CPMS User Guide

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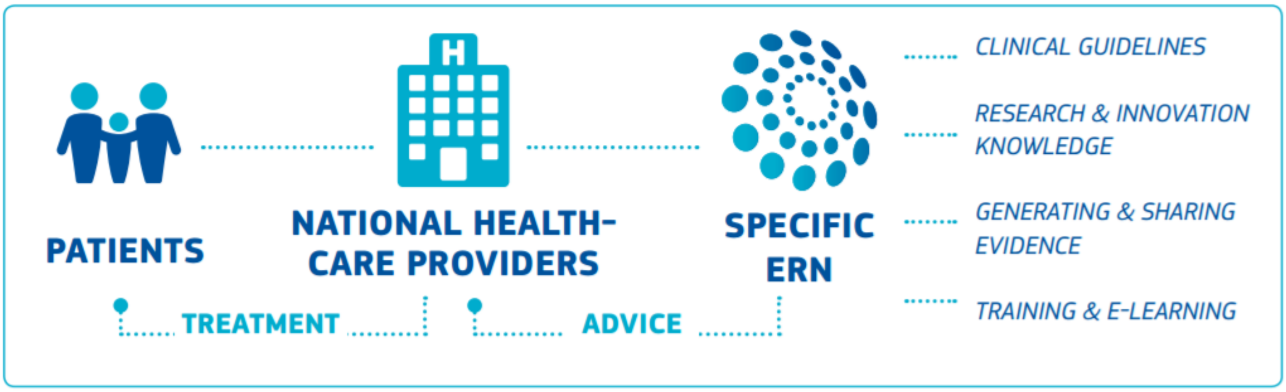
1. Welcome to the CPMS

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.



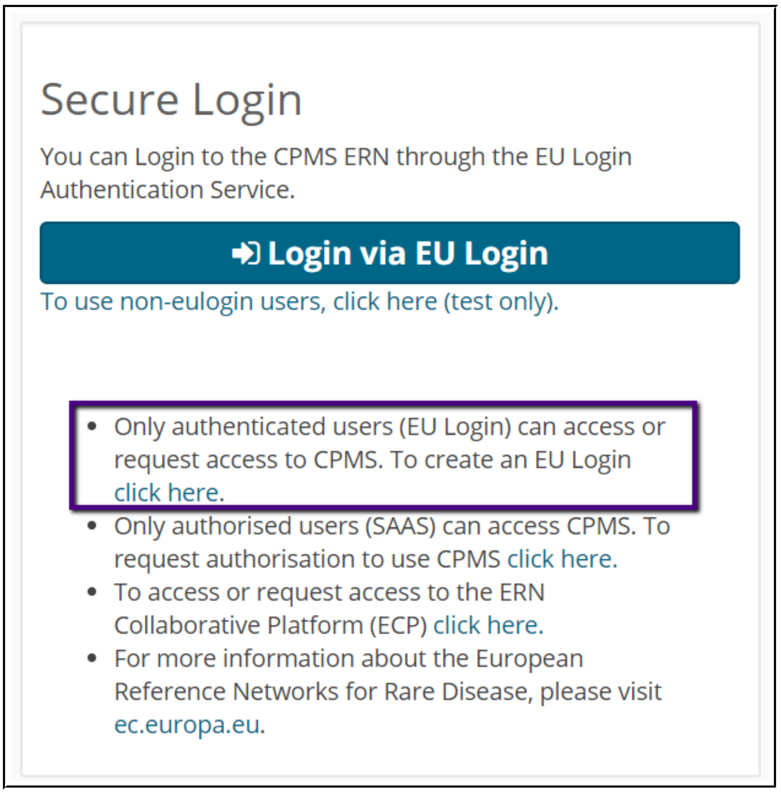
2. Getting Started

2.1. Access to CPMS

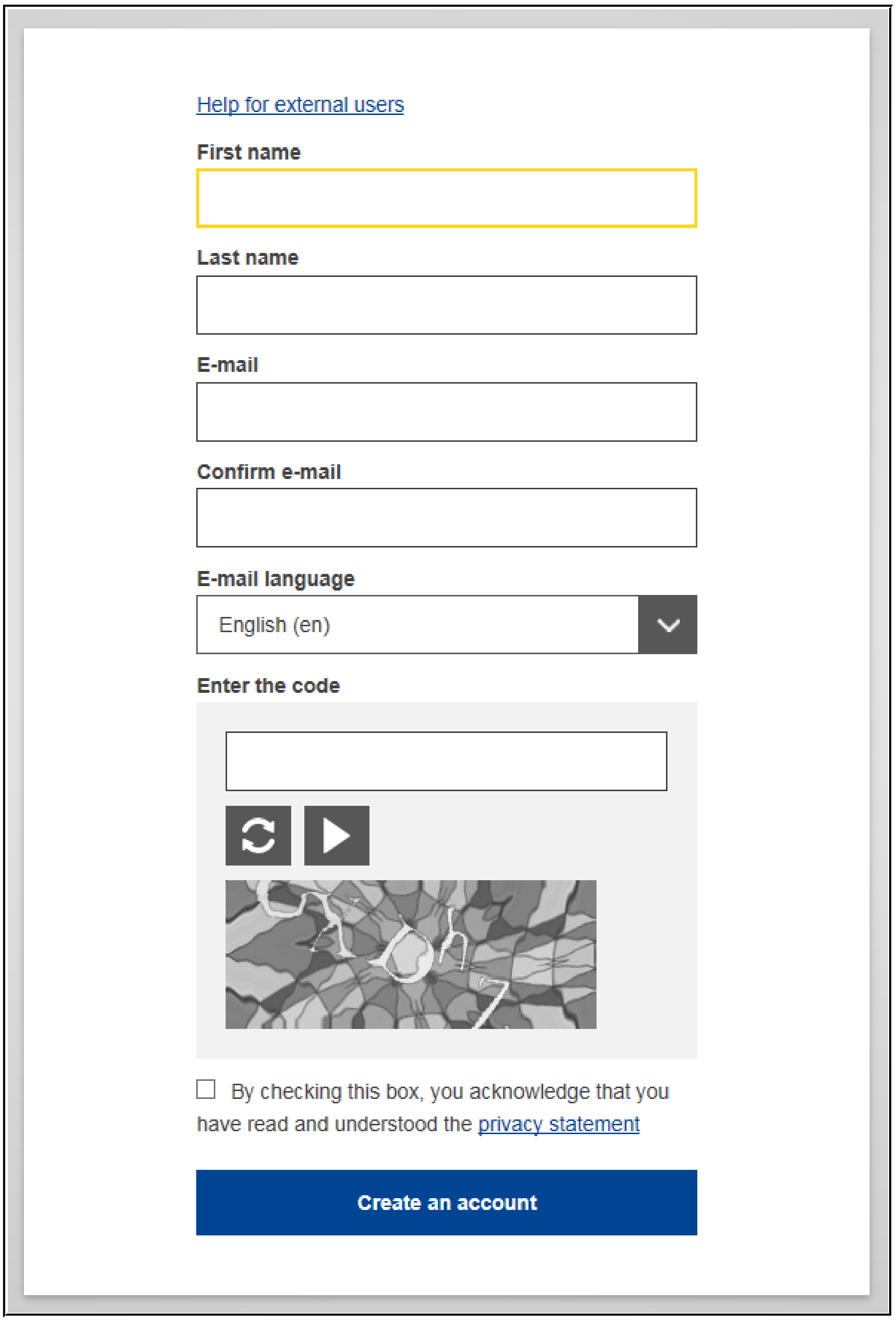
Access to the Clinical Patient Management System (CPMS) is strictly regulated to protect the data privacy rights of the patients. Only authenticated users (ECAS) can request **authorisation** (SAAS) from the ERN to use the CPMS. Each ERN has member Healthcare Provider **centres** (HCP) and it is envisaged 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.**



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



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.

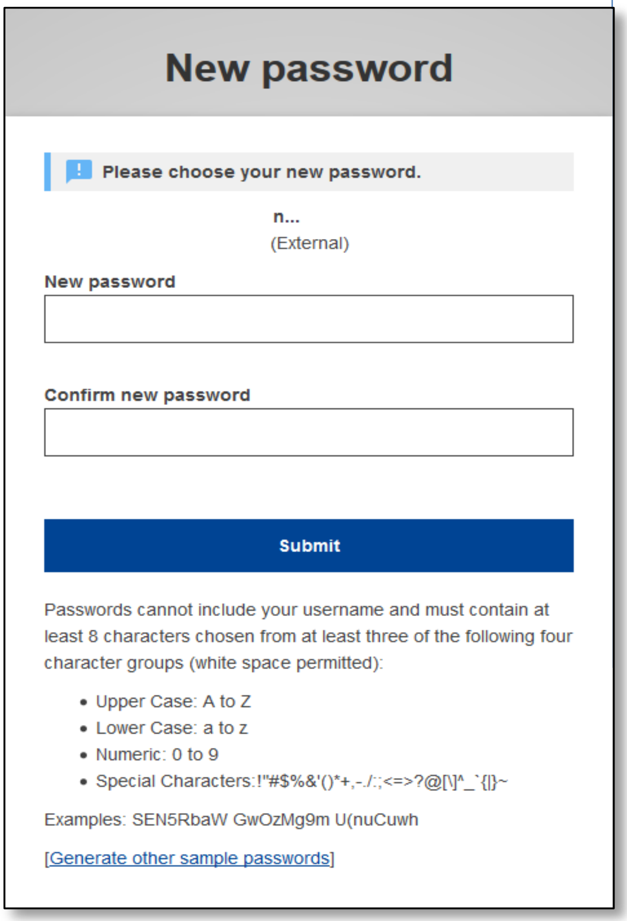
Sent to you by EU Login

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.



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.

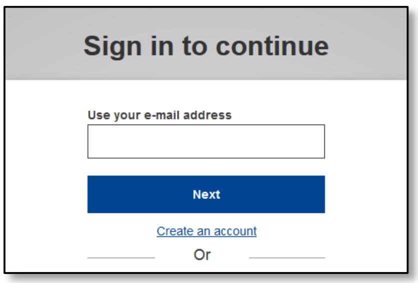
Select a password as long and as complex as you can in order to make your account more secure but keep in mind that you will have to remember it.

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.

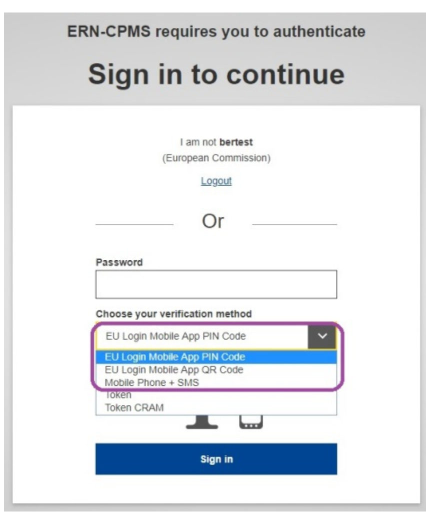


Enter the e-mail address you provided when creating your EU login account in the "Use your e-mail address" field and click on "**Next**".

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 you 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) **<u>ECAS Mobile App PIN code</u>** – 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) **<u>ECAS Mobile App PIN code</u>** – 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) **<u>ECAS Mobile App QR code</u>** – 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.

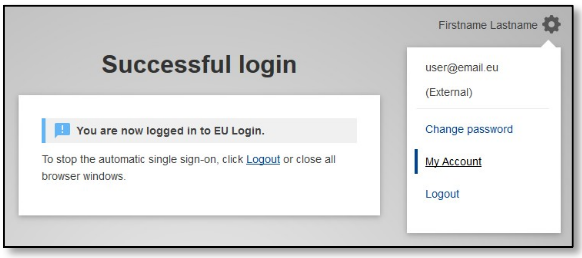
4) **<u>Mobile phone + SMS</u>** – Your mobile phone allows you to connect to EU login by receiving an SMS, if your number is registered in your EU login account. In some countries, you might not receive the SMS and should rather use another verification method.

<u>You then have to register your phone number in your EU login account:</u>

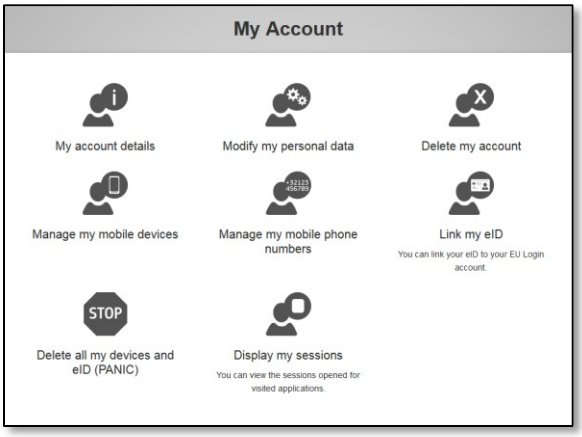
Register a mobile phone number for receiving verification SMS

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

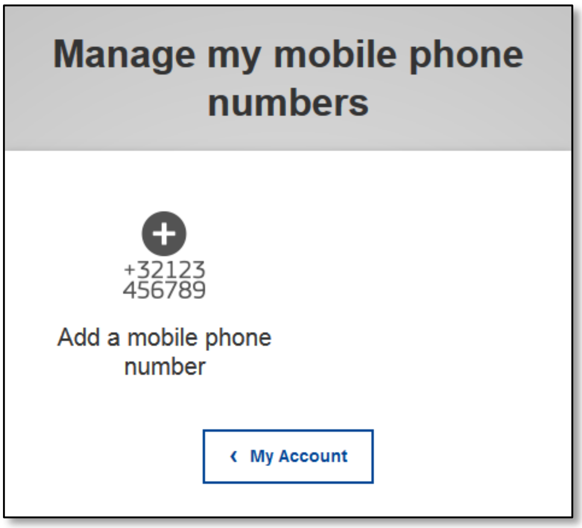
In order to register your mobile phone number, open a browser and **go to the following URL:** https://ecas.ec.europa.eu/cas



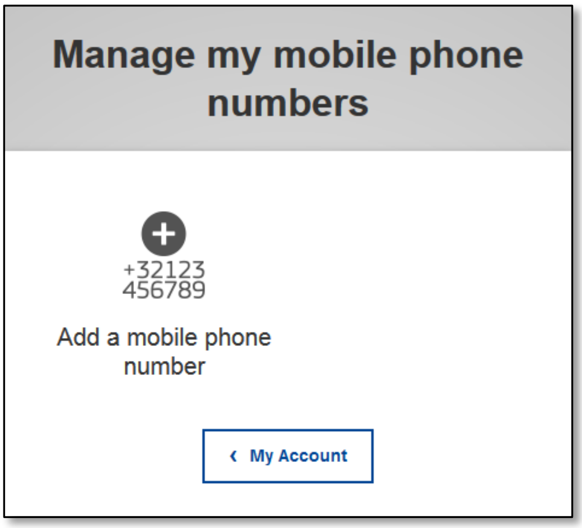
Once successfully authenticated, move the mouse over the gear at the top right corner to display the menu and select "My Account".



Click on "Manage my mobile phone numbers".



Click on "Add a mobile phone number".



Click on "Add a mobile phone number".

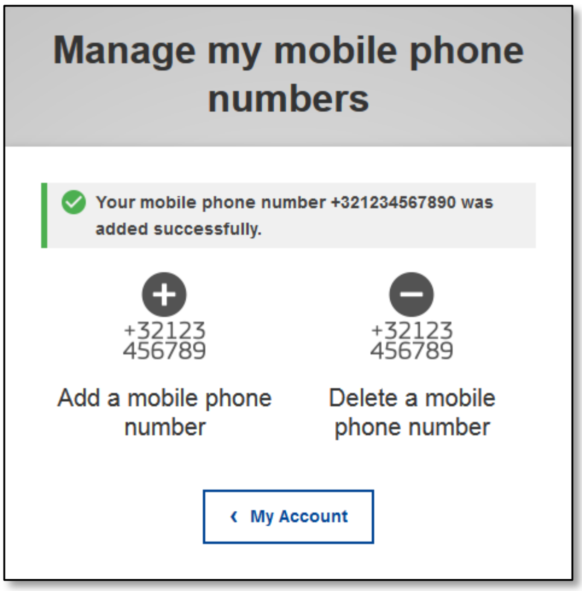
Enter your mobile phone number in the "Mobile phone number" field, starting with a plus sign and with the country code.

Do not include dots, parenthesis or hyphens.

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

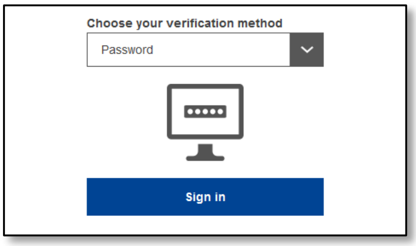
The SMS contains a challenge code made of eight characters separated with a hyphen (minus sign).

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



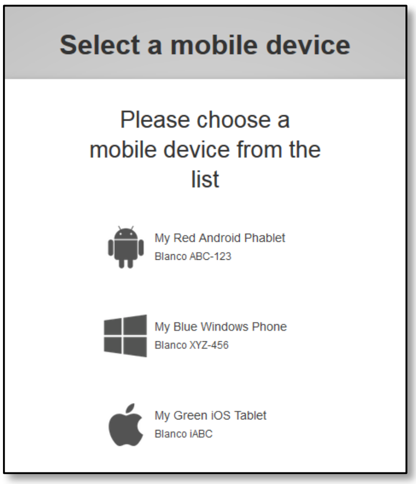
Your mobile phone number is successfully registered and can now be used for authenticating.

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.

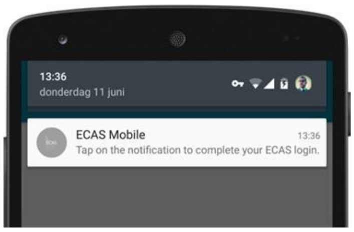
Sign in with an EU login account using the ECAS Mobile App PIN code



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.



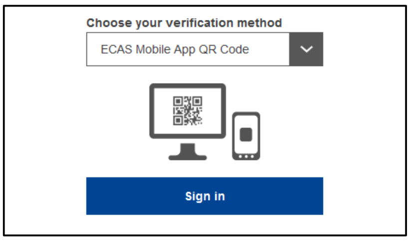
EU login sends a **notification** to your mobile device.

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.

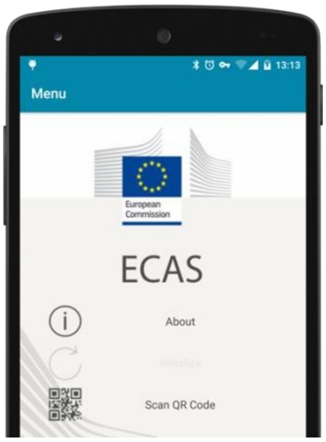
Sign in with an EU login account using the ECAS Mobile App QR code



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

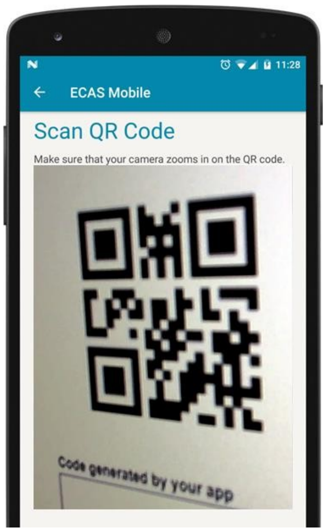
Enter your password in the "Password" field and click on "**Sign in**".

A QR code is displayed on screen.



