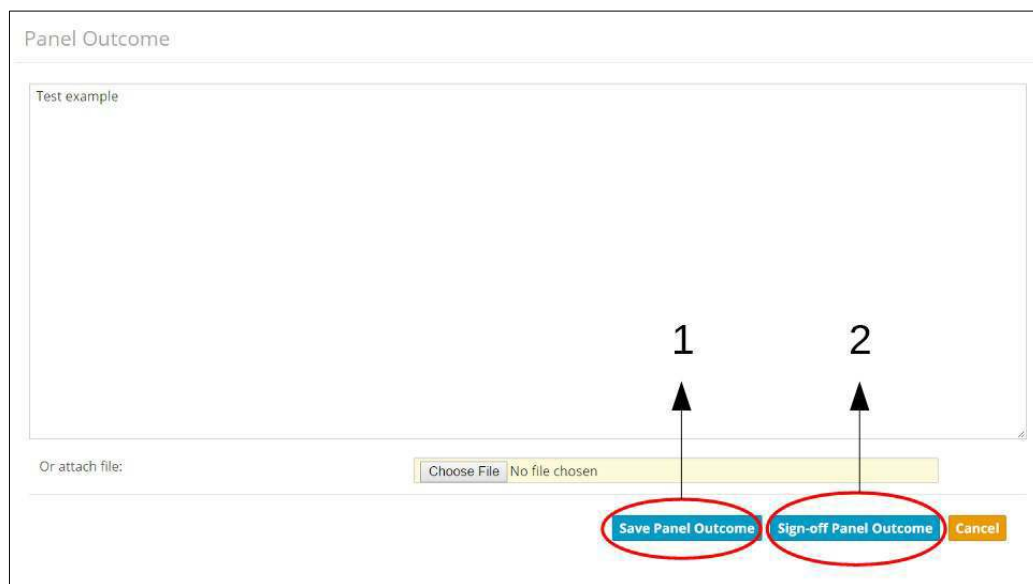
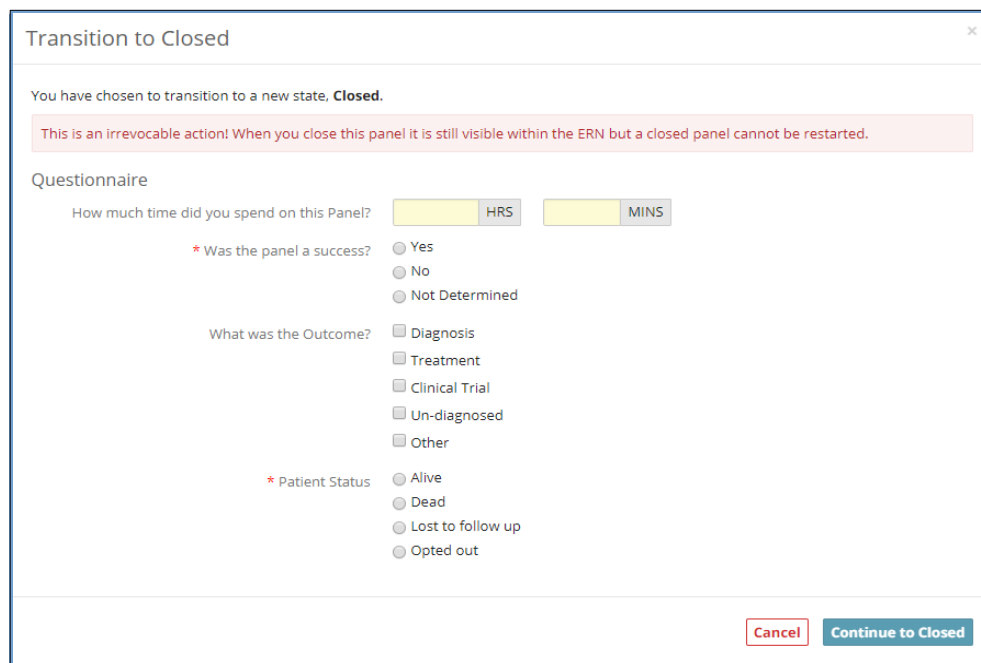


Figure 27: Panel Sign-Off

1. **Save Panel Outcome:** This saves the outcome, but only as a draft. The outcome can still be edited, and saving here does not allow the panel to be closed.
2. **Sign-off Panel Outcome:** Signing-off the panel outcome will mean that it can no longer be edited, and this must be done before the panel can be closed.

10.8. Closed

Once the outcome has been signed-off, the panel can be closed. Only the Panel Lead can close the panel and he/she must first complete the 'Transition to Closed' form shown in Figure 28 below:



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**

Figure 28: 'Transition to Closed' Questionnaire

Please note if the patient is marked **Dead** at the end of the panel consultation, the patient record will be frozen meaning that:

1. Any active panel shall be Aborted
2. Any closed panel shall archived automatically
3. No future panel can be opened for this patients
4. The patient record will be always marked as **Frozen**

 Patient ID: ERN-de16-002 Potter, Harry DOB: 01/02/2019 (M) Enrolled: 06/Feb/2019							 Frozen
Panels							
Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage	
<input type="radio"/> #435	Peter Pan	19/02/2019	Diana Well	BOND - Bone Disorders	Ollier Maffucci	Aborted	
<input type="radio"/> #442	Peter Pan	19/02/2019	Diana Well	BOND - Bone Disorders	Ollier Maffucci	Aborted	
<input type="radio"/> #443	Peter Pan	19/02/2019	Diana Well	BOND - Bone Disorders	Achondroplasia	Archived	
<input type="radio"/> #445	Medical DOCument uploads	19/02/2019	Diana Well	BOND - Bone Disorders	Achondroplasia	Aborted	
<input type="radio"/> #446	Demo PM	19/02/2019	Diana Well	BOND - Bone Disorders	Acromelic dysplasia	Aborted	

The outcome document will be available for all panel members to view, and the Panel Lead will have the option to make the panel available for research, as shown in Figure 29 below.

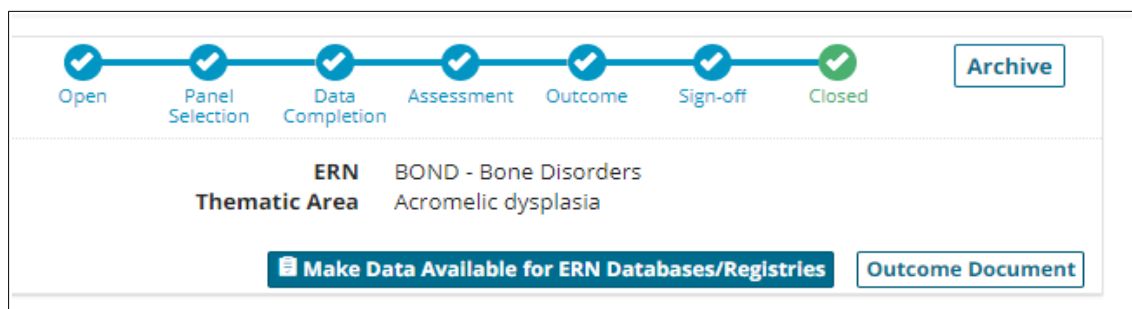


Figure 29: A Closed Panel

10.9. Archived

The Panel Lead can choose to Archive the panel after it is closed. This will mean the panel can only be viewed from the 'Centre' application by members of the **centre** that the patient was enrolled at, and not from the 'ERN' application.