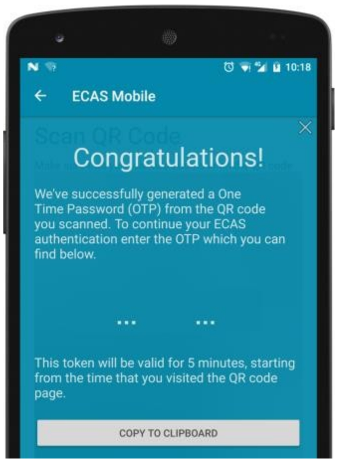
Start the ECAS Mobile App on a mobile device where it has been previously **initialised**.

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

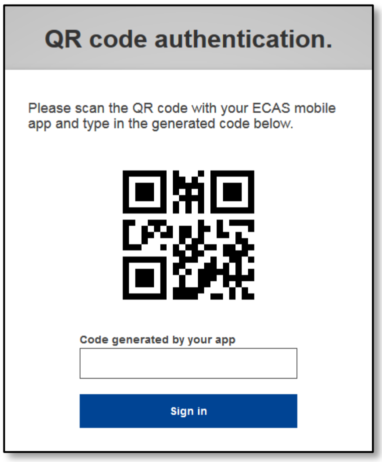


The QR code scanner starts on your mobile device.

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



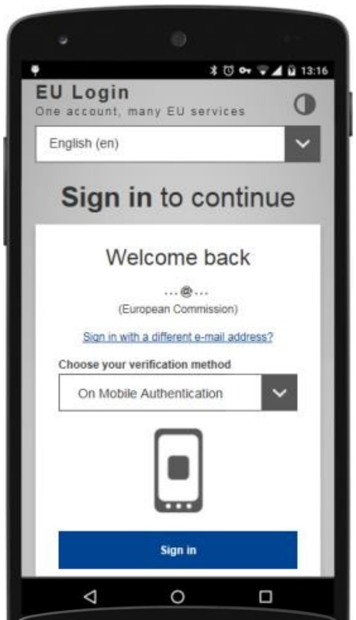
The ECAS Mobile App displays a **one-time password** composed of 8 digits.



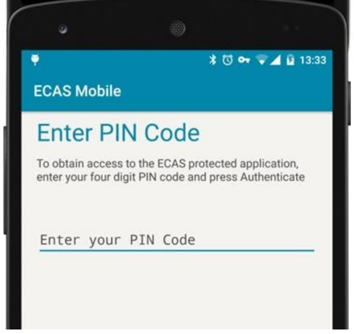
Type the one-time password in the "code generated by your app" field and click "**Sign in**" to proceed to the service you requested to use.

Sign in with an EU login account using On Mobile authentication

The "On Mobile" verification method is only available when browsing on a mobile device and should only be used if an ECAS Mobile App has been previously installed and **initialised** on that device.



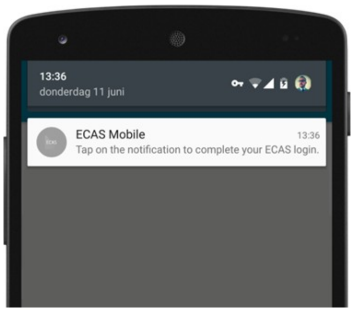
Select "On Mobile Authentication" as the verification method and tap on "**Sign in**".



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

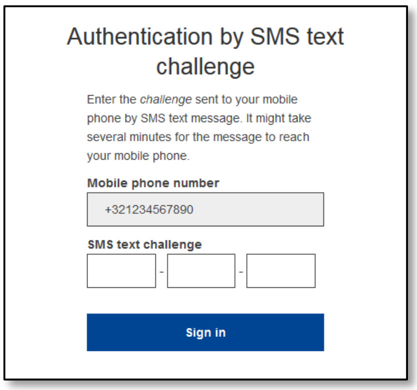
Enter your PIN code and tap on "**Authenticate**".

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



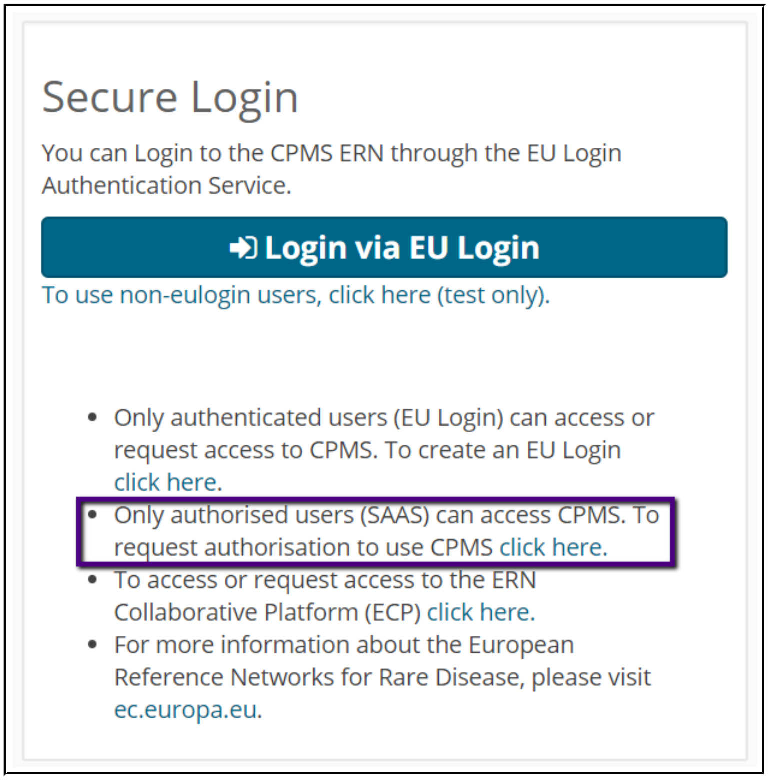
Select "Mobile Phone + SMS" as the verification method.

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.

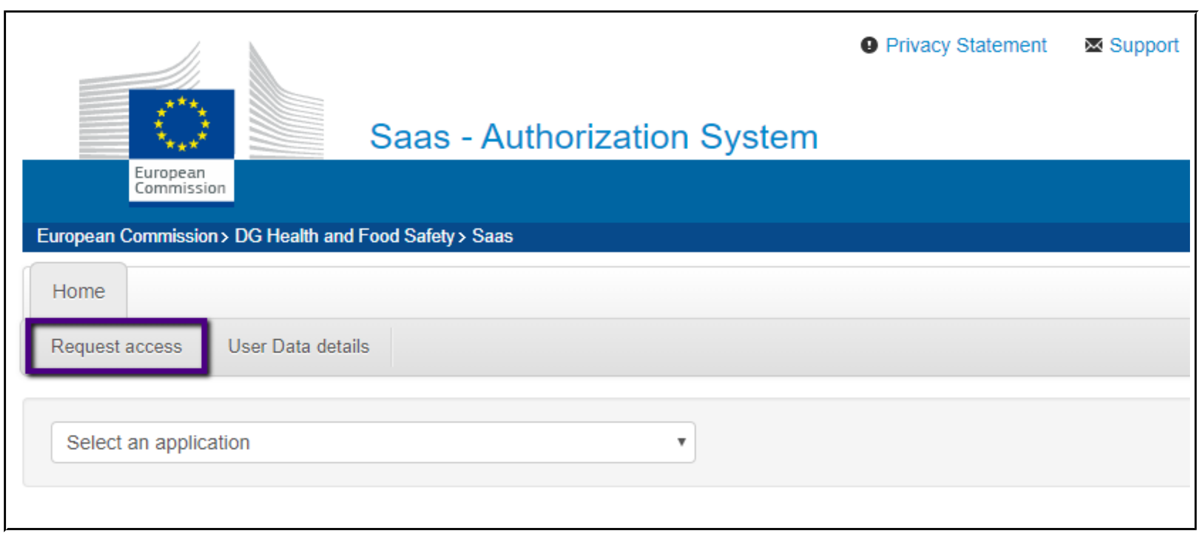
When clicking "**Sign in**", an SMS is sent to your mobile device. The SMS contains a challenge code made of nine characters separated with hyphens (minus sign).

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.

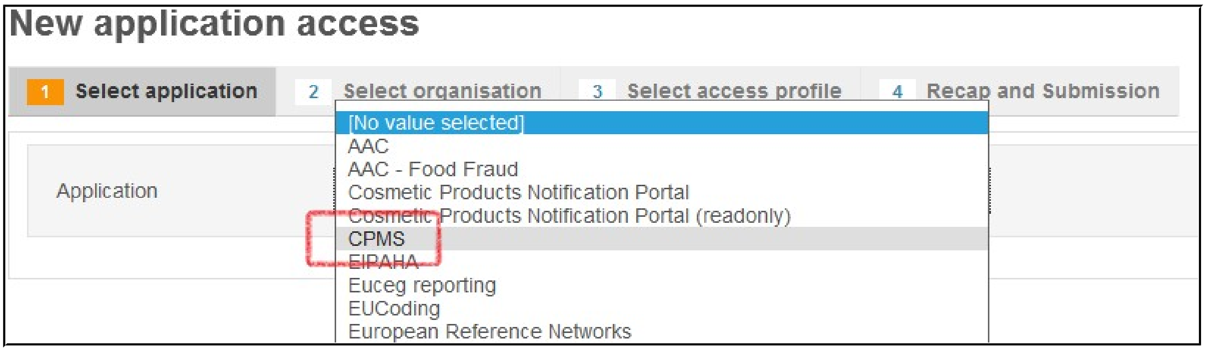
Once the EU login has been created you are ready to request access to the CPMS. Go back to the login page for CPMS on https://cpms.ern-net.eu/login/. This time click on the link to request **authorisation** to use CPMS.



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

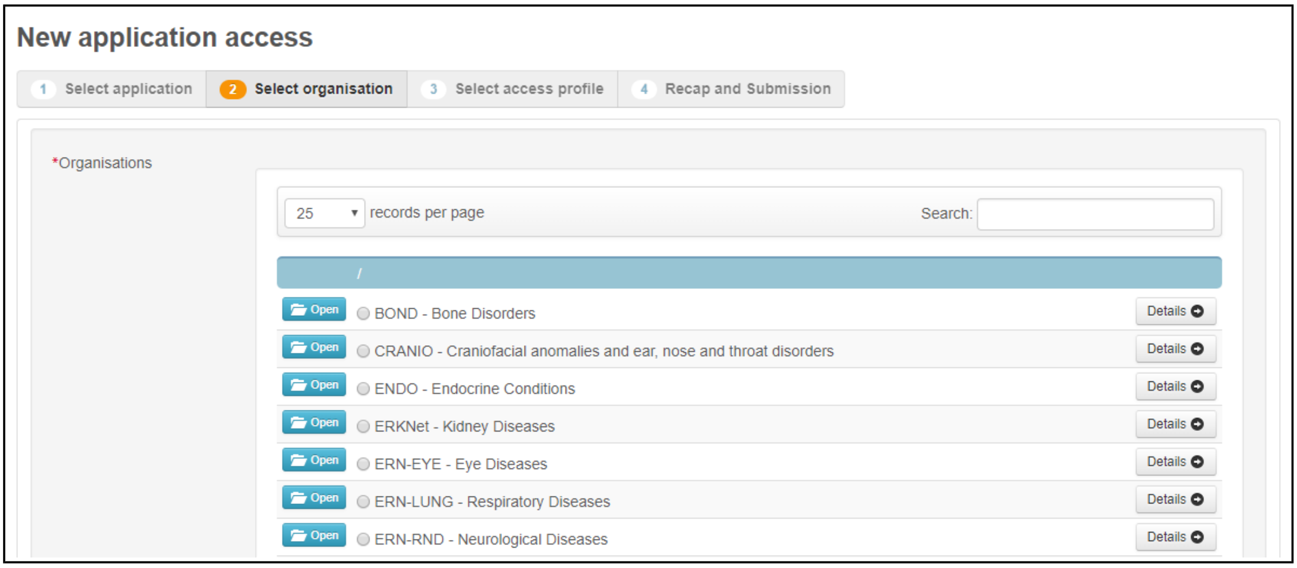


On the page, that appears select **CPMS** in the Application box:



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

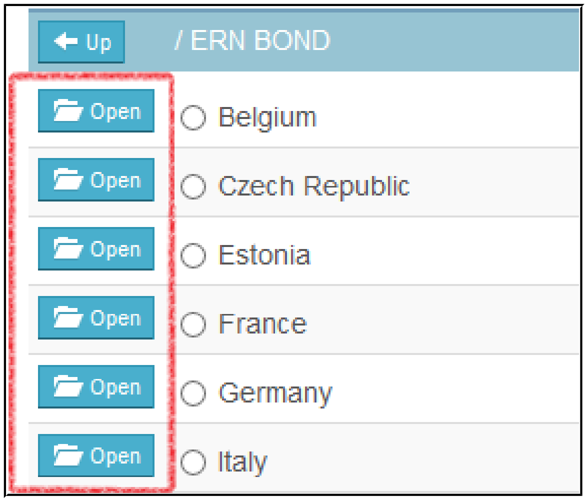
On the **Select Organization** page you need to select which ERN you wish to request access for by clicking on **Open** next to it. **You do not need to click in the circle until the very last step when you select your healthcare provider*



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:

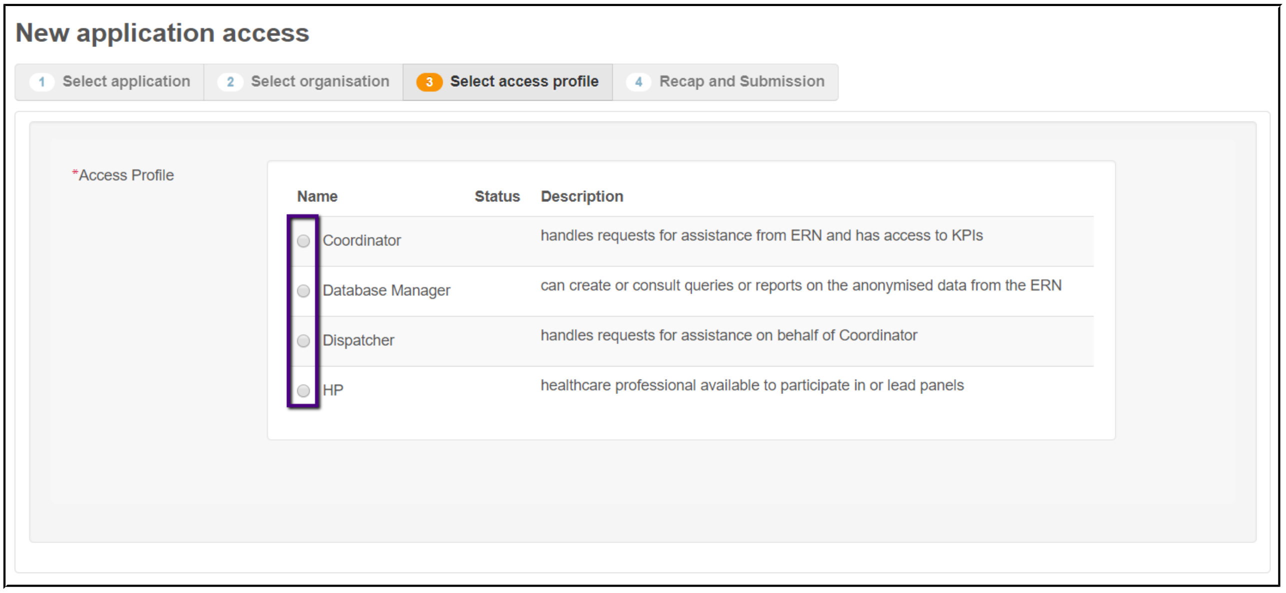
After clicking **Open,** you need to select which country your Healthcare Provider is located in. Again, you select this by clicking **Open**



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

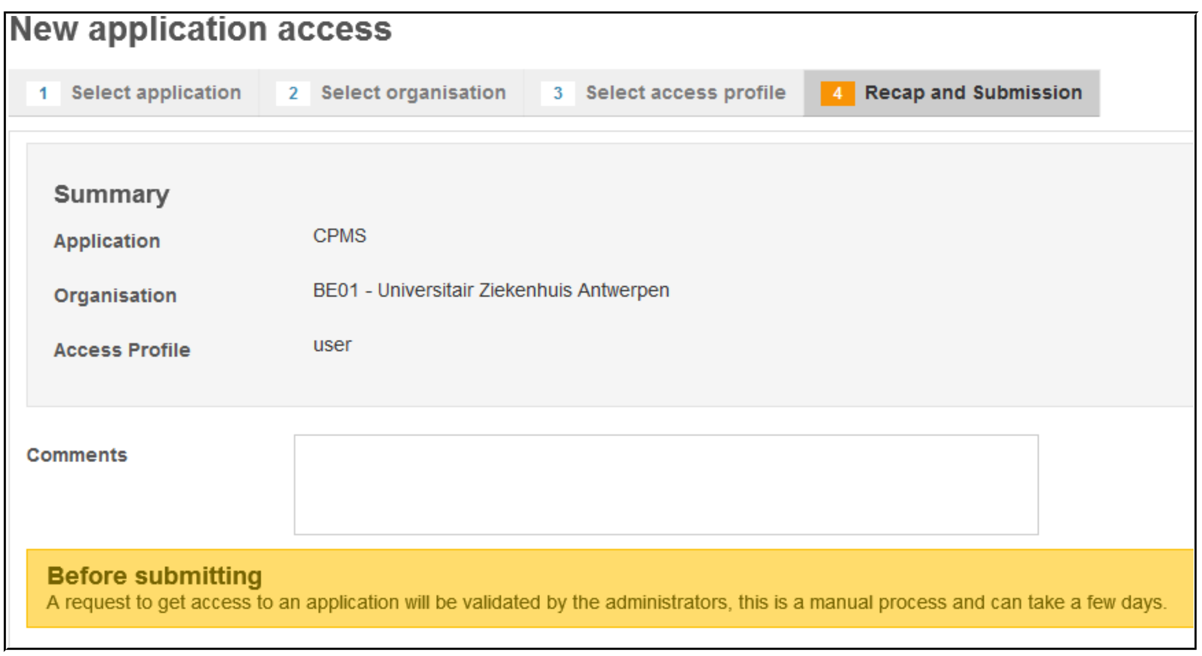
Once selected you click on **Step 3: select an access profile** to continue

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:



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

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*



When you are ready click on **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 works to its full potentials on **Google Chrome** preferably latest version, or ver. 64 and above. **Google chrome** is the **most recommended web browser** by which users can avail of all CPMS technical functionalities.

However, other browsers are can still be used but **NOT fully supported.** There might be certain difficulties when using some components in CPMS particularly the video conferencing technology.

- Mozilla Firefox (ver.60 and above)
- Internet Explorer (ver.11.0 or later)
- Microsoft Edge (ver.HTML 17.17134)

Note:

- Cameras and microphones have to be enabled to be accessed through the browser.
- When using devices with Mac operating system, all users are requested to access the CPMS with **Google Chrome**
- Please **AVOID** using **Safari** web browser since it is **NOT** fully compatible with CPMS components
- 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:

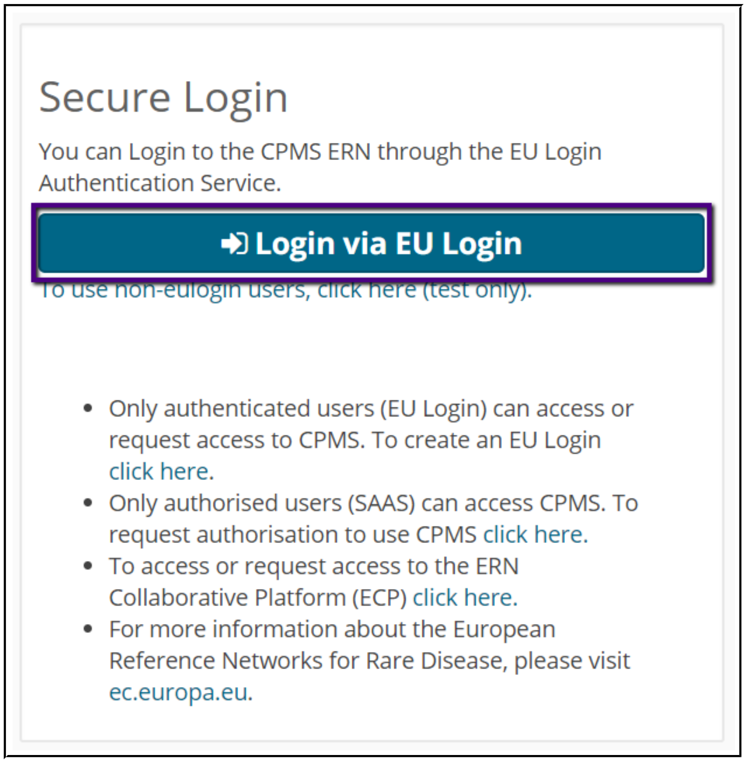
https://cpms.ern-net.eu

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:

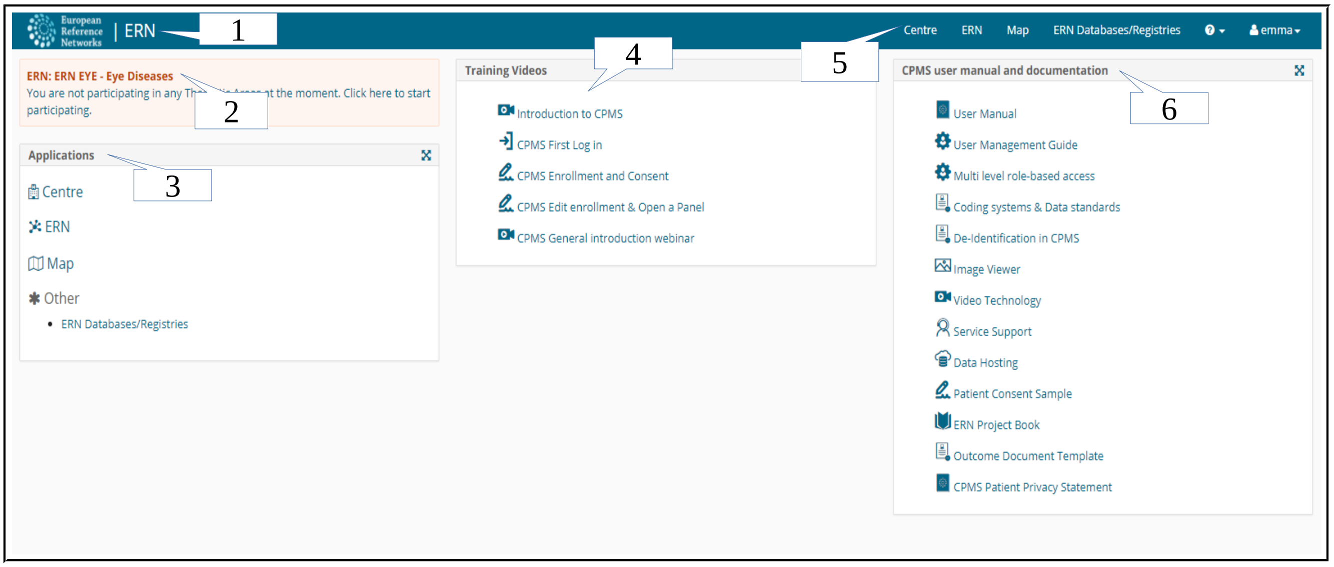


Figure 3: Home Page

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:

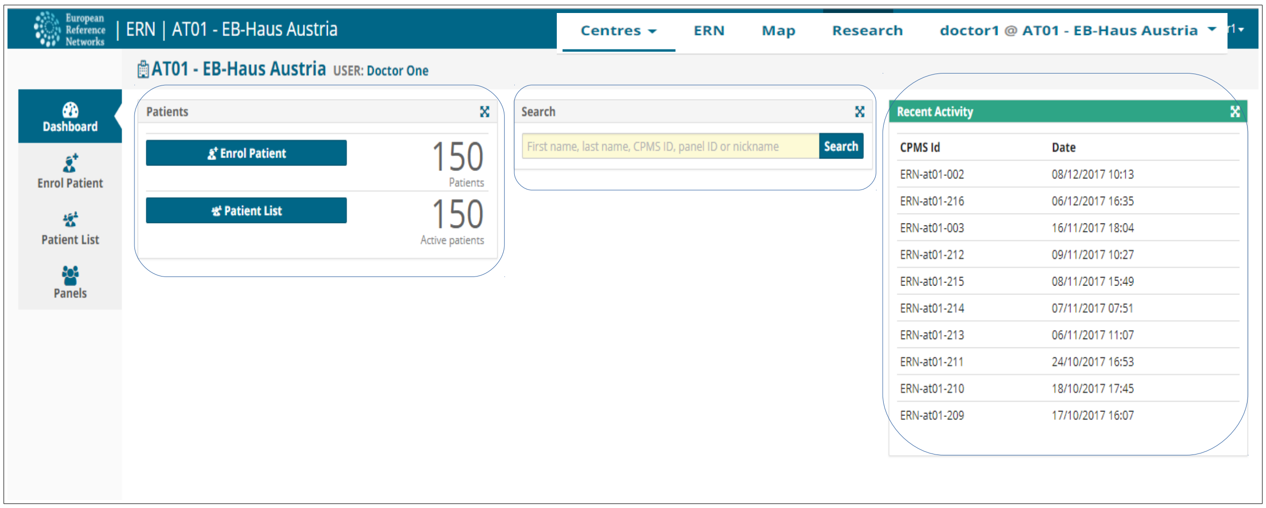


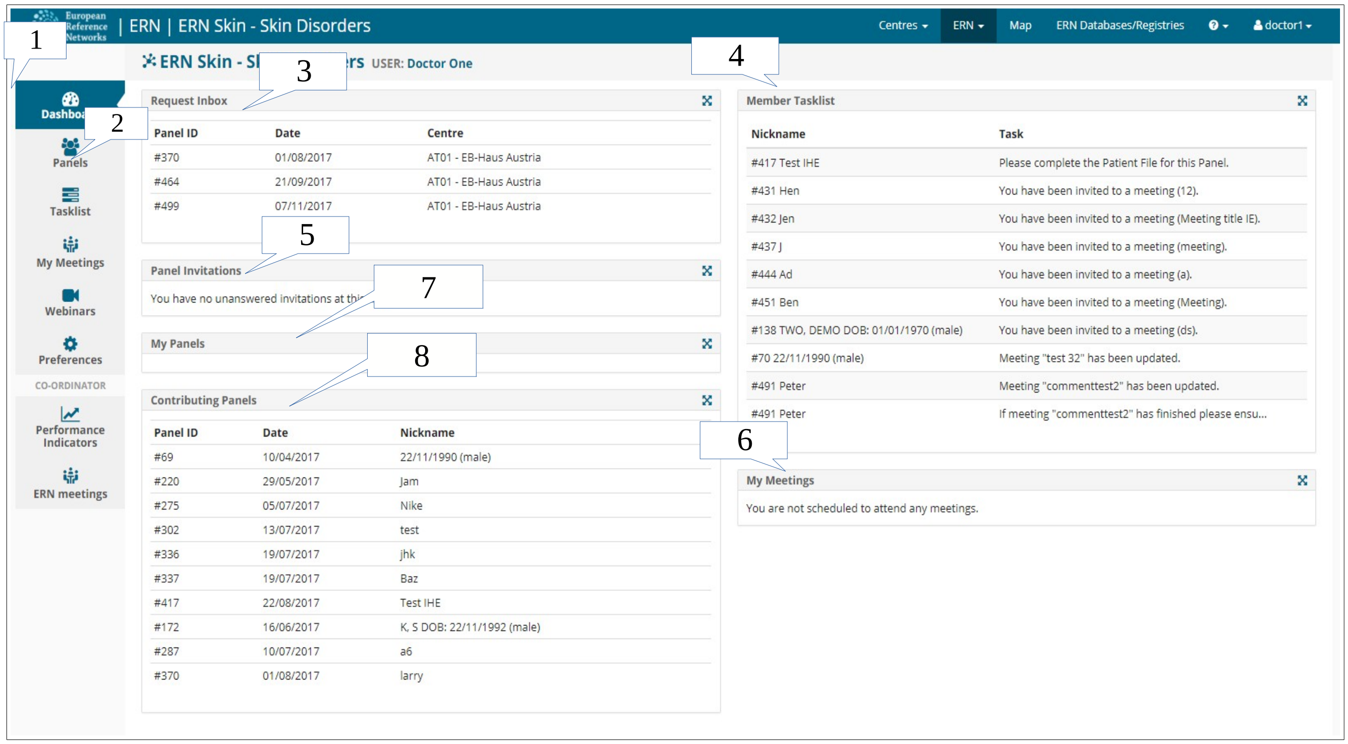
Figure 4: Medical Centre Dashboard

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



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.

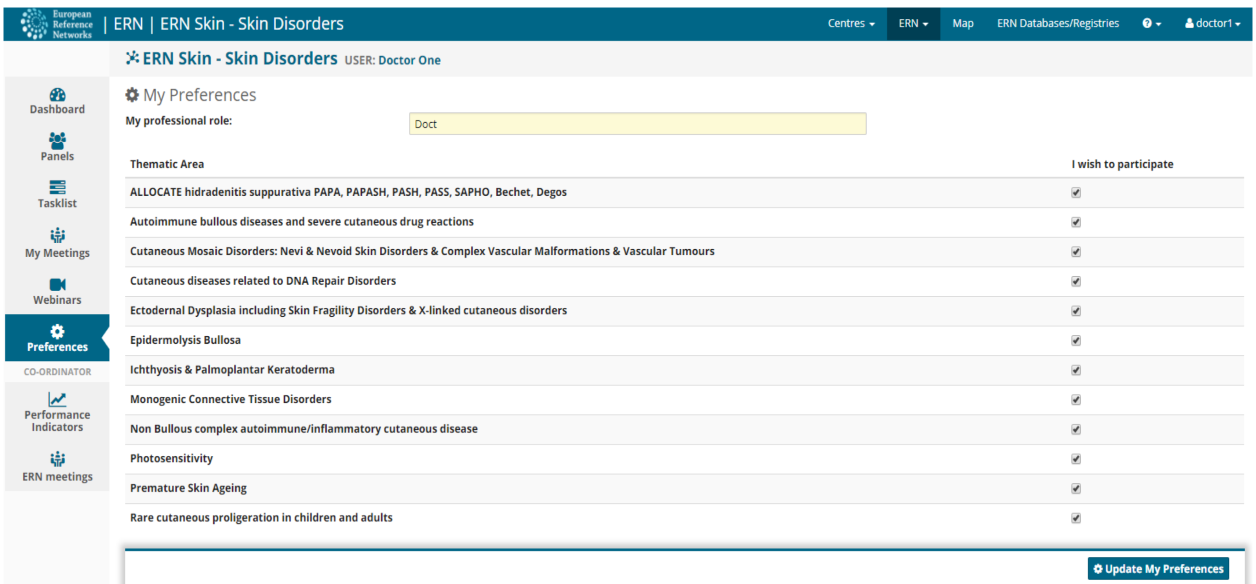


Figure 6: User preferences

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

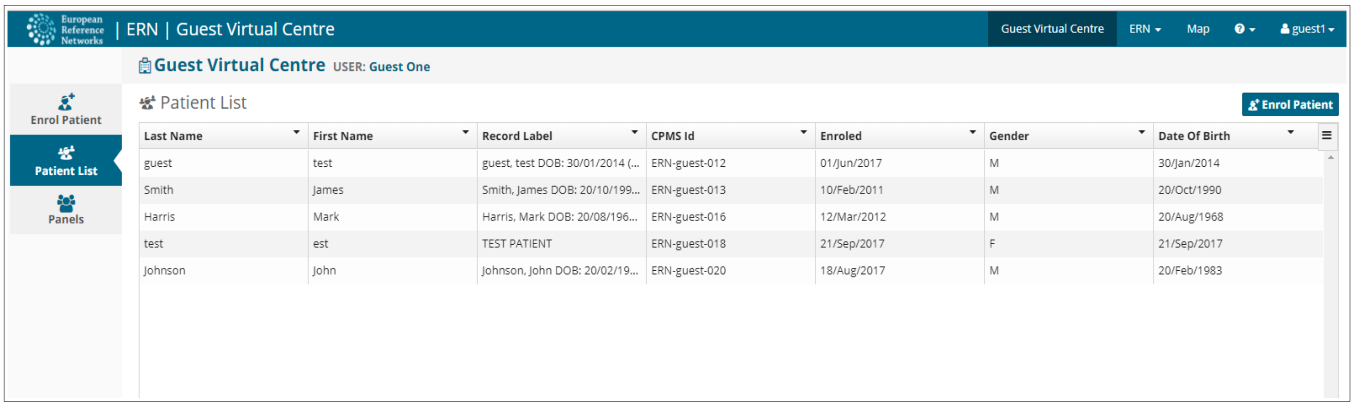
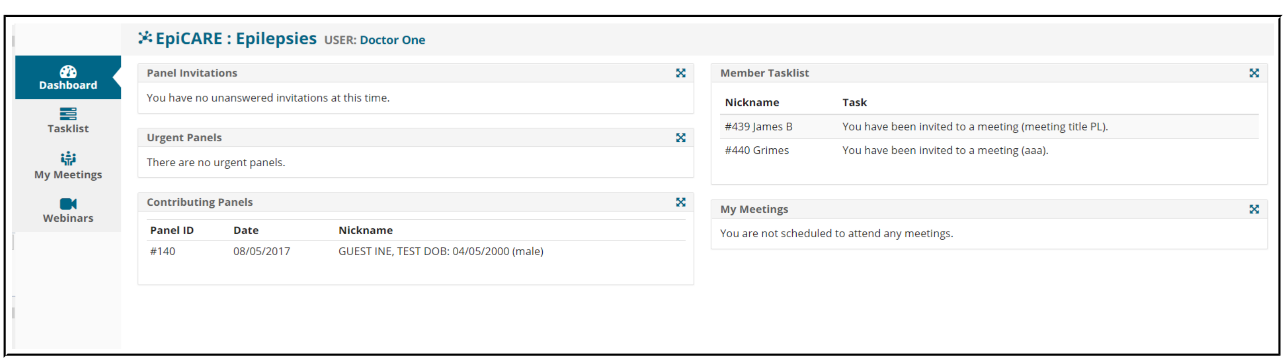


Figure 7: Guest Dashboard

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.

Important: 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

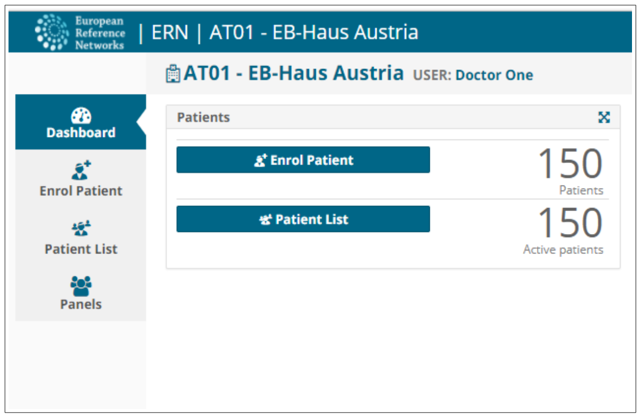
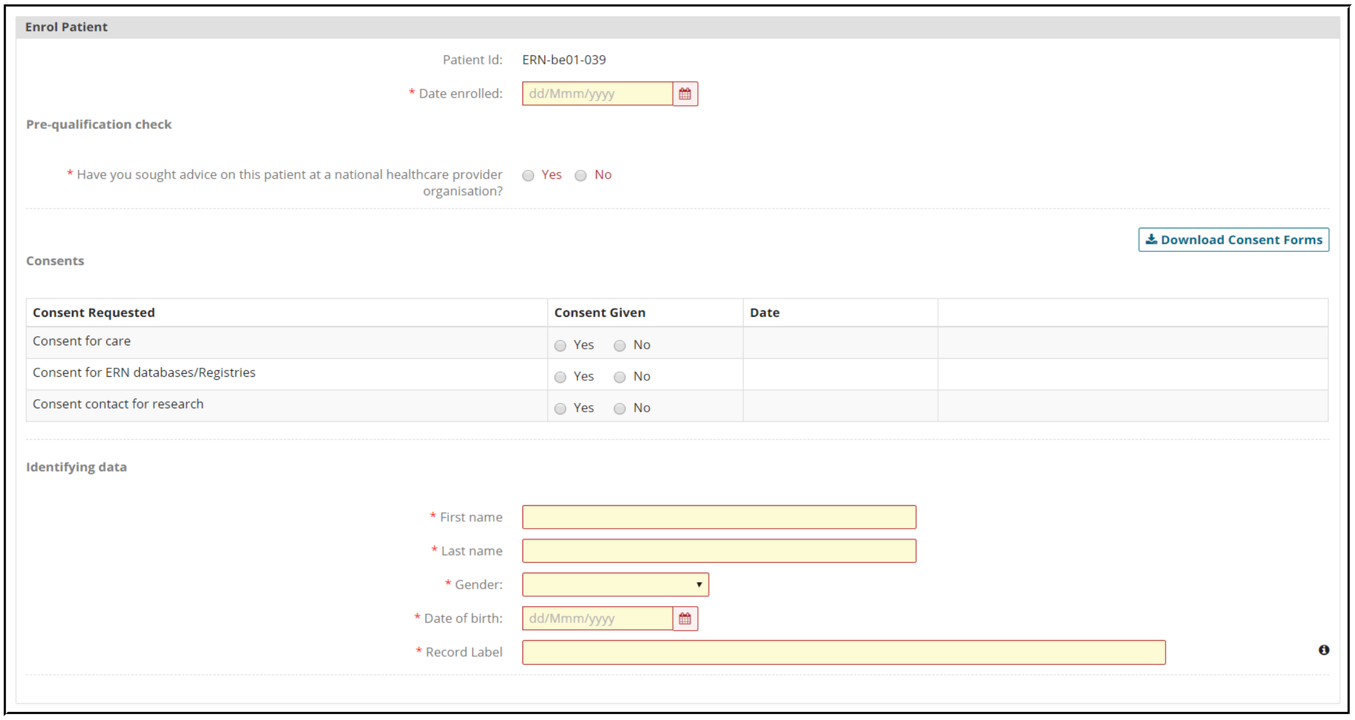


*Figure 8: **Enrol** Patient Buttons*

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: dd/Mmm/yyyy

Pre-qualification check

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

Download Consent Forms

Consents

Consent Requested	Consent Given	Date	
Consent for care	Yes No		
Consent for ERN databases/Registries	Yes No		
Consent contact for research	Yes No		

Identifying data

* First name

* Last name

* Gender:

* Date of birth: dd/Mmm/yyyy

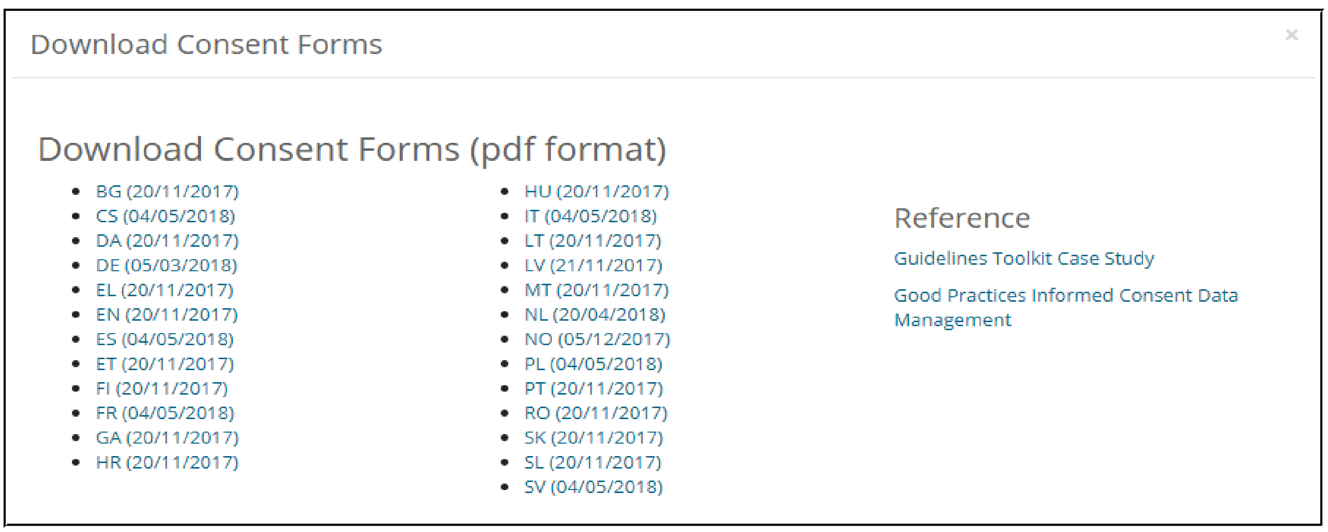
* Record Label

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.