10.10. Copying Panels

In order to avoid data re-entry, copying panels is a feature that provides users a functionality to copy data previously entered in older panels. In order to do this, click on the patient list and choose a patient.

Patient ID: **ERN-DEU1-UU6** Smith, Jack DOB: 04/05/2017 (male) Enrolled: 06/May/2017

Open New Panel Copy Panel Cancel or Restart Panel

Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage
#208	Jack	26/05/2017	Mr. Emma Jackson	EURACAN - Adult Cancers	Rare neoplasm of the brain, spinal cords	Data Completion
#318	Rick	17/07/2017	Mr. Emma Jackson	ERN-LUNG - Respiratory Diseases	Cystic Fibrosis	Open
#324	Nerd	17/07/2017	Mr. Emma Jackson	ERN-LUNG - Respiratory Diseases	Chronic Lung Allograft Dysfunction	Data Completion
#327	ddd	17/07/2017	Mr. Emma Jackson	ERN-LUNG - Respiratory Diseases	Chronic Lung Allograft Dysfunction	Open

Once the patient that needs to be copied is selected, click on copy panel. As soon as you click Copy Panel, the consultation request section is automatically selected. You can then choose what medical images (DICOM) or medical attachments you may or may not want to copy. Once you choose the sections that you want to copy, click copy panel. The panel that you just copied will now show up at the bottom of the panel list.

Copy Panel

Sections

Consultation Request ☒

Medical Images (DICOM)

Tra T1 SE, T2, FLAIR, T2 MV, 3D T1, T2 FFE, BrainViews, FLAIR SPIR Date: 20120101 ☒

Part: BRAIN Date: 20080617 ☒

Medical Attachments

26789_ClinicalVisitSummary_CCDA.xml ☒

Close Copy Panel

11. Meetings

11.1. Video conferencing requirements

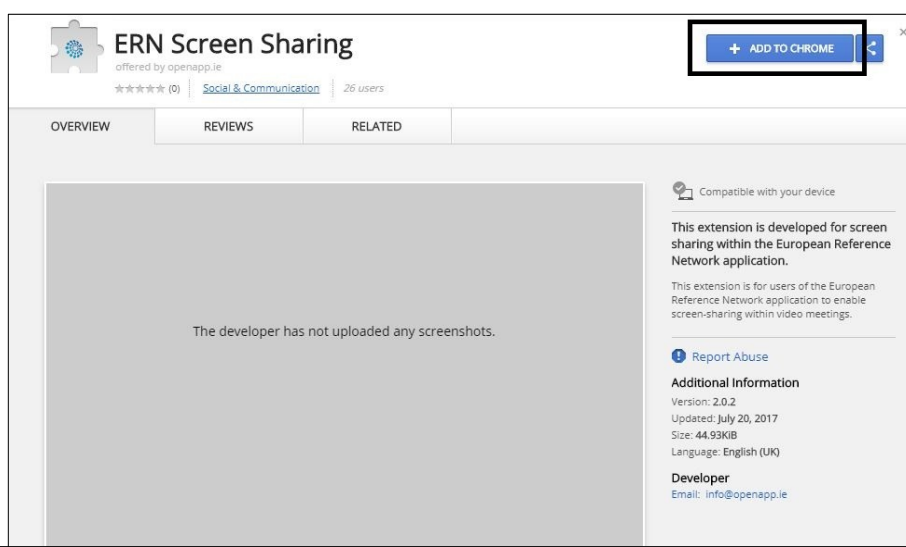
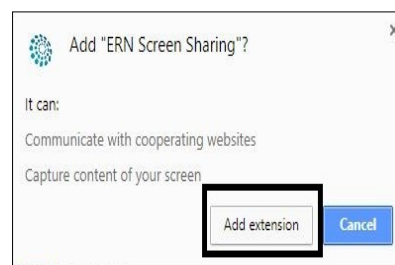
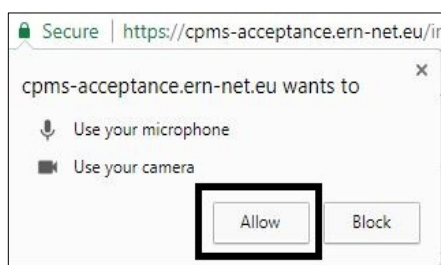
The minimum required hardware is to have a device with camera and microphone to enable you participate actively in video meetings on CPMS. Below are other requirements that potentially can affect the uptake of CPMS to run smoothly within your organization.

WebRTC video technology incorporated into the CPMS can be tested on your machine via this link: <https://cpms-training.ern-net.eu/video-testing>

Users on latest version of Google Chrome and Firefox do not need any plug-in or extensions to install for running video meetings or sharing screen.

Please note the following when using video meetings:

- Safari does **NOT** support screen sharing. Safari users can view screen-sharing streams from other participants but cannot share their own screen.
- For sharing your screen on older version of Google Chrome may require an extension to install. The extension can be downloaded after user clicks on “Share Screen” icon in the video conference tool bar.



11.2. Conflicting video applications

Please make sure that you are not using another video conferencing application (e.g. Skype, GoToMeeting, Zoom, etc.) or similar video stream through another browser or a tab in the same browser (e.g. when recording a webinar). This may cause difficulty for your device to switch on your camera and microphone in several applications.

11.3. Network

Video conferencing uses a variable amount of bandwidth; this variation may affect the quality displayed to the user. This may result in low quality or dropped video connections if the available bandwidth falls below a reasonable threshold. The user is informed of this as clearly as possible.

Video quality dynamically adjusts based on the strength of a user's network connectivity. This is done by the Subscriber sending feedback packets to the publisher that say, "My network quality is at 'x' level. Please adjust your published video bit-rate to accommodate my current bandwidth". The faster and more stable a Subscriber's broadband connection is, the better the video quality it will request. This mechanism works well until a certain point. If a Subscriber's bandwidth drops below a certain threshold, or if a Publisher has very little bandwidth to upload video, **behaviour** can be unpredictable.

Ideally, it is recommended a minimum dedicated 350kb/s per downloaded stream, as well as 350kb/s uploaded stream to maintain a stable video connection.

For Example: In a meeting of 3 participants, you will be uploading 1 stream and downloading 2 streams, so you will need around 1mb of internet bandwidth to support a stable video connection.

To check the video, next to the blue button Join Meeting, you can click on the test video link and it will perform a test to inform about your devices abilities to run it in good conditions. This test should be performed every time before the session starts

For various resolutions and quality combinations, the bandwidth requirements are outlined below.