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:

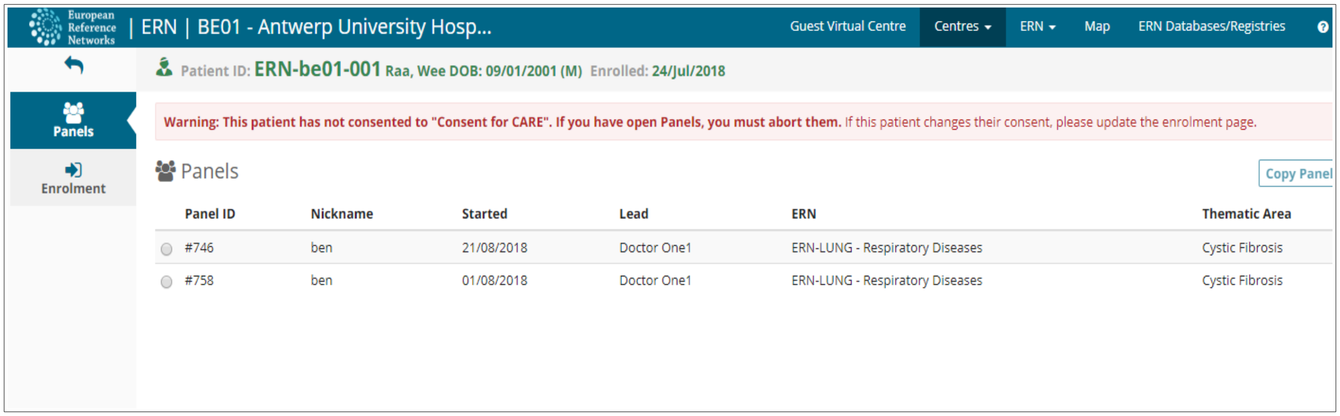
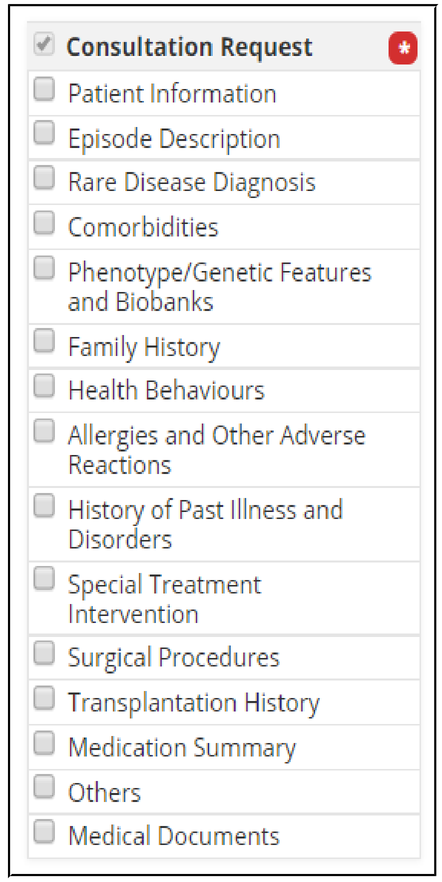


Figure 10: Error Message to remind the user to cancel any open panels for a patient who has revoked consent for care.

6. 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.

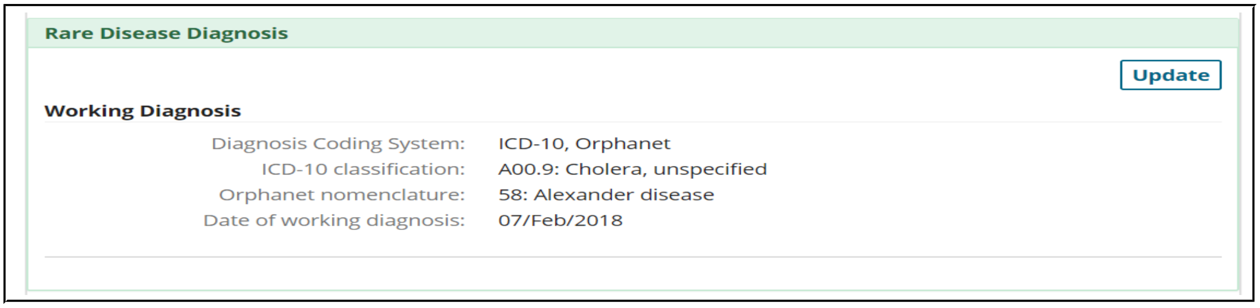
The form can be only edited in the "Edit view" to allow doctors to record patient data into the form at two stages in the workflow namely: "Open" and "Data Completion". Whilst, during the assessment process and the later stages of the workflow, the form will be displayed in view mode only beside to the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

All ERNs will be using one generic data set known at 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.

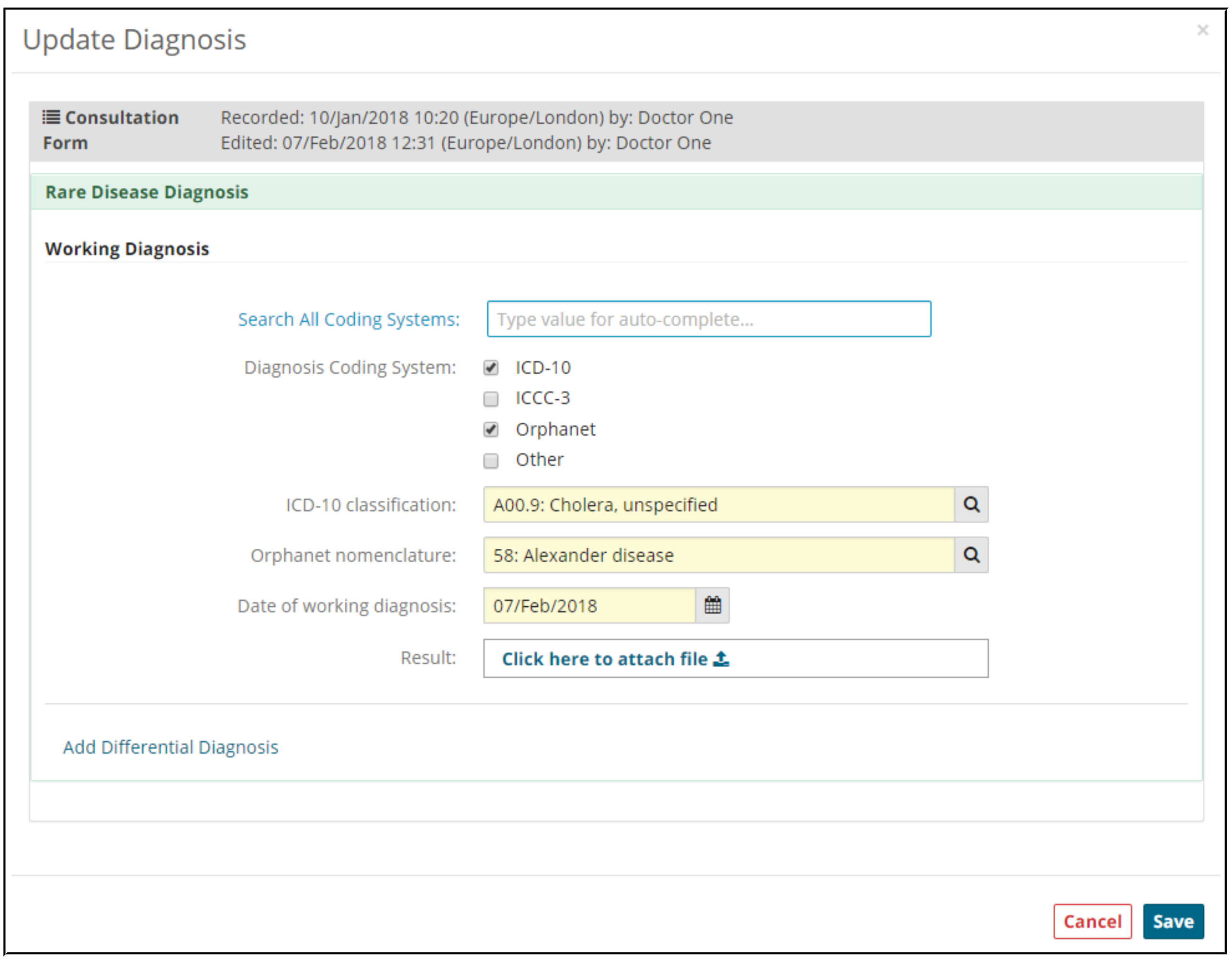
The following coding and terminology systems have been used to build the Basic Data-Set in the consultation form:

- 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.

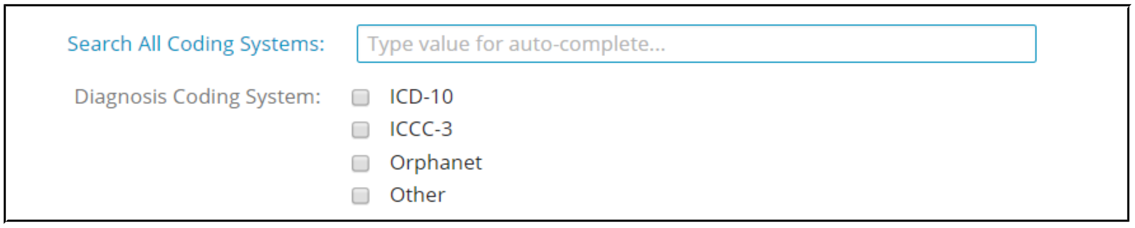


When clicking on “Update” button, a pop up will be displayed on the screen to enable users to edit this section.



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

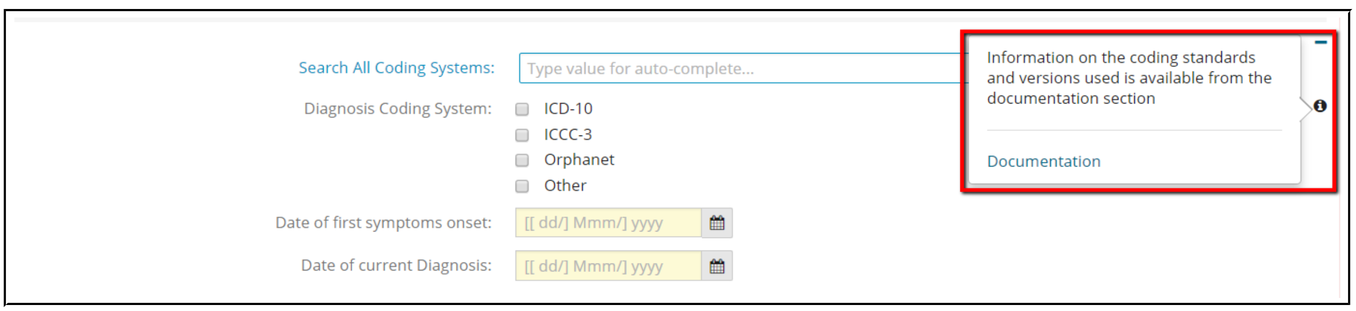
Search widget: Please note that a search widget is provided in some sections of the consultation form to help Health Professionals select a medical condition without prior knowledge to the coding systems such as ICD-10, Orphanet and ICCC-3 in the diagnosis section.



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 ICCC-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.



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)

6.1. File Upload

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

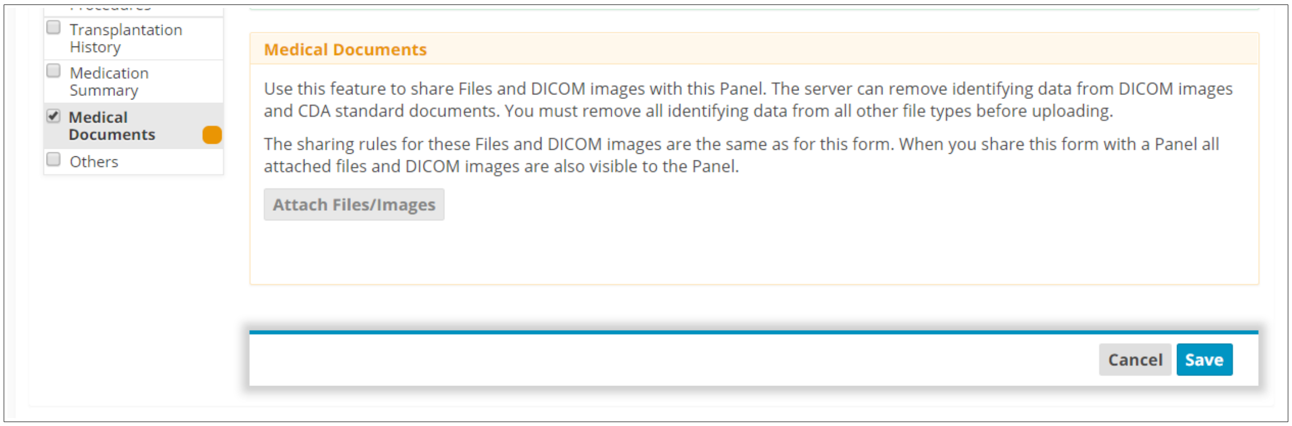


Figure 11: Attaching Files in the Consultation Form

After clicking on 'Attach Files/Images', the user will be prompted to acknowledge that there is "no identifiable personal data in the uploaded file(s)". This checkbox must be ticked if the user wants to proceed. The user will then have the opportunity to upload files under the 'Add Files' tab as shown below:

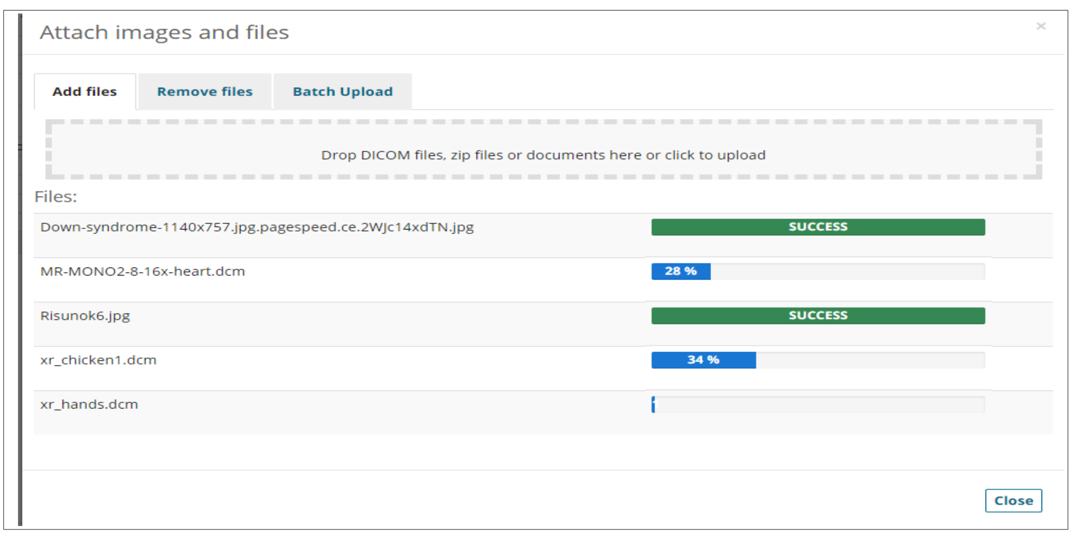


Figure 12: Drag or Browse Files to Upload

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

PDF	pdf					
Excel	xml	csv	xls	xlsx	xlsm	
PowerPoint	ppt		pptx		pptm	
Word	doc		docx		docm	
Open Doc	odt	ods	odp	odc	odi	
Image	dcm	jpg	jpeg	bmp	tiff	png
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!*

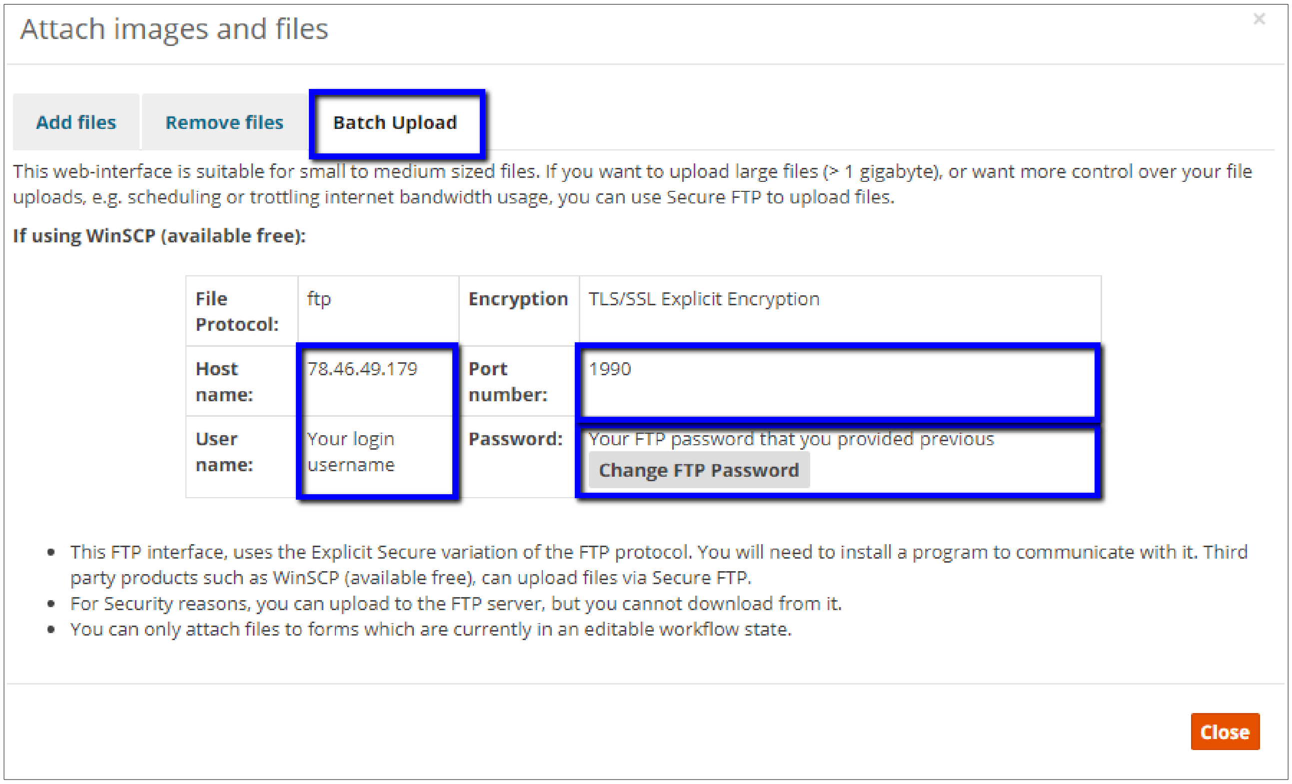
Batch Upload

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.

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

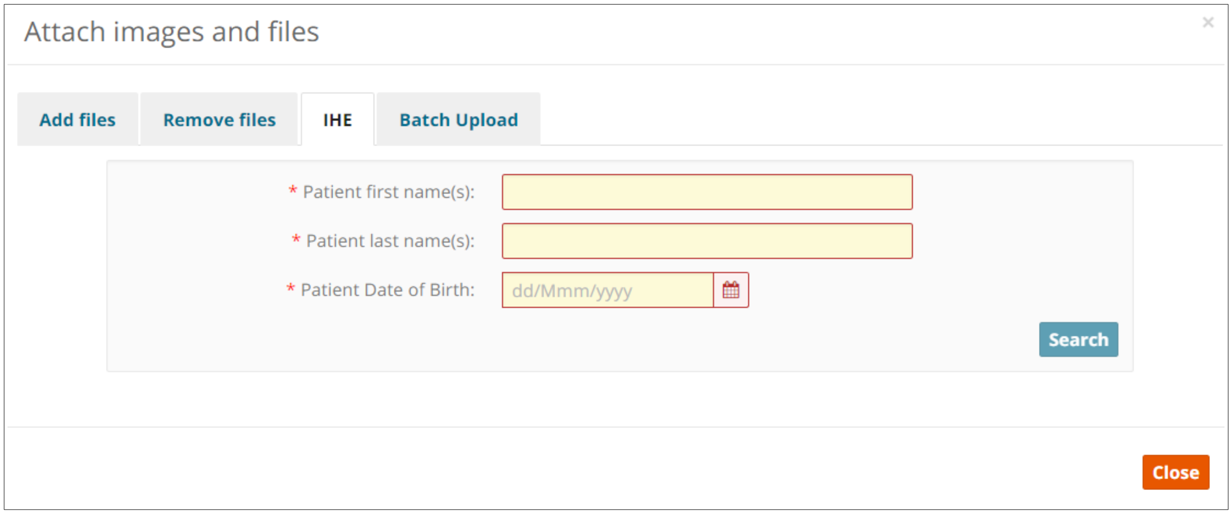


IHE

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 ‘Batch Upload’ in the Medical Documents section.



6.2. 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. The user can cycle through the images in the series manually or automatically, at a frame rate of their choosing.

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.
4. Allows the user to download the series.

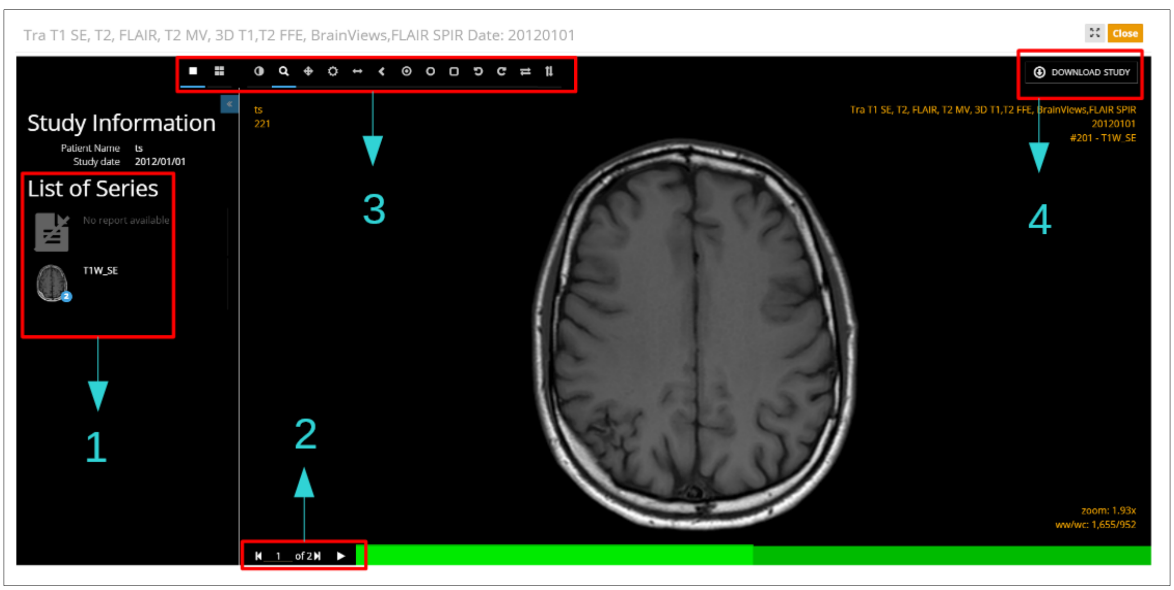


Figure 13: DICOM Viewer

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

Study types supported

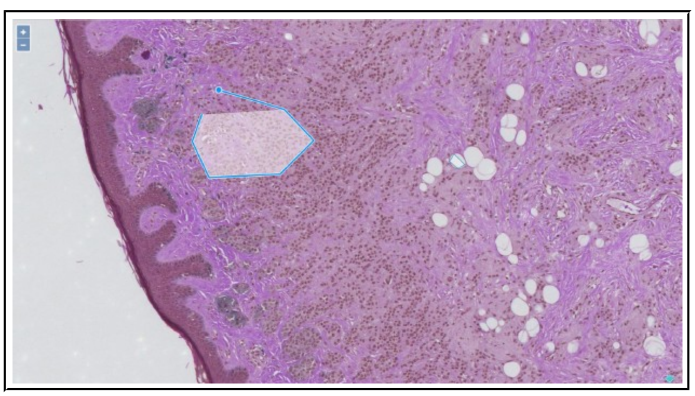
The following types of exams are supported by the viewer:

- 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.



6.3. 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. They

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.

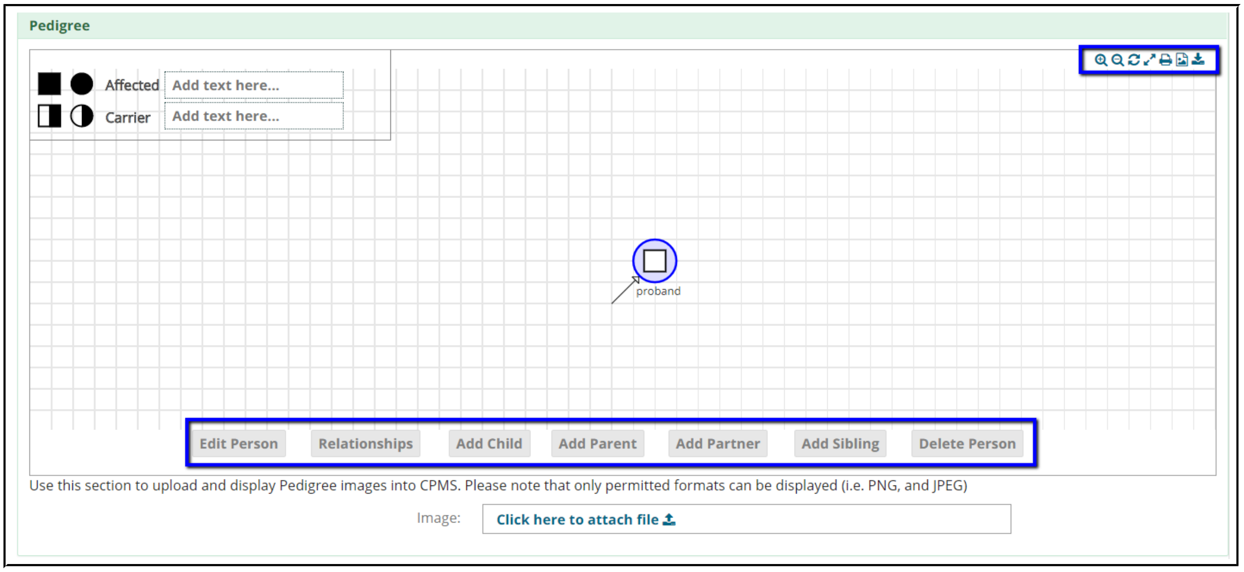


Figure 15: Pedigree Chart

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:

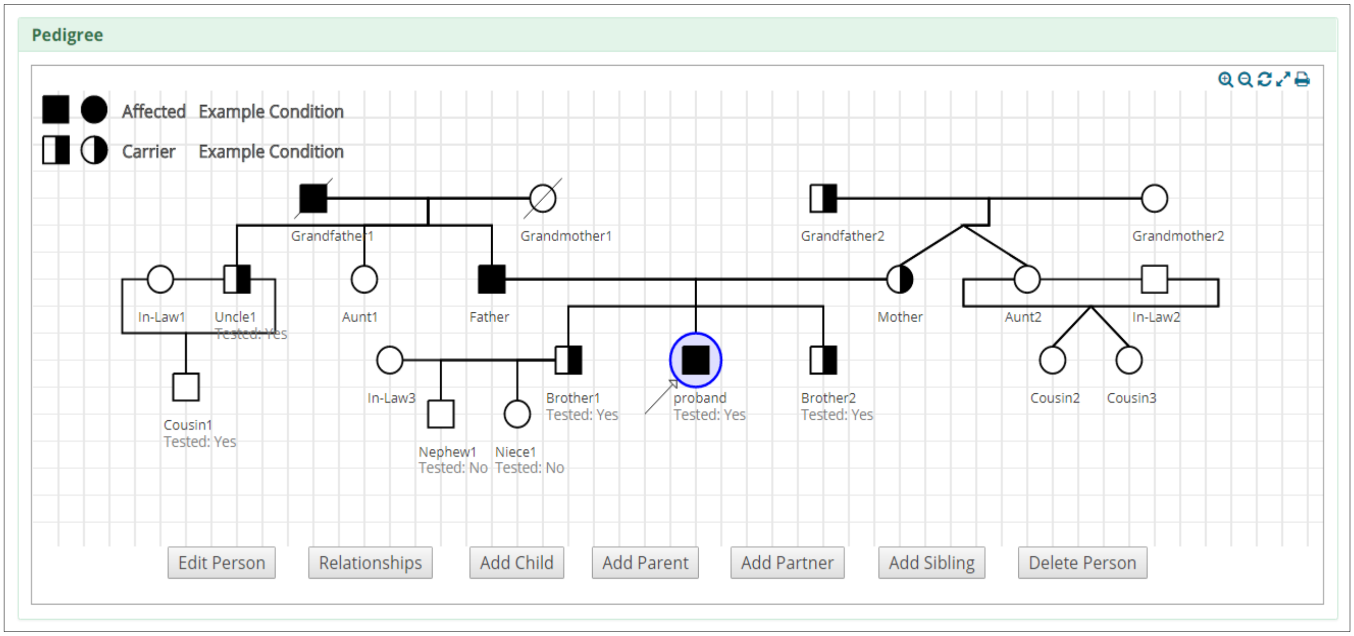


Figure 16: Example of a Pedigree Chart

7. 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.

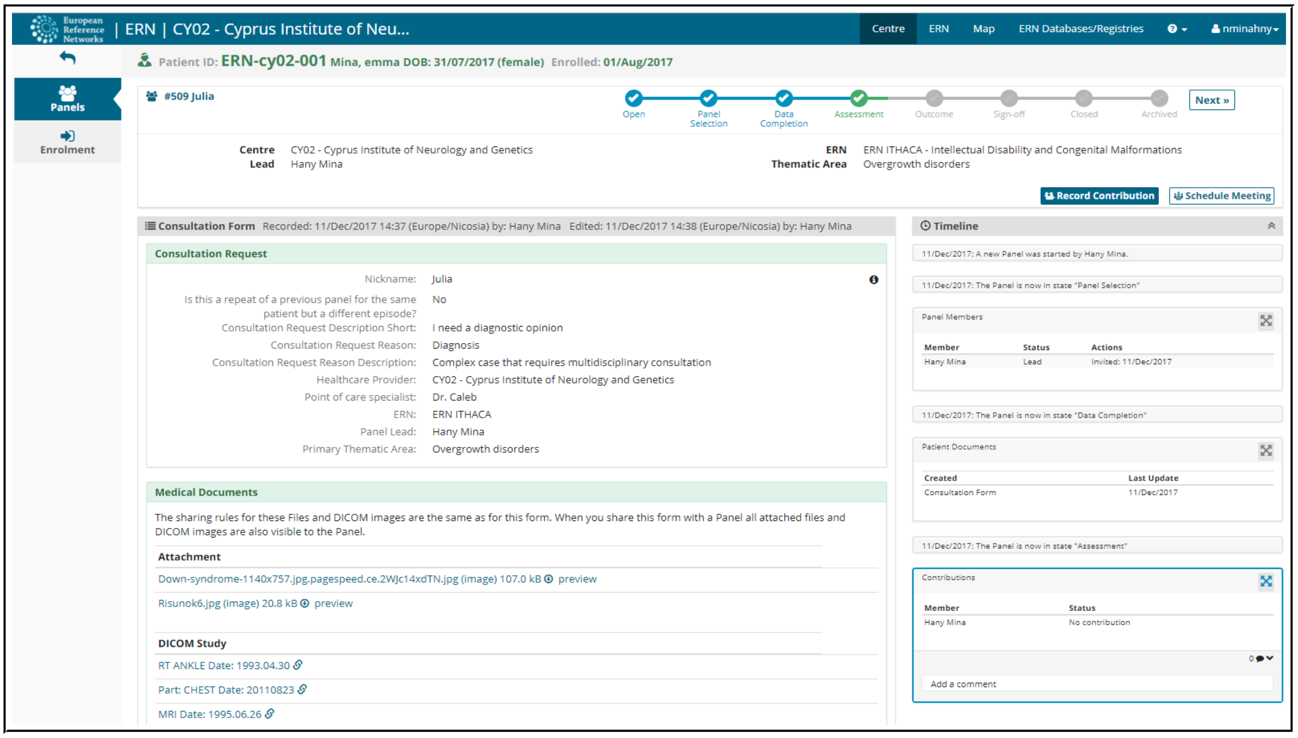


Figure 17: Panel Home Page

7.1. 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.

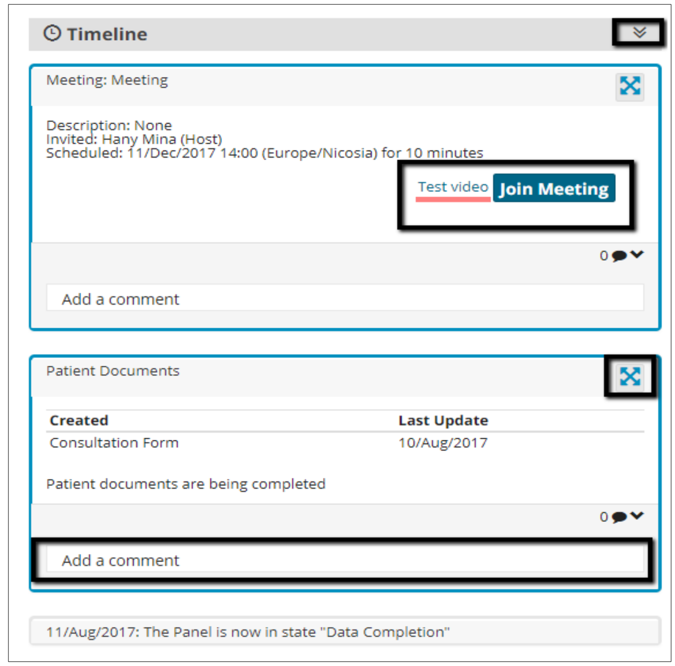


Figure 18: Timeline of Panel

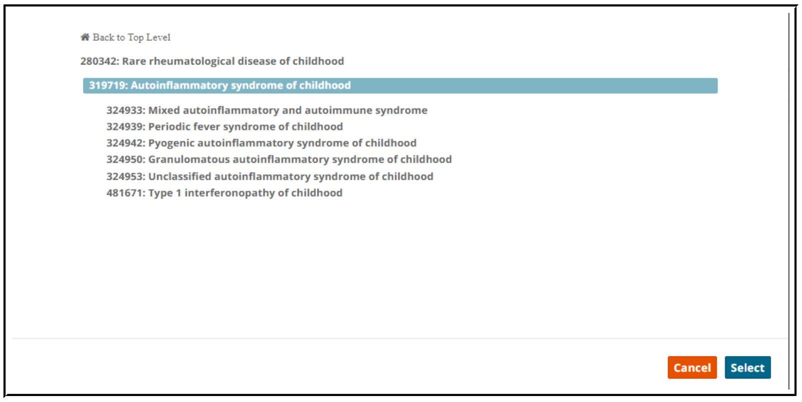
The Timeline is not only a chatting mechanism over the panel but rather a secure approach for exchanging messages in several modal types. It allows panel members to make comments on images, contributions and outcome documents.

*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.

7.2. 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.



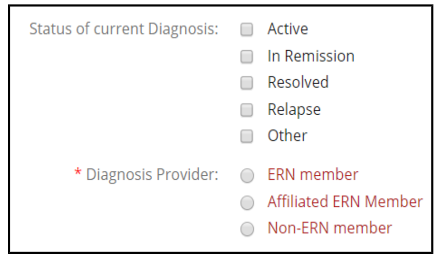


Figure 19: Data Picker

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.

8. Panel Workflow – Virtual Consult Process

8.1. 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.

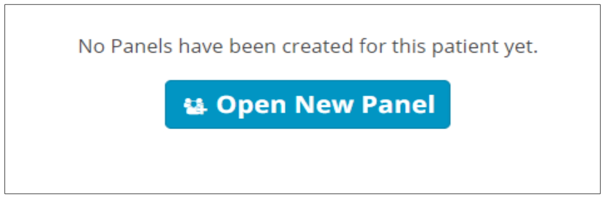


Figure 20: New Panel – New Patient

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.