- Excellent - None or imperceptible impairments in media
- Acceptable - Some impairments in media, leading to some momentary disruptions

Quality	Video Resolution @ FPS	Video kbps	Packet Loss
Excellent	1280x720 @ 30	> 1000	< 0.5%
Excellent	640x480 @ 30	> 600	< 0.5%
Excellent	352x288 @ 30	> 300	< 0.5%

Excellent	320x240 @ 30	>300	< 0.5%
Acceptable	1280x720 @ 30	> 350	< 3%
Acceptable	640x480 @ 30	> 250	< 3%

11.4. Create a Meeting

Organising a meeting to discuss a patient typically happens after the Data Completion stage (Section 7.4) is finished, but this can be done in the earlier stages if the panel deems it necessary. To set up a meeting, the Panel Lead or a Panel Member, can click on ‘Schedule Meeting’ from the main page of that particular panel. The Host of the meeting (i.e. whoever creates the meeting), shall fill out the details shown below:

Type of meeting*: ☐ Part of ERN recurring meeting
☐ Individual meeting
☐ Proposed meeting

Title of meeting*:

Description:

Three options are presented for the Meeting Creator to pick from:

1. **Part of ERN Recurring meeting**
2. **Individual meetings**
3. **Proposed meeting**

If the meeting is an ‘Individual Meeting’, the user simply picks a date, time and duration for the meeting.

Title of meeting:

Description:

Type of meeting: ☐ Part of ERN recurring meeting
☒ Individual meeting
☐ Proposed meeting

When: Europe/Berlin

Duration: minutes

If, however, the meeting is part of a ‘**ERN Group/Recurring meeting**’, the Host must select an available time slot as shown in Figure 31 below:

Meeting group:

☒ ERN Skin Monday Meetings (Every week on Monday)

29/May/2017	05/Jun/2017	12/Jun/2017	19/Jun/2017	26/Jun/2017	03/Jul/2017
<input type="radio"/> 11:00	<input type="radio"/> 11:00	<input type="radio"/> 11:00	<input type="radio"/> 11:00	<input type="radio"/> 11:00	<input type="radio"/> 11:00
<input type="radio"/> 11:15	<input type="radio"/> 11:15	<input type="radio"/> 11:15	<input type="radio"/> 11:15	<input type="radio"/> 11:15	<input type="radio"/> 11:15
Slot taken	Slot taken	<input type="radio"/> 11:30	<input type="radio"/> 11:30	<input type="radio"/> 11:30	<input type="radio"/> 11:30
<input type="radio"/> 11:45	<input type="radio"/> 11:45	<input type="radio"/> 11:45	<input type="radio"/> 11:45	<input type="radio"/> 11:45	<input type="radio"/> 11:45
<input type="radio"/> 12:00	<input type="radio"/> 12:00	<input type="radio"/> 12:00	<input type="radio"/> 12:00	<input type="radio"/> 12:00	<input type="radio"/> 12:00
<input type="radio"/> 12:15	<input type="radio"/> 12:15	<input type="radio"/> 12:15	<input type="radio"/> 12:15	<input type="radio"/> 12:15	<input type="radio"/> 12:15

☐ ERN Eye Monday Meetings (Every week on Monday)

☐ ERN CRANIO Monday Meetings (Every week on Monday)

☐ CRANIO Tuesday (Every week on Tuesday)

Figure 31: Time slots for group meeting

The **ERN Group/Recurring meeting** is to discuss multiple panels within the same meeting and with no need to disconnect and connect to another slot as all slots are grouped within the same modal and for moderators to move from one patient to the other until they mark meeting as finished.

As for **proposed meeting**, this is to specify time slots for your invitees to vote on then the meeting creator shall confirm the meeting slot as appropriate.

Schedule meeting

Title of meeting: Meeting Slots

Description: Meeting for achondroplasia case

Type of meeting:

☐ Part of ERN recurring meeting

☐ Individual meeting

☒ Proposed meeting

Duration: 30 minutes

Proposed slots:

SAT 23 FEB 14:24

FRI 1 MAR 14:24

THU 7 MAR 11:00

+

Date & Time Participants Summary

Test video Starts in: 1 day(s)

Invite the members of your panel

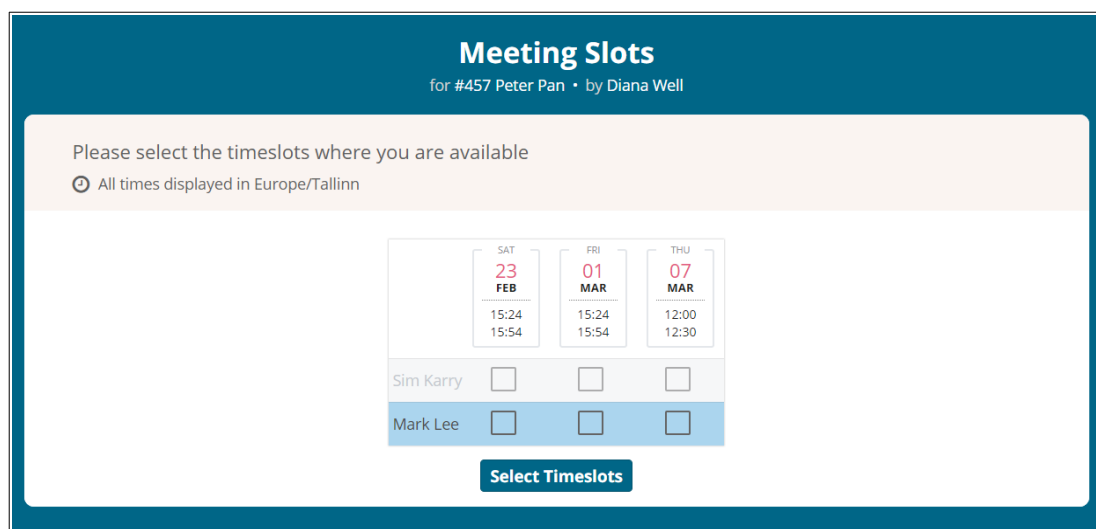
Thematic Area: --- Entire ERN ---

There are no more available Healthcare Professionals

Name	Invited	Status
Doctor One	21/oct/2019 19:13 (Europe/Helsinki)	Moderator
doctor X	21/oct/2019 19:13 (Europe/Helsinki)	Host

The Host can then invite other Health Professionals to join the meeting, including those who are not part of the panel. The Panel Lead is invited to all meetings for that particular panel by default, but the other members are not. By default, the Panel Lead and the Host will get the Moderator rights when joining a meeting.

The meeting invitees shall get a notification in **My Meetings widget** on the ERN dashboard. When a meeting is scheduled or proposed with time slots, the invitees will receive an immediate email notification to respond to the meeting invite or proposal. Users can record their response to the meeting invite/proposal through a link provided in the email or can also log in to CPMS and pick the corresponding task from the Task-List or My meeting/Proposed Meeting widget in the ERN Dashboard.



Meeting Slots
for #457 Peter Pan • by Diana Well

Please select the timeslots where you are available

🕒 All times displayed in Europe/Tallinn

	SAT 23 FEB	FRI 01 MAR	THU 07 MAR
	15:24 15:54	15:24 15:54	12:00 12:30
Sim Karry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mark Lee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Select Timeslots

Member Tasklist	
Nickname	Task
#1140	You have been invited to a meeting (Test) with proposed time slots.
msh_panel	Please choose the times that suit you by clicking here .

The meeting creator can confirm the timeslot after collecting the invitee's votes by confirming a time slot from the **Proposed Meetings** widget on the ERN dashboard

My Proposed Meetings

test email shceudlling

for #435: Peter Pan

Please confirm the time slot for the meeting.