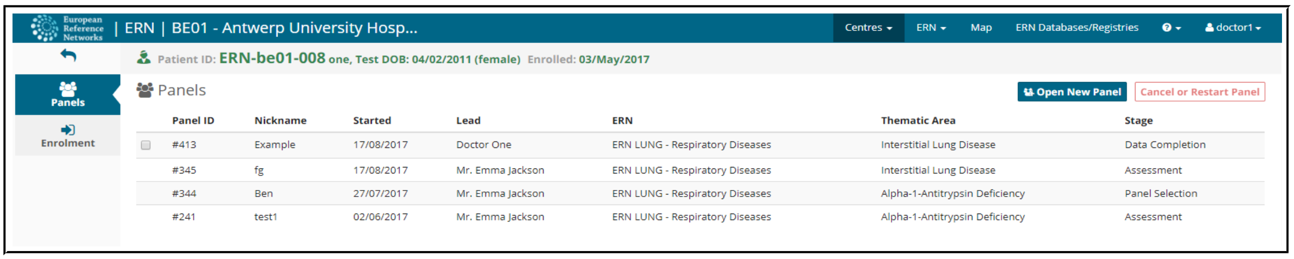
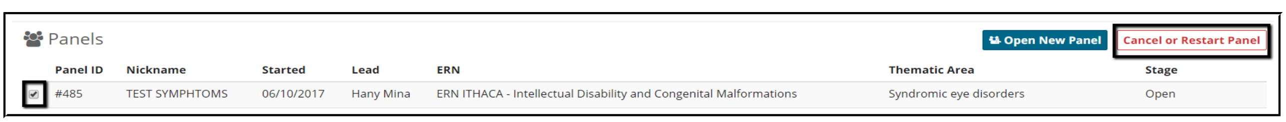


Figure 21: New Panel - Existing Patient

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**.



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.

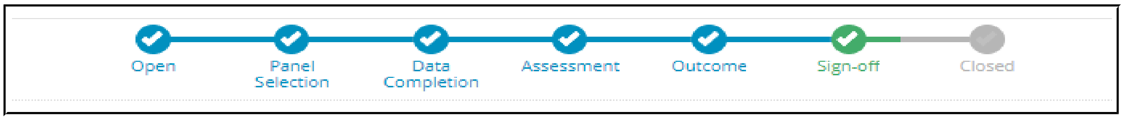
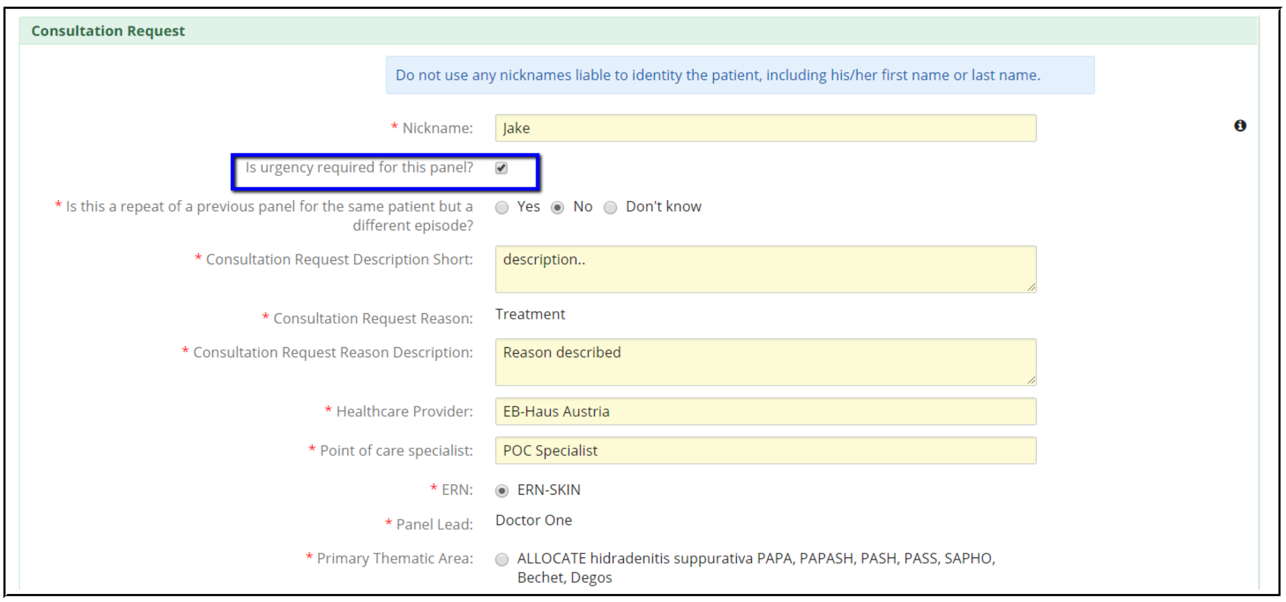
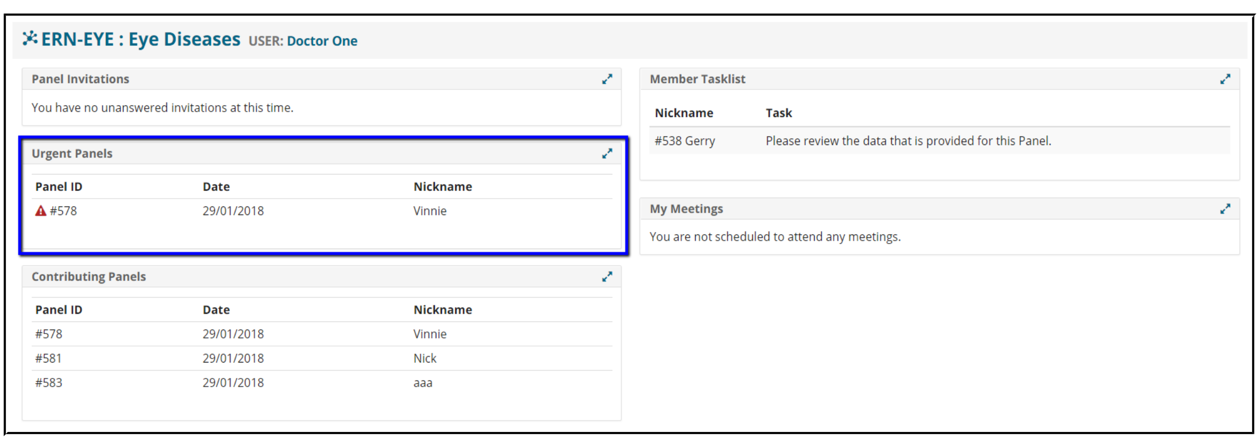


Figure 22: Stages of the consult process

8.2. 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.





8.3. Panel Selection

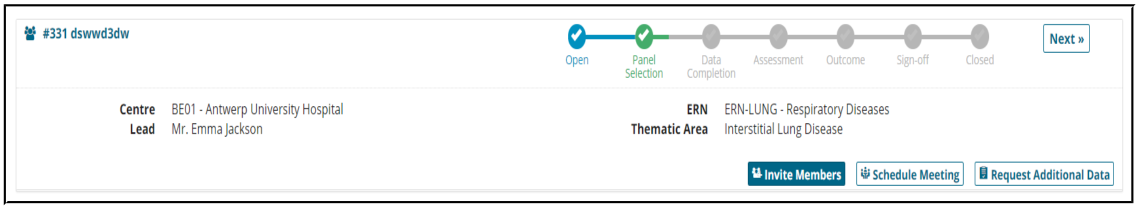


Figure 23: Invite Members and Schedule Meeting

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.

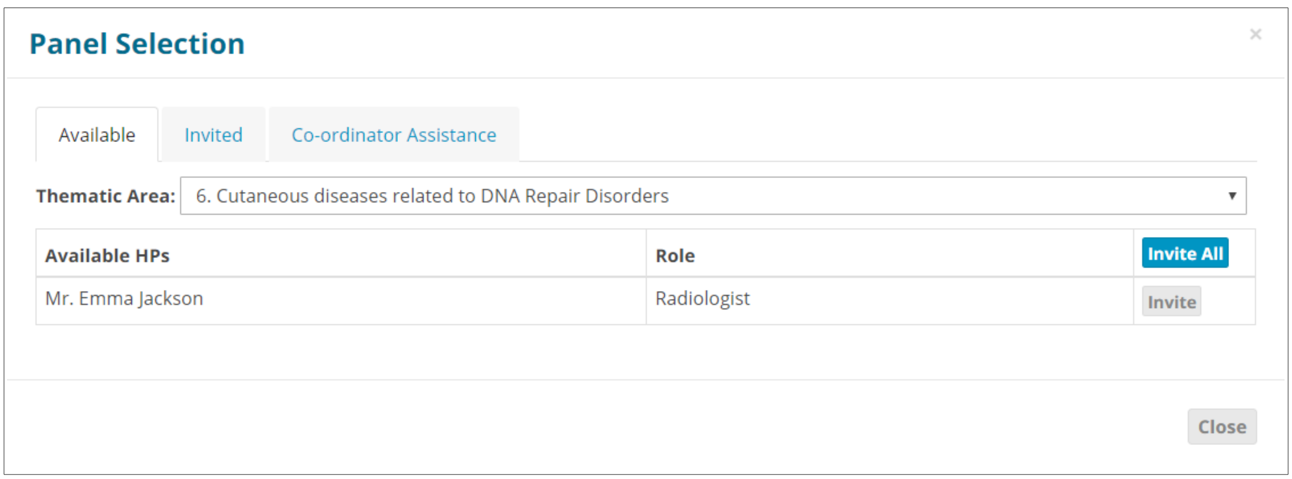


Figure 24: Panel Selection

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.

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

8.4. 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.

8.5. 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.

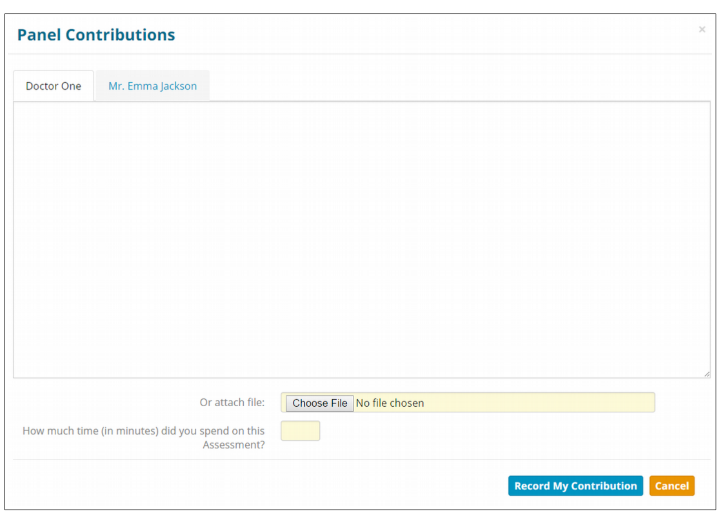
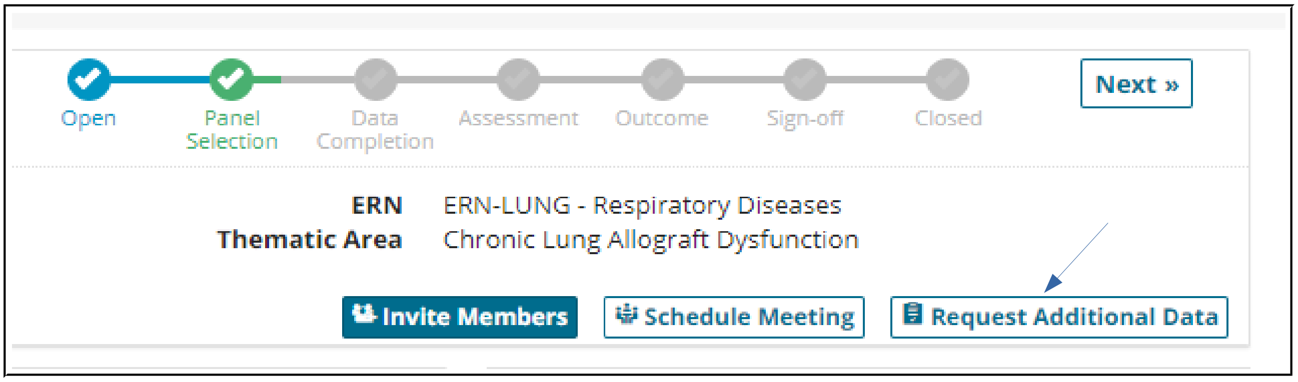
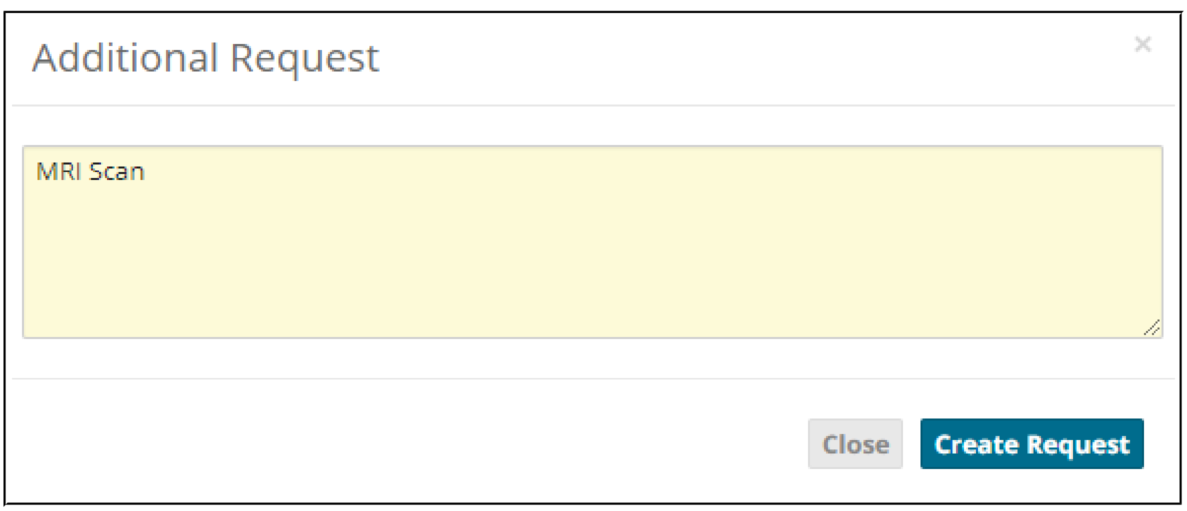


Figure 25: Panel Contributions

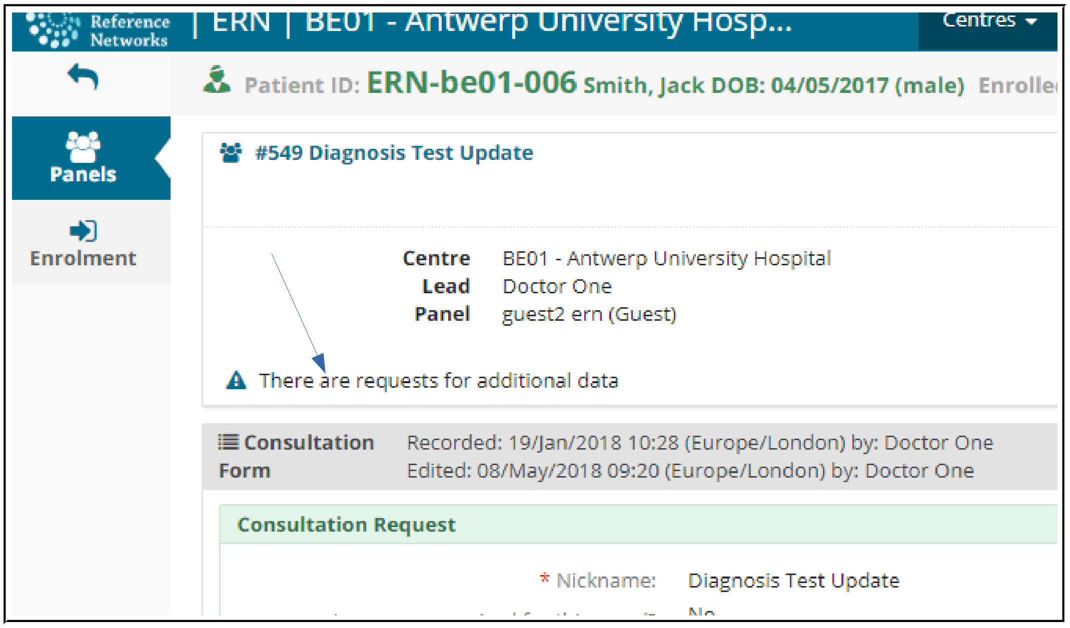
From the panel selection stage up to the outcome stage, panel members will be able to submit a request for additional test results, data or information. See figure below:



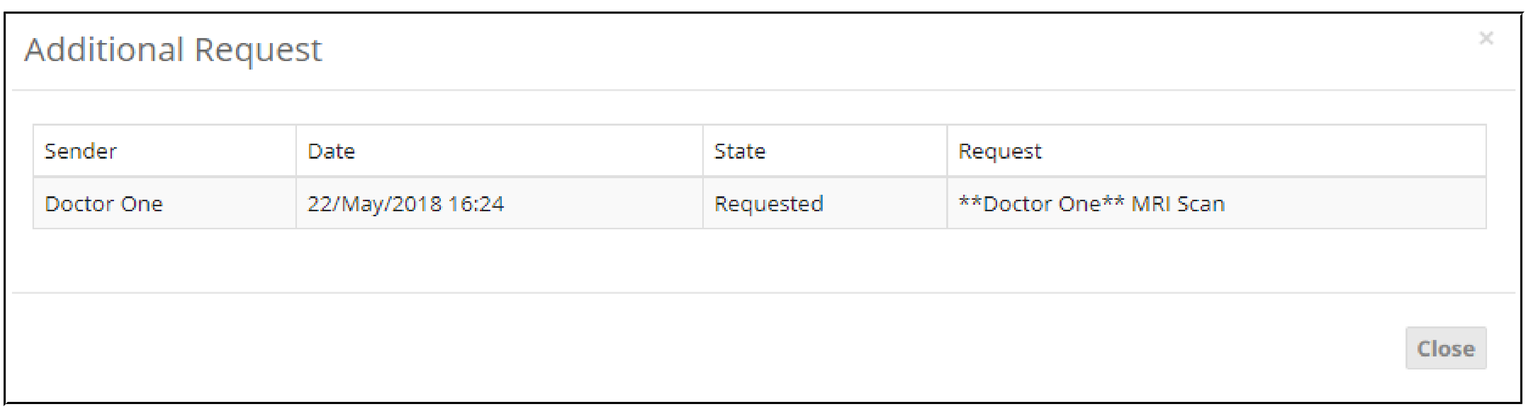
Once the request additional data button has been selected, the data that you want to request must be input into the text box. See example below:



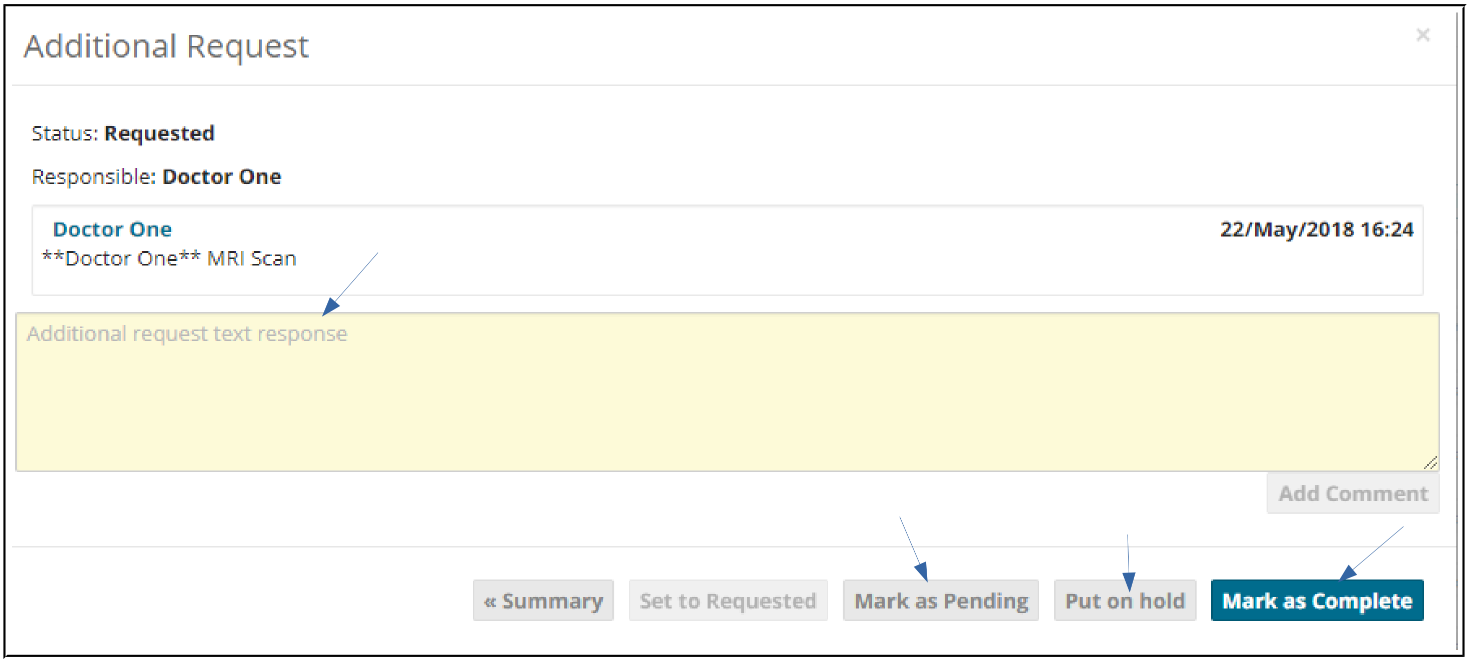
Once the request has been created, it will then show up above the consultation form and also in the timeline. See example below:



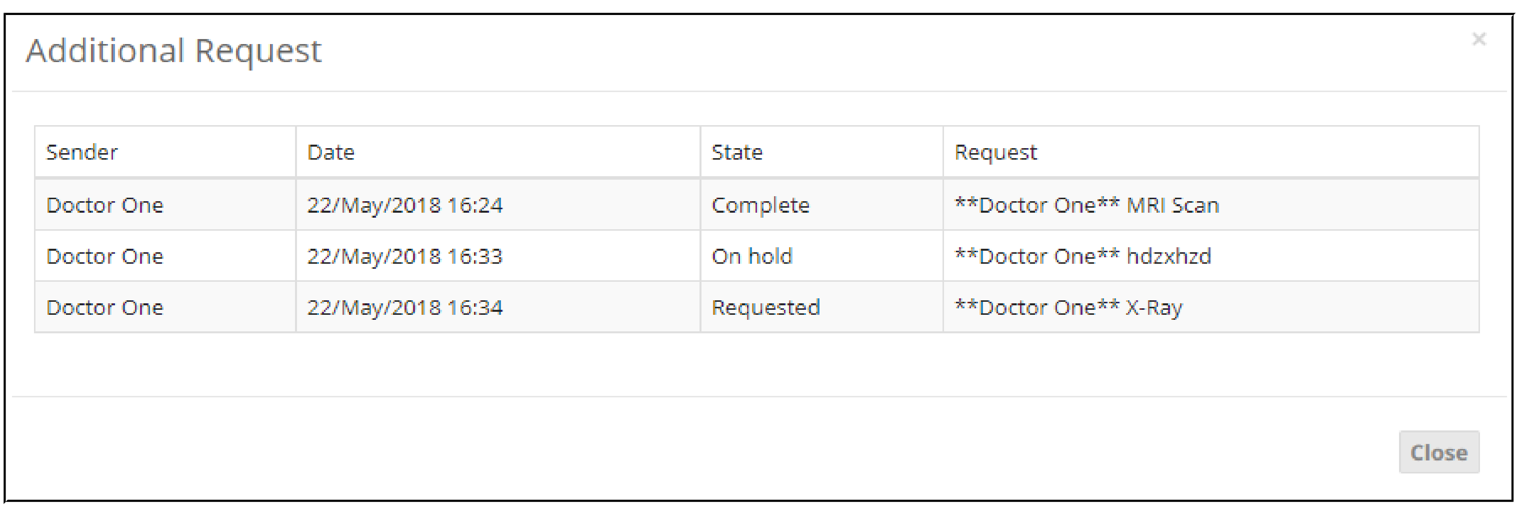
The information and the status of the request will show up once you click on it. See example below:



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** hdzxhzd
Doctor One	22/May/2018 16:34	Requested	**Doctor One** X-Ray

Close

8.6. 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

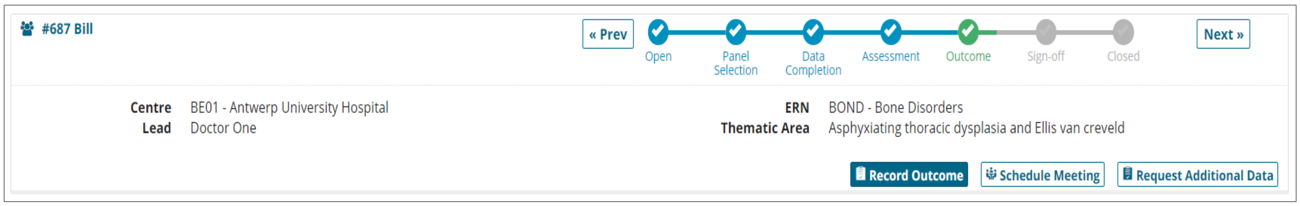


Figure 26: Outcome

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.

8.7. 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.

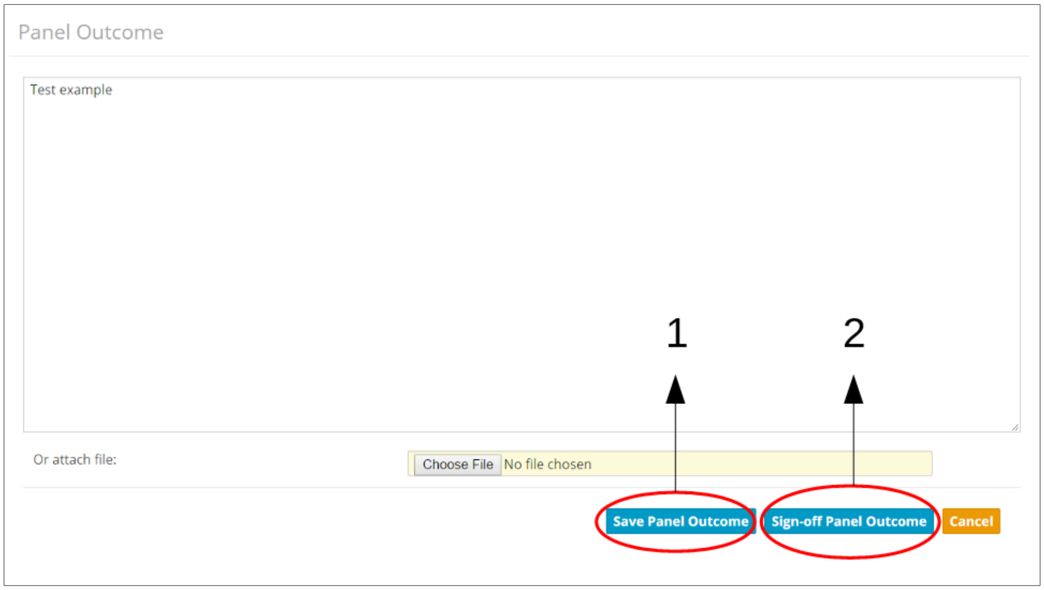


Figure 27: Panel Sign-Off

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.

8.8. 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:

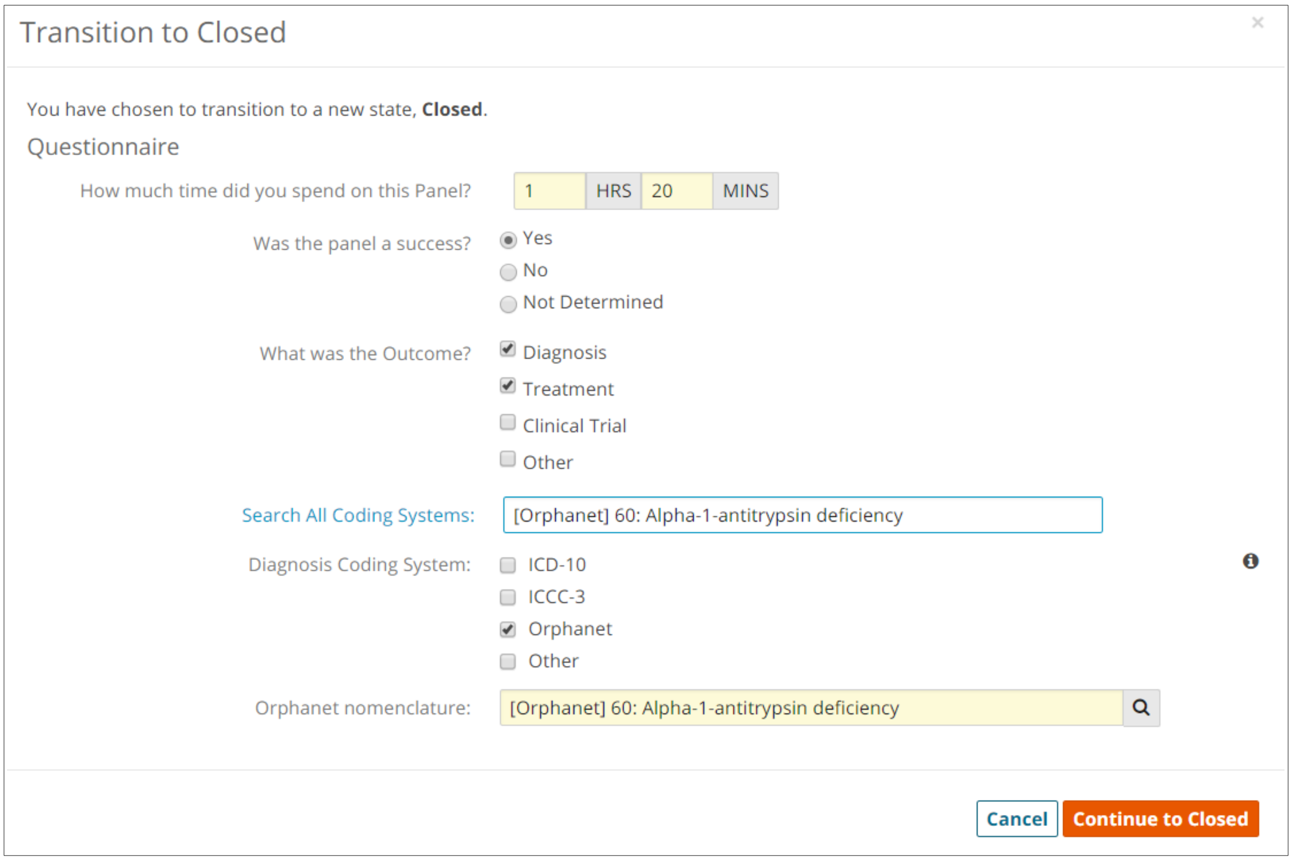


Figure 28: 'Transition to Closed' Questionnaire

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.

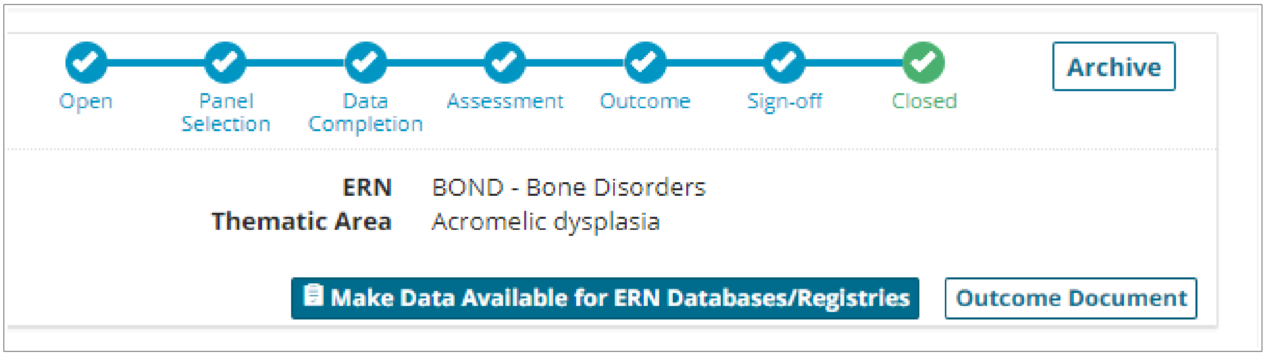


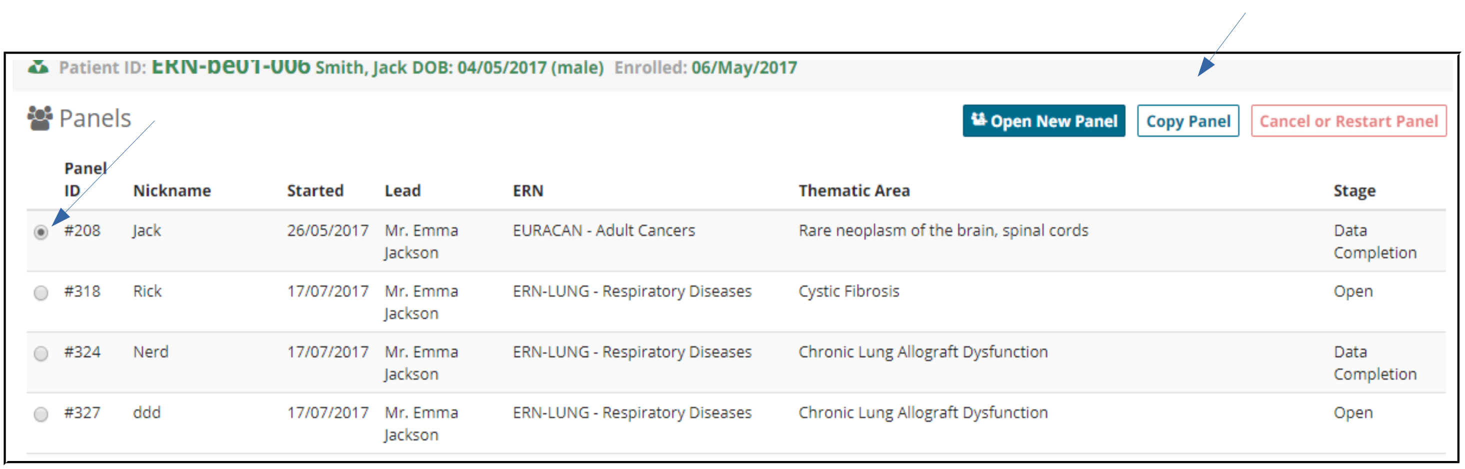
Figure 29: A Closed Panel

8.9. 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.

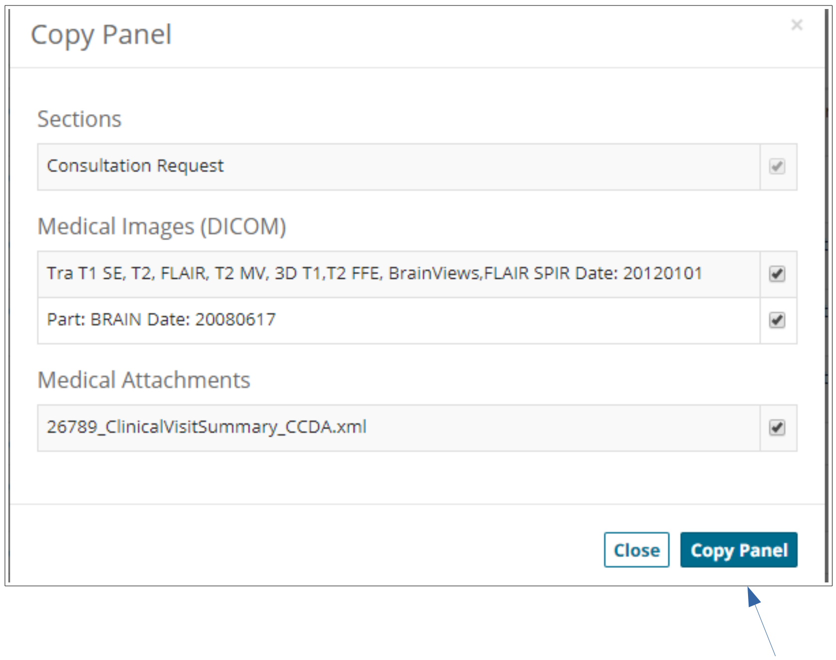
8.10. Copying Panels

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 then choose a patient. See example below:



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. See example below:



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.

9. Meetings

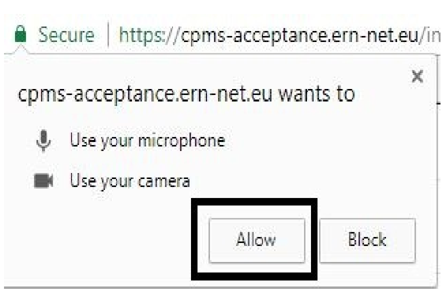
9.1. Video conferencing requirements

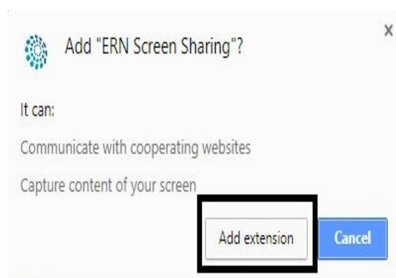
The minimum required hardware is to have a device with camera and microphone to enable you participate actively in video meetings on CPMS. Below are other requirements that potentially can affect the uptake of CPMS to run smoothly within your organization.

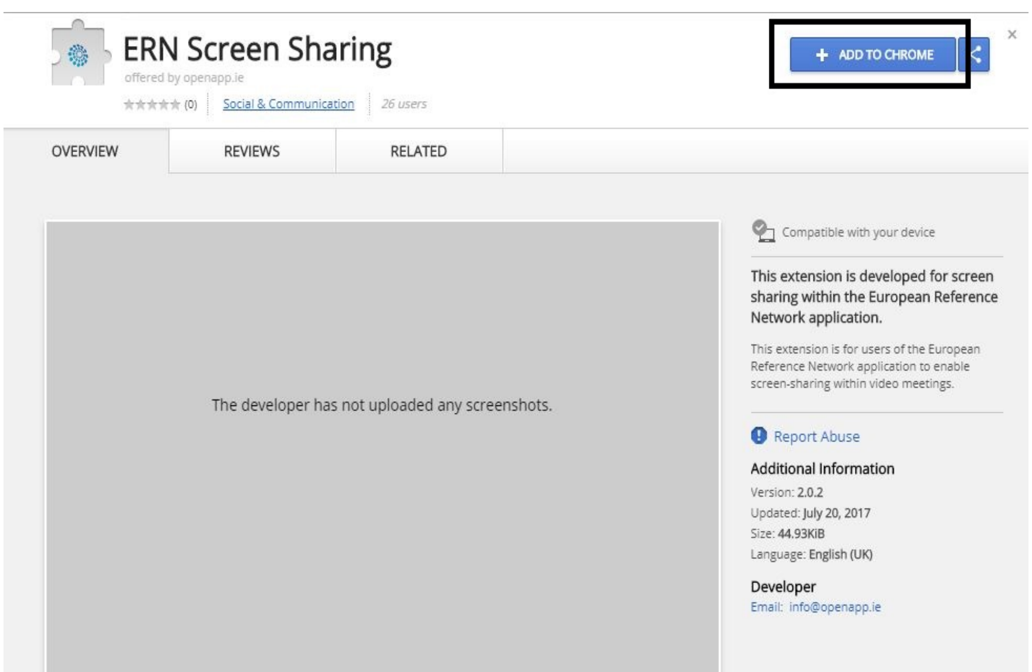
WebRTC video technology incorporated into the CPMS can be tested on your machine via this link: https://cpms-training.ern-net.eu/video-testing

Please note the following when using video meetings:

- When using Internet Explorer, you will be requested to automatically download a Plug-in on your browser.
- For sharing your screen on Google Chrome and Mozilla Firefox, users will need to enable an extension to run on the browser.