	FRI 22 02 10:16	SAT 23 02 10:16	SAT 09 03 10:16
Mark Lee (Invited)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
John Smith (Invited)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Confirm meeting time	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

Cancel
Confirm

When any meeting is scheduled or a proposed meeting has been confirmed, the meeting appears in **My Meetings** widget on the ERN dashboard. Moreover, users can download the meeting time and date to their calendars by clicking on the **Calendar** icon in **My Meetings**.

My Meetings			
When	Title	Status	
23/feb/2019 12:00 (Europe/Berlin)	TEST	Host	

11.5. Join a Meeting

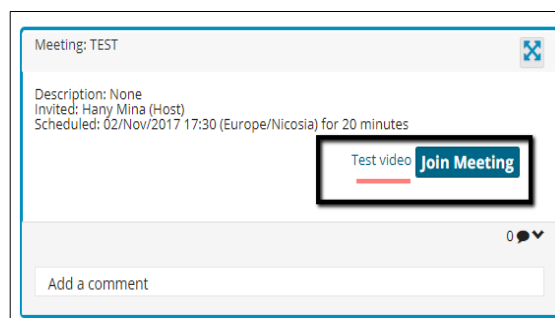
When a Health Professional, is invited to a meeting, he/she must first accept or decline the invitation. The invitees will receive an email notification of the invitation and it will appear also in the footer of the Panel banner as seen below.



Figure 33: Meeting Notification on the main page of the Panel

Additionally, more notifications on the meeting can be seen:

- In the 'My Meetings' section of the ERN Dashboard. (5 minutes before start button join meeting button isn't active (counter going down). Only below 5 minutes.
- In the Panel, via a banner as shown below:

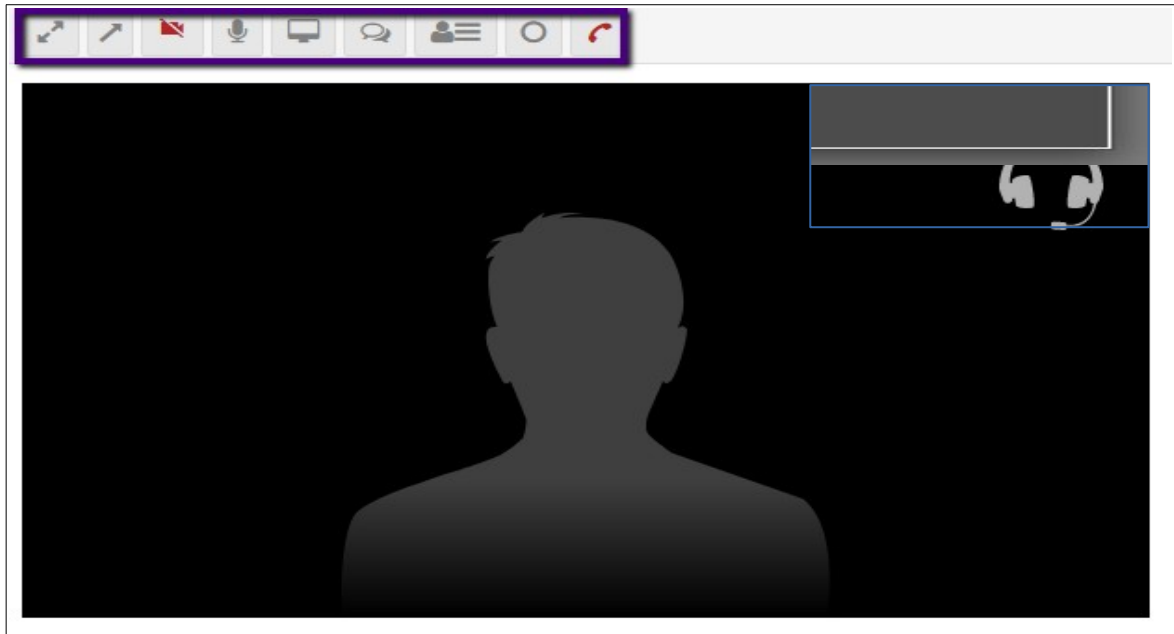


Users can test using the video meeting feature prior to the actual meeting by clicking on “Test Video” link next to the “Join Meeting” button. Nevertheless, if a user wish to test their video settings without logging into the CPMS, they can use the following link: <https://cpms-training.ern-net.eu/video-testing>

The following features are available to use within the video environment to facilitate the interaction between participants and ensure efficient communication during the meeting. You can hover with the mouse on the tool bar of the video to get a help-text on each functionality:

- Moderator has full control over the meeting to add/mute/remove participants
- Meeting can be recorded
- Ability to view who is connected to the meeting
- Ability to share your screen and documents

- Ability to do live streaming/webcast (e.g. for teaching)



11.6. Meeting Summary

When a meeting has finished, the moderator should complete the following steps:

1. Update the meeting status to 'finished', via the 'Time/Place' tab (shown in Figure 32), which can be accessed through the panel Timeline by clicking on the full-screen (arrows) icon shown in Figure 33 above. Alternatively, the status can be updated in 'My Meetings' by clicking edit in general settings of the meeting in question, as shown in Figure 35 below:



Figure 35: Update the Meeting Status by Clicking on 'Edit'

2. Record a meeting summary via the 'Summary' tab, which can also be accessed via the panel Timeline.

Both the meeting Host and the Panel Lead will receive notifications reminding them that these steps should be completed. The notifications will appear both in the Host and Panel Lead's Task List and on the front page of the panel that the meeting is for, as shown in Figure 36 below.

The screenshot shows the 'Doctor One' interface for a meeting titled '# 311 Meeting Tester'. A progress bar at the top indicates the stages: Open (checked), Panel Selection (checked), Data Completion (unchecked), and Assessment (unchecked). Below this, the meeting details are listed: Centre (EB-Haus Austria), Lead (Doctor One), and Panel (Mr. Emma Jackson). A red oval highlights a warning message: 'If meeting "Summary Test" has finished please ensure meeting status is changed to finished and meeting summary is recorded.' Below the warning, there is a 'Consultation Form' section with a 'Recorded: 14/jul/2017 11:16 (Europe/Dublin) by: Doctor One' entry and a 'Consultation Request' section. A 'Timelir' button is visible on the right.

Figure 36: Meeting Summary Reminder

If the meeting has been recorded by the meeting moderator, the recorded video can be seen in a few minutes after the meeting has been ended. This can be found by going to “My Meetings” in the ERN Dashboard and access the meeting page or clicking on “Meeting Recording” in the Timeline from the Panel view.

The screenshot shows the 'ERN ITHACA - Intellectual Disability and Congenital Malformations' meeting page. The page is titled 'Meeting: TEST' and shows the following details: Title of meeting: TEST, Description: (empty), Meeting Status: Finished, When: 02/Nov/2017 17:30 (Europe/Nicosia), and Duration: 20 minutes. Below the meeting details, there is a 'Participants For Meeting' table with one participant: Hany Mina, invited on 02/Nov/2017 18:20, with the status 'Host'. There is also a 'Panel For Meeting' table with one panel: Nickname: s, Proposed date: 02/Nov/2017 18:20, Proposed by: Hany Mina, with a 'View' button. At the bottom, there is a 'Recordings' section with a video player showing a black screen, indicating a recording is available. The video player has a progress bar at 0:00 / 0:03 and a volume icon.

12. CPMS Task-List

The Task List in the ERN dashboard contains a list of pending tasks awaiting the user's interaction.

Those tasks range between different activities such as:

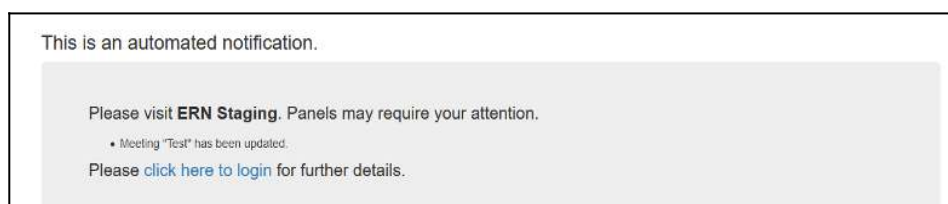
- Respond to an invitation to a Panel
- Record a Contribution in a Panel
- Record a meeting summary
- Review an Outcome document
- Check final outcome document
- Appointment as Panel Lead
- Appointment as Panel Manager

Member Tasklist	
Nickname	Task
#417 Test IHE	Please complete the Patient File for this Panel.
#431 Hen	You have been invited to a meeting (12).
#432 Jen	You have been invited to a meeting (Meeting title IE).
#437 J	You have been invited to a meeting (meeting).
#444 Ad	You have been invited to a meeting (a).
#451 Ben	You have been invited to a meeting (Meeting).
#138 TWO, DEMO DOB: 01/01/1970 (male)	You have been invited to a meeting (ds).
#70 22/11/1990 (male)	Meeting "test 32" has been updated.

13. Email Notifications

CPMS users receive a **Daily Digest** email with a link to login when they are part of any active panel as well as pending tasks may require their attention. This digest email is sent out at 9:00 am CET when any of the above-listed tasks appears in the Task-List.

In addition to the daily digest email, when a user is invited to take part in a virtual meeting, an immediate email will go to their email as provided.



14. Roles & Rights

14.1. ERN Coordinator

In the CPMS, the ERN Coordinator is supposed to be a Health Professional working at one of the ERN **centres**. ERN Coordinators will use the Key Performance Indicators of the ERN for reporting purposes such as numbers of newly enrolled patients and open and closed panels.

A vital role of ERN Coordinators will be to receive all requests made by panel leads who seek assistance in inviting suitable members into a particular panel from within and outside their ERN. If the panel lead is not aware of other experts who can help within the same ERN or other ERNs, the ERN Coordinator can assist.



Panel Selection

Available Invited Co-ordinator Assistance Invite Guest Members Forward Panel

Thematic Area: Entire ERN

Available Healthcare Professionals	Role	Invite All
Birmingham Two	a	Invite
Mr. French Fella	Paris HP	Invite

Inviting members from another ERN is an exclusive action to be done through the ERN Coordinator's assistance.



Panel Selection

Available Invited Co-ordinator Assistance Invite Guest Members Forward Panel

You can invite participants in a Panel who are member of other ERNs.

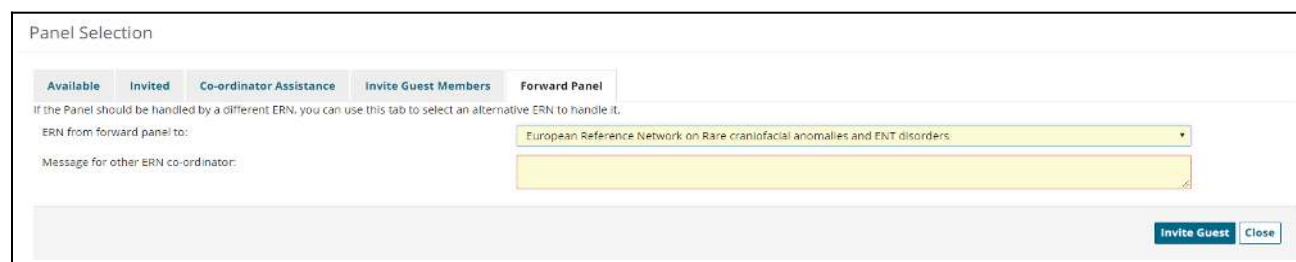
ERN from which to select member: European Reference Network on Rare Bone Disorders

Member: Dr. ERN Specialist

Invite Guest Close

The ERN Coordinator is given the right to assign a Panel Lead if needed, in order to ensure the panel workflow is working smoothly.

The ERN Coordinator can also deal with any incoming panel requests that are not relevant to his/her ERN. He/she may transfer the Panel request back to the Coordinator of the originating ERN or forward it to another ERN Coordinator.



Panel Selection

Available Invited Co-ordinator Assistance Invite Guest Members Forward Panel

If the Panel should be handled by a different ERN, you can use this tab to select an alternative ERN to handle it.

ERN from forward panel to: European Reference Network on Rare craniofacial anomalies and ENT disorders

Message for other ERN co-ordinator:

Invite Guest Close

4 use-cases were identified when a Panel is forwarded from an ERN to another in respect to the access rights of the Panel Lead and panel Members.

Use-case 1: Panel Lead who is HP in both of Referring and Receiving ERNs

As a Panel Lead, I would like to remain the Panel Lead when the Panel is forwarded to another ERN my HCP is part of, so that I can control the Panel workflow with the rights as Lead.

Use-case 2: Panel Lead who is HP in the referring ERN but NOT the receiving ERN

As a Panel Lead, I would like to become a Guest Member when the Panel is forwarded to another ERN my HCP is NOT a part of, so that I can participate actively and track the updates of the panel.

Use-case 3: Panel Member who is HP in both of Referring and Receiving ERNs

As a Panel Lead, I would like to remain a Panel Member when the Panel is forwarded to another ERN my HCP is a part of, so that I can participate actively and track the updates of the panel.

Use-case 4: Panel Member who is HP in the referring ERN but NOT the receiving ERN

As a Panel Lead, I would like to become a Guest Member when the Panel is forwarded to another ERN my HCP is NOT part of, so that I can actively participate and track the updates of the panel.

The ERN Coordinator can request access for an external Health Professional to **enrol** a patient into a particular ERN. Based on the requested access type, the external guest can be permitted to **enrol** a patient or even become a panel member to interact actively with other Health Professionals in an ERN.

Additionally, the ERN Coordinator can schedule a periodic meeting for the Health Professionals of a particular ERN. If discussing multiple patients, the meeting can be divided into timeslots.

The 'ERN Meetings' section allows a **co-ordinator** for an ERN to establish regular meeting times for panels within their ERN.

By clicking on 'Create ERN meeting', shown in the top right corner of Figure 38, the ERN **co-ordinator** can set up a new recurring meeting for their ERN. The established time slots are then available to be selected by Panel Leads when they are scheduling meetings for their panels.

✱ ERN Skin - Skin Disorders USER: Doctor One			
ERN meetings Create ERN meeting			
Name	Schedule	Number of slots	Duration of slots
ERN Skin Monday Meetings	Every 2 weeks on Monday	6	00:15:00
CRANIO Tuesday	Every week on Tuesday	8	00:15:00
Test	Every week on Tuesday and every week on Friday	2	00:10:00
ERN Meeting	Every month on the 2nd Tuesday	10	00:15:00
ERN CRANIO Monday Meetings	Every week on Monday	4	00:15:00
ERN Eye Monday Meetings	Every week on Monday	4	00:15:00

Figure 37: Meeting Groups

Figure 38: Create ERN Meeting

ERN Coordinator/Dispatcher can assign/overwrite Panel Manager to any active panels in their ERN. The Panel Management console can be accessed from the ERN Dashboard by clicking on **Panel Management** Tab. ERN Coordinator/Dispatcher can assign a Panel Manager by clicking on the drop-down menu on the right hand side for each panel active in their ERN. More filters are also available on the top for better search.

<p>BOND - Bone Disorders USER: Mr. Emma Jackson</p>		<p>Thematic Area HCP Panel Manager Nickname Panel ID State</p>				
<p>Panel Management</p>		<p>Report type: Panel Management</p>				
Panel ID	Nickname	Thematic Area	HCP	Panel Manager		
1143	test schedule	Fibrodysplasia Ossificans Progressiva	DE32 - University Hospital Essen	Mark Zuck		
1141	Peter Pan	Acromelic dysplasia	DE32 - University Hospital Essen	Mark Zuck (1)		
1140	msh_panel	Achondroplasia	BE01 - Antwerp University Hospital	Mr. Emma Jackson (19)		
1118	Cute	Ollier Maffucci	EE02 - Tartu University Hospital	bond man (2)		
1117	Peter Pan	Achondroplasia	IT51 - Rizzoli Orthopaedic Institute of Bologna	Bond Test (2)		
				Mr. Emma Jackson		

14.2. ERN Dispatcher

An ERN Coordinator can assign another user the role of ERN Dispatcher. The Dispatcher role is similar to that of the Coordinator in clinical context to process requests coming into the ERN seeking assistance as well as assigning Panel Managers to active panels. Therefore, the Dispatcher's role might be to ease the workload of the Coordinator during busy periods for example, or to cover for the Coordinator when he/she is on vacation.

This role in CPMS, reflects the system flexibility and capacity to fulfil various business needs.

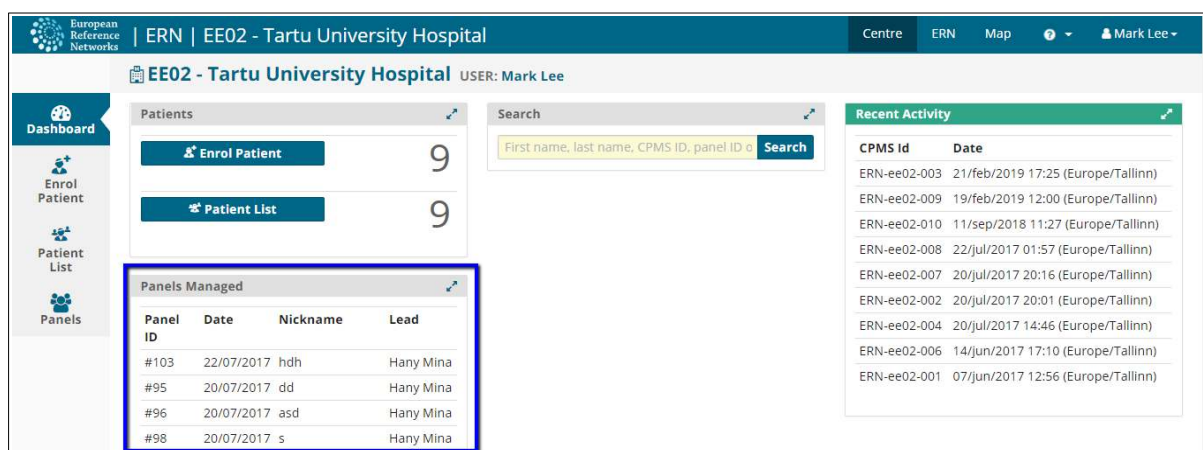
14.3. Panel Manager

Panel Manager role in CPMS is quite similar to the Panel Lead. This role focuses on monitoring the panel performance and make sure no impediment is blocking the workflow is move smoothly from the State **Open** and up to **Outcome** when the Panel Lead is drafting the outcome.

Panel Managers can not edit the data in the consultation form and their role is limited o transitioning the workflow, and assist in panel selection, scheduling meetings, and monitor the requests for additional data if any. They also can record the Contribution on behalf of the Panel Lead but can't record an outcome or Sign off the panel outcome document.

HCP Panel Manager

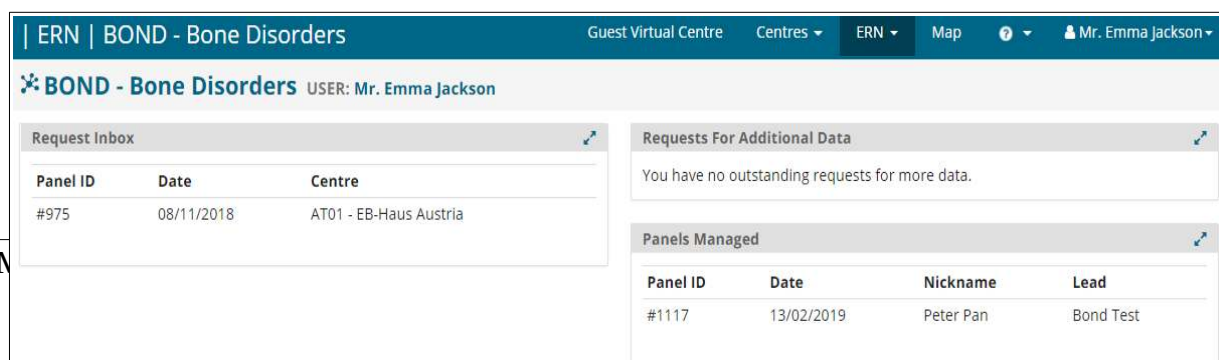
HCP Panel Manager is assigned by a centre to look after all panel originated from this particular centre to one or multiple ERNs. Panel Manager in HCP can also be a Panel Manager and ERNs too. This is an internal business process which is defined by each centre and ERN if necessary. A widget appears on the Centre Dashboard when the user is involved in a panel as Panel Manager in their Centre.



Panel ID	Date	Nickname	Lead
#103	22/07/2017	hdh	Hany Mina
#95	20/07/2017	dd	Hany Mina
#96	20/07/2017	asd	Hany Mina
#98	20/07/2017	s	Hany Mina

ERN Panel Manager

ERN Panel Manager is assigned to a specific panel by the ERN Coordinator or the ERN Dispatcher. Please note that Panel Managers assigned to panels from the centre or ERN can be overwritten if necessary to distribute the workload better among the Panel Manager available in Centre or ERN. A widget appears on the ERN Dashboard when the user is involved in a panel as Panel Manager in their ERN.



Panel ID	Date	Centre
#975	08/11/2018	AT01 - EB-Haus Austria

Panel ID	Date	Nickname	Lead
#1117	13/02/2019	Peter Pan	Bond Test

15. Webinars

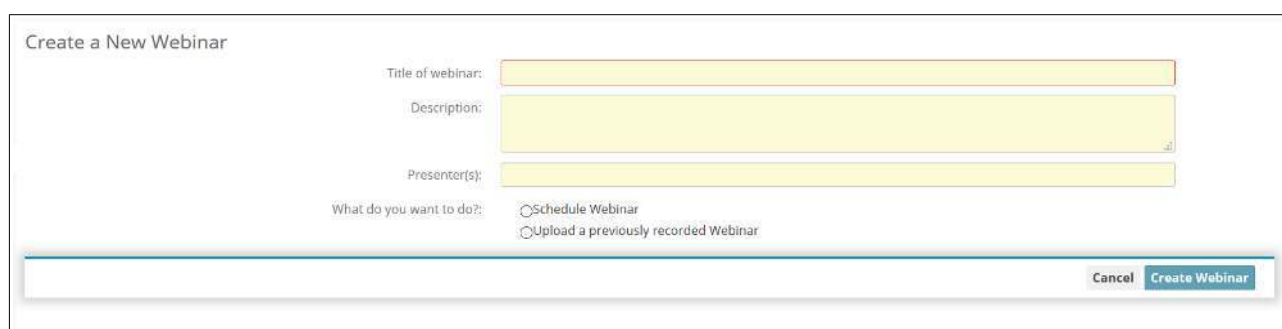
In the 'Webinars' section the user can create a new webinar or upload a previously recorded one.



The screenshot shows the 'Webinars' section of the application. At the top right is a 'Create webinar' button. Below the header, there are two sections: 'Planned Webinars' and 'Recorded Webinars'. Each section contains a table with columns for 'Title', 'Presenters', 'When', and 'Description'. The tables are currently empty.

Figure 39: Webinar Section

A webinar is mainly used for education and training purposes, and it differs from a meeting in that all of the users only see the presenters screen.



The screenshot shows the 'Create a New Webinar' form. It includes input fields for 'Title of webinar:', 'Description:', and 'Presenter(s):'. Below these fields, there is a section titled 'What do you want to do?:' with two radio button options: 'Schedule Webinar' and 'Upload a previously recorded Webinar'. At the bottom right of the form are 'Cancel' and 'Create Webinar' buttons.

Figure 40: Create a New Webinar

16. ERN Map

This application allows the users to view all of the medical **centres** (hospitals) on the CPMS. The side menu allows for filtering based on specific ERNs.

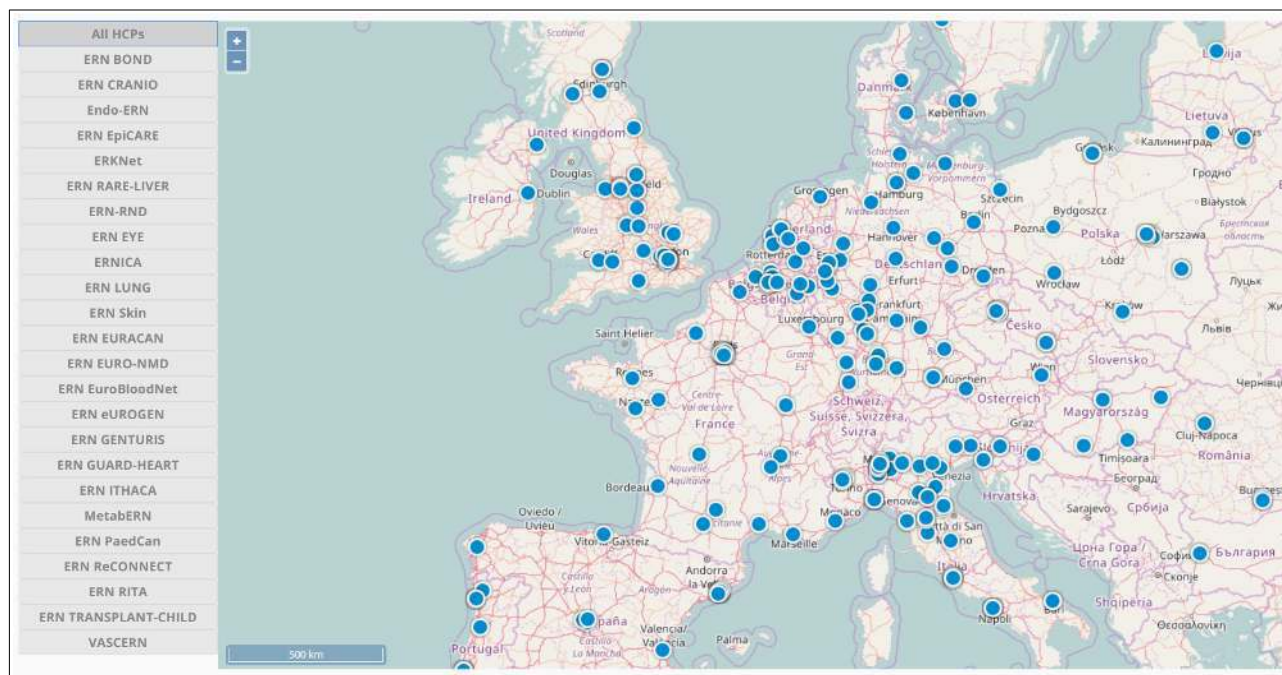
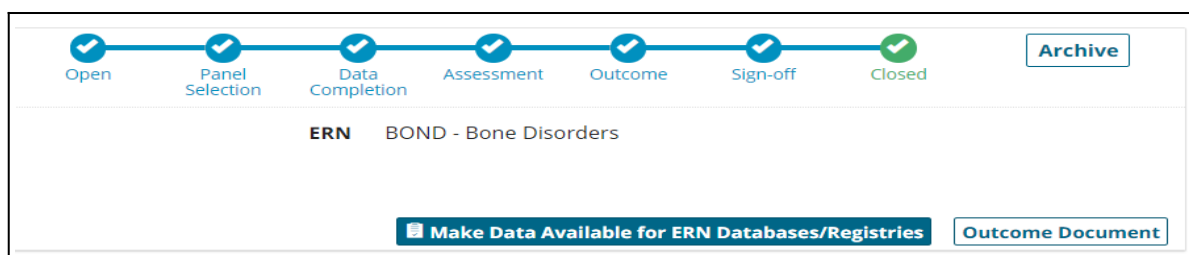


Figure 41: ERN Map

17. ERN Databases/Registries

In the ERN Databases/Registries, the query builder environment in the CPMS, pseudonymised data is made available for authorised users (using the role 'data manager/researcher') subject to the condition that the second consent has been opted-in by the patient (i.e. ERN Databases/Registries).

When the panel has been closed and the second consent is valid, the Panel Lead or any Health Professional from the enrolling Centre can make the data collected in the panel available in the ERN registries/database query builder.



If the second consent was not indicated, then this option does not appear on screen. When the panel data is pushed to the ERNregistries/databases query builder, a unique identifier (Research ID) is assigned, other than the identifier that was used during the consultation phase of the panel. The data stored in the ERNregistries/databases query builder can be queried by an authorised user by combining particular fields, e.g. without the identifier or aggregated, in which way the data would be classed as anonymized. If the authorised user does include the unique identifier in the query (i.e. Research ID), the data output from the query would be classed as pseudonymised rather than anonymised.

If the Research ID is included in the query and there is requirement to re-identify the patient for further contact with regard to a specific research purpose, this is only possible if the patient has opted-in for the third consent, i.e. to be contacted for a specified research purpose. A detailed request has to be made to enable re-identification by a software engineer.

Note: The role of a data manager/researcher in CPMS is independent of the role of the health professional and the data manager/researcher role cannot see or participate in panels (unless combined with the role of a health professional (HP)).

The authorised user with the data manager/researcher role can see the different section titles of the Consultation Record within the query builder, from which fields can be dragged and dropped. The user can mouse-hover over a database field name to show the name as it is displayed in the form. The 'info' button displays all of the fields, allowing the user to quickly search for a specific name.



The authorised user with the data manager/researcher role can drag and drop sections containing the data they are interested in into the 'Selected Tables' column, and the required fields into the 'Outputs' column. The report can then be previewed in the 'Preview' tab.

ERN-SKIN - Skin Disorders USER: Research Man

Columns Preview Cancel work (start over) Save Query

Study Templates info

Consultation Record

METADATA

workflow

patient_info

birth_comp

functional_status

episode

symptoms

treatment

exam_findings

laboratory_findings

imaging_findings

other_findings

previous_clinical_trial

other_information

diagnosis

working_diagnosis

differential_diagnosis

comorbidities

genetic_features

family_history

other_carrier

carrier

RFI

Selected Tables

nickname

ern

disease_group

thematic_area

accepted_date

description

reason_description

repeat

healthcare_provider

point_of_care_specialist

thematic_area_secondary

patient_information

gender

ppl

country_of_birth

country_of_residence

education_level

occupation

pregnancy

rare_disease_diagnosis

orpha_code

diagnosis_status

onset_date

Outputs

PATIENT

submission_date

ern

thematic_area

AND OR Data Filters

AND

Sort Order

Then by clicking the Preview Button tab, the selected fields or tables of interest shall be shown.

ERN-SKIN - Skin Disorders USER: Research Man

Research Cancel work (start over) Save Query

Columns Preview Report Type - Settings

Reports

Display As - Settings

METADATA		Ern panel	
PATIENT	Submission date	Ern	Thematic area
RESEARCH-8956097	01/Nov/2018 11:53 (Europe/Berlin)	ERN-SKIN	Premature Skin Ageing
RESEARCH-147765903	05/Nov/2018 13:39 (Europe/Berlin)	ERN-SKIN	ALL LOCATE hidradenitis suppurativa PAPA, PAPASHI, PASII, PASS, SAPHO, Bechet, Degos
RESEARCH-4553328	06/Dec/2018 18:49 (Europe/Berlin)	ERN-SKIN	Ectodermal Dysplasias including Incontinentia Pigmenti and p63-related disorders
RESEARCH-1944277	26/Nov/2018 17:36 (Europe/Berlin)	ERN-SKIN	Cutaneous Mosaic Disorders: Nevil & Nevold Skin Disorders & Complex Vascular Malformations & Vascular Tumours

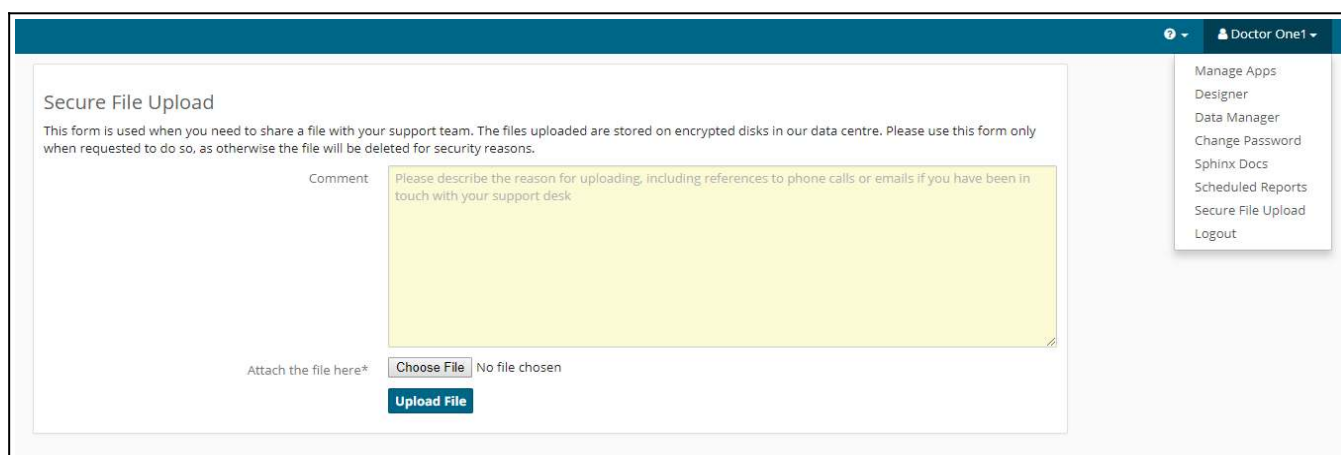
1 to 4 of 4

first prev next last 10

18. Secure File upload


OpenApp have developed a functionality to enable users exchange large files with CPMS support team when needed. Simply, the feature provides a secure communication mechanism for users to share materials with the support team when investigating an issue. User have to click on “secure file upload” in the drop-down menu appearing under their login username. Users must first send an email to SANTE-CPMS-ITSUPPORT@ec.europa.eu so that the support issue can be followed up.

The reference number received must be included when any material is being uploaded. There is a restriction in that no identifying or personal data can be uploaded, however, there is no restriction on the number or size of files to be uploaded here.



The screenshot displays the 'Secure File Upload' interface within the OpenApp application. At the top, a dark blue header bar contains a user profile icon and the name 'Doctor One1'. A dropdown menu is open, showing options: 'Manage Apps', 'Designer', 'Data Manager', 'Change Password', 'Sphinx Docs', 'Scheduled Reports', 'Secure File Upload' (highlighted), and 'Logout'. The main content area is titled 'Secure File Upload' and includes a sub-header: 'This form is used when you need to share a file with your support team. The files uploaded are stored on encrypted disks in our data centre. Please use this form only when requested to do so, as otherwise the file will be deleted for security reasons.' Below this, there is a 'Comment' section with a text area containing the placeholder text: 'Please describe the reason for uploading, including references to phone calls or emails if you have been in touch with your support desk'. At the bottom, there is a file upload section with the label 'Attach the file here*', a 'Choose File' button, and the text 'No file chosen'. An 'Upload File' button is located below the file upload section.

19. Appendix – Outcome Document Template

 <p>European Reference Networks</p>	Panel: #	Attending	
	ERN:	Thematic area:	Date:
	Panel Lead	of	
	Panel:		

[ERN Code]
[ERN Panel Start Date]
[ERN Panel End Date]

[CPMS Patient ID]
[HCP Code and Name]

Dear Dr [Point of Care Specialist name]

RE: [ERN13 Referral Request Reason]

Thank you for enrolling this patient file on [ERN5 Patient Enrolment Date] for assessment by a panel of the European Reference Network [ERN], regarding [ERN12 Referral Request Description Short]. Note that this outcome document is the result of the consolidated collaboration based on the information provided in relation to the patient.

[PANEL OUTCOME]

Yours faithfully

Panel Lead:
[Panel lead name and HCP code and name]

Panel Members:
[Panel Members who recorded Contributions]