9.2. 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.

9.3. 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

For the given qualities and resolutions, all the following conditions must met:

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%

9.4. 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 in Figure 30 below:

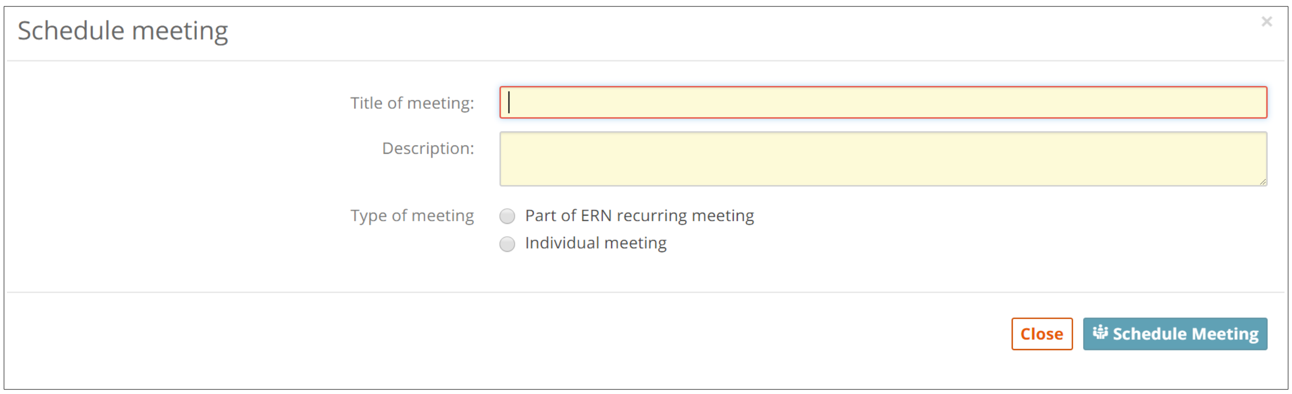


Figure 30: Schedule Meeting

If the meeting is an 'Individual Meeting', the user simply picks a date, time and duration for the meeting. If, however, the meeting is part of a 'meeting group', the Host must select an available time slot as shown in Figure 31 below:

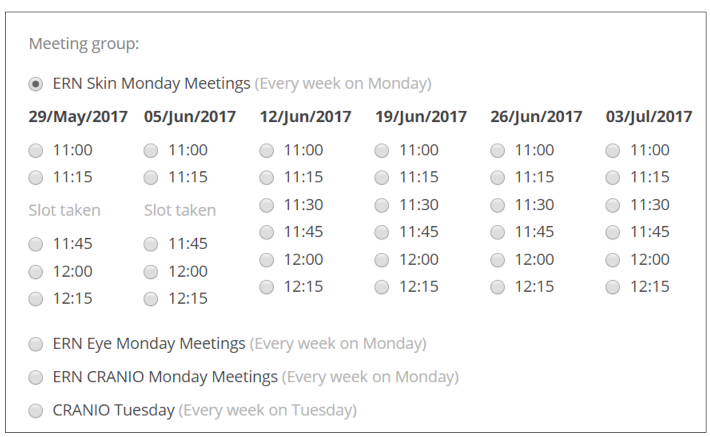


Figure 31: Time slots for group meeting

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.

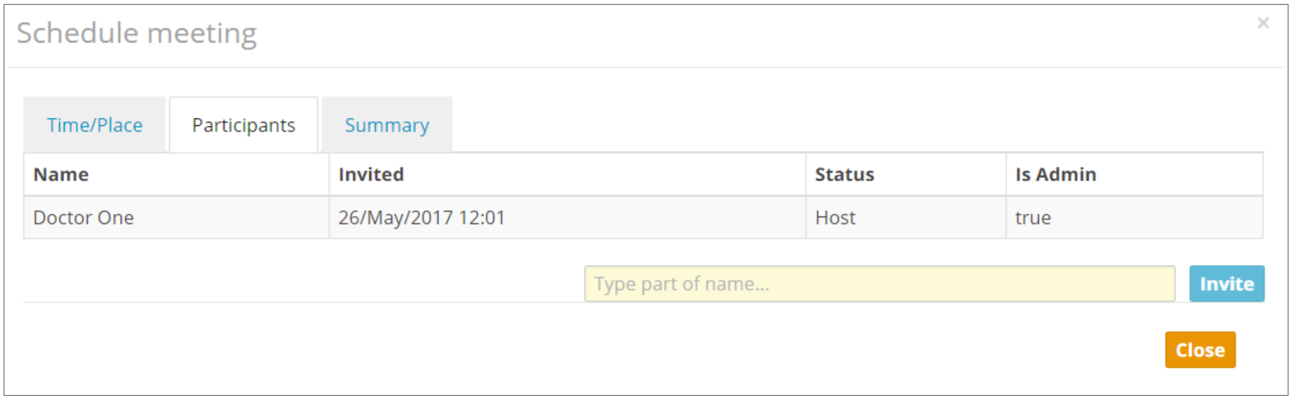


Figure 32: Invite Participants

9.5. 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.

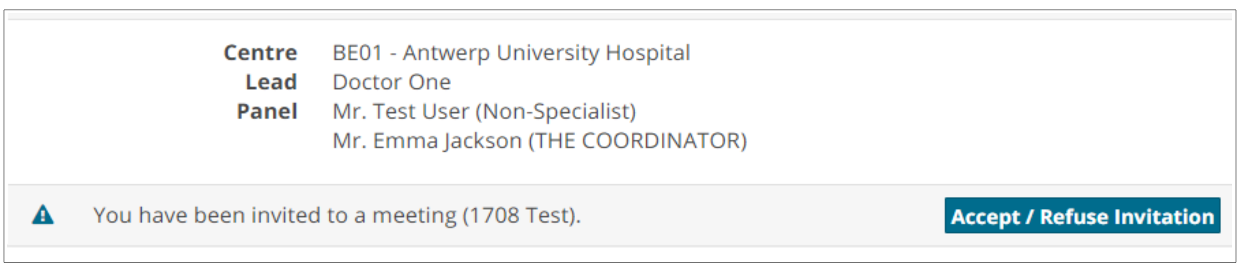
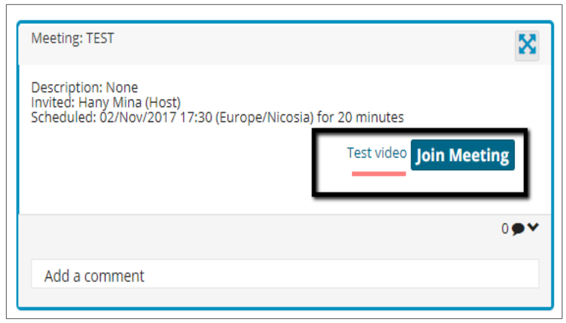


Figure 33: Meeting Notification on the main page of the Panel

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)

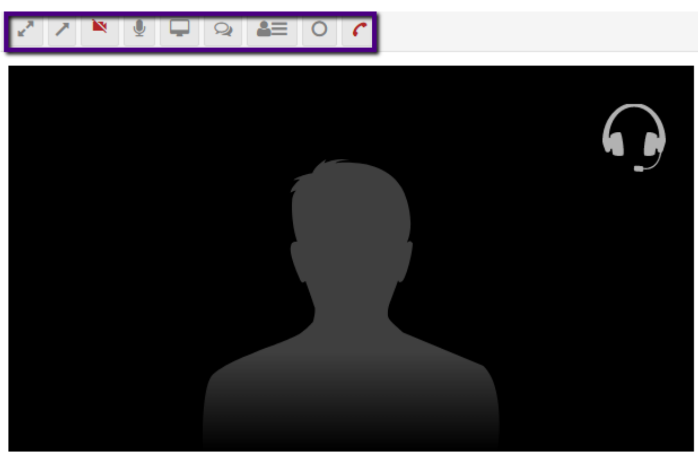


Figure 34: Meeting Interface

9.6. 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:

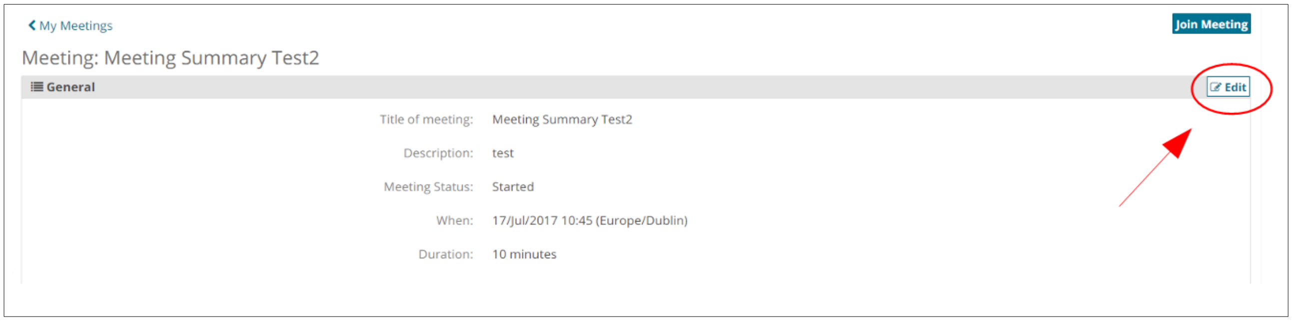


Figure 35: Update the Meeting Status by Clicking on 'Edit'

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.

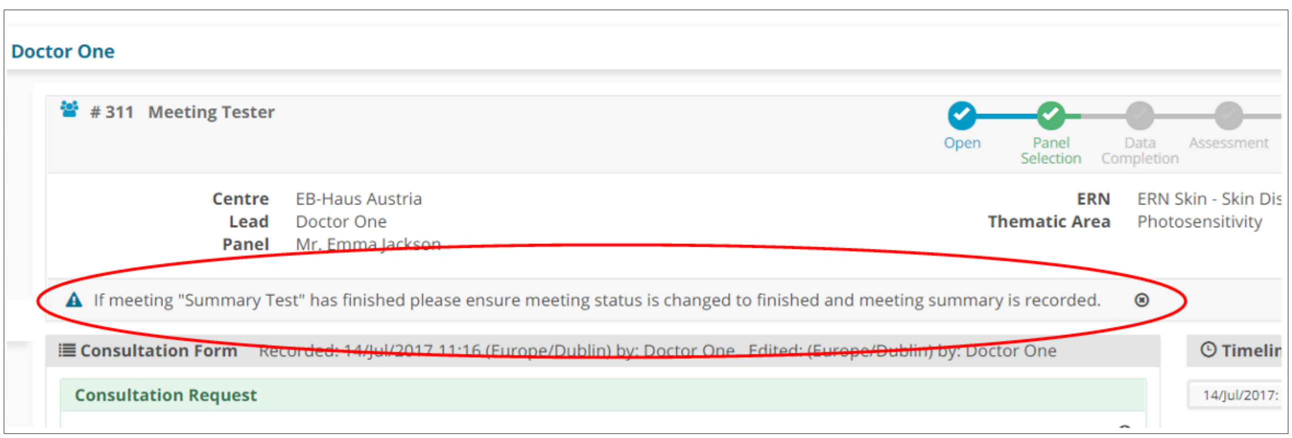
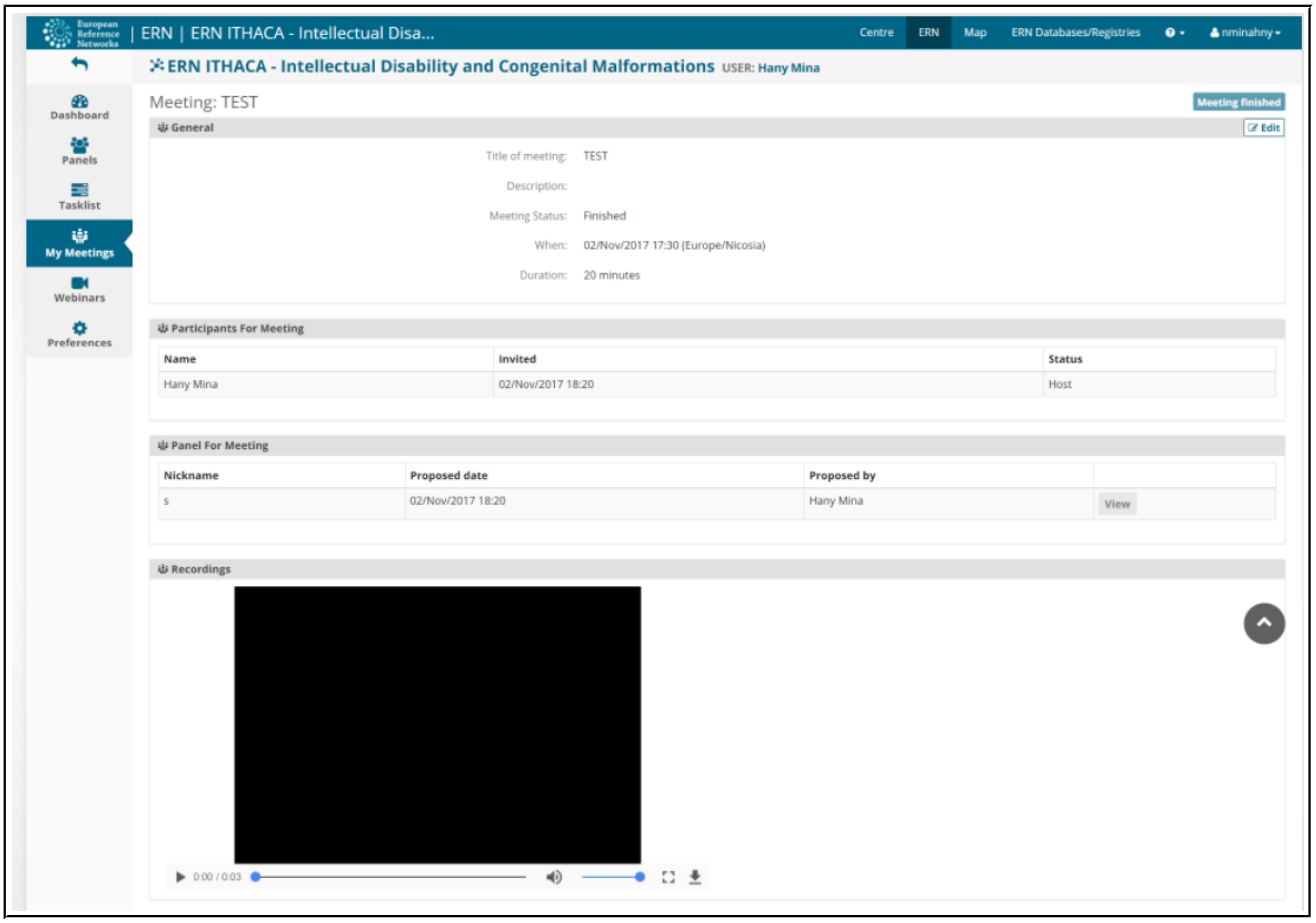
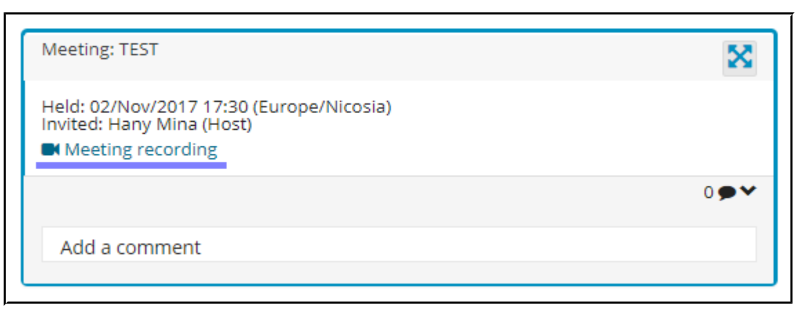


Figure 36: Meeting Summary Reminder

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.



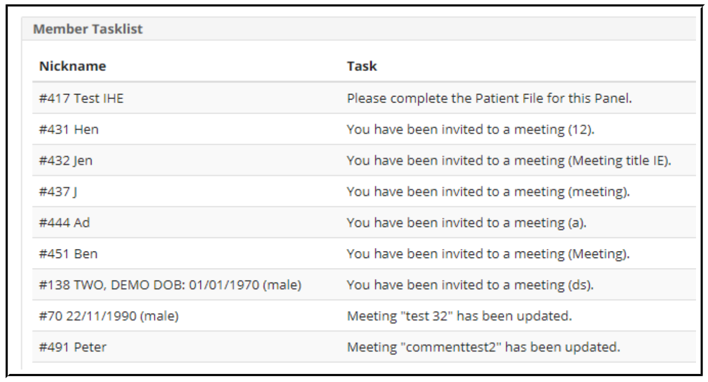


10. CPMS Task-List

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

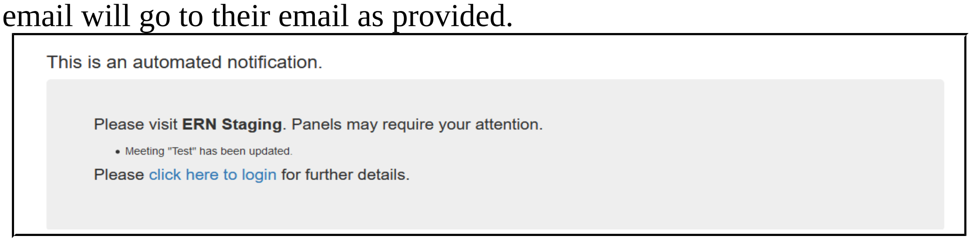

Member Tasklist

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.
#491 Peter	Meeting "commenttest2" has been updated.

11. Email Notifications

CPMS works in synchronization with users' emails when provided. CPMS users receive a notification email with a link to login when they have tasks to do in their Task-list such as accept/refuse participating in a Panel, record a contribution, invitation to a meeting or review an outcome. This digest email will be sent out at 8:00 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.

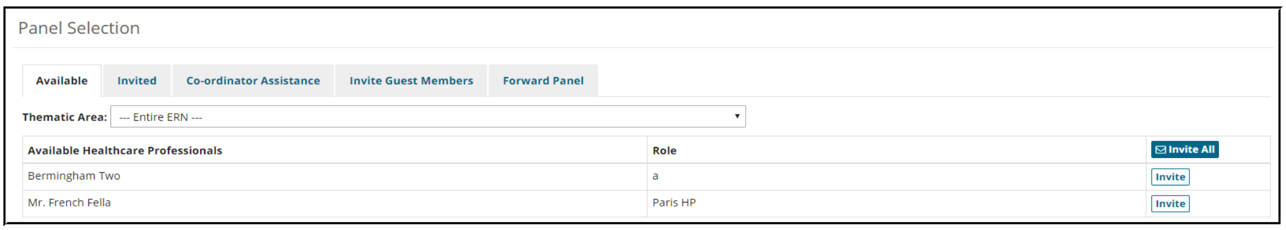


12. Roles & Rights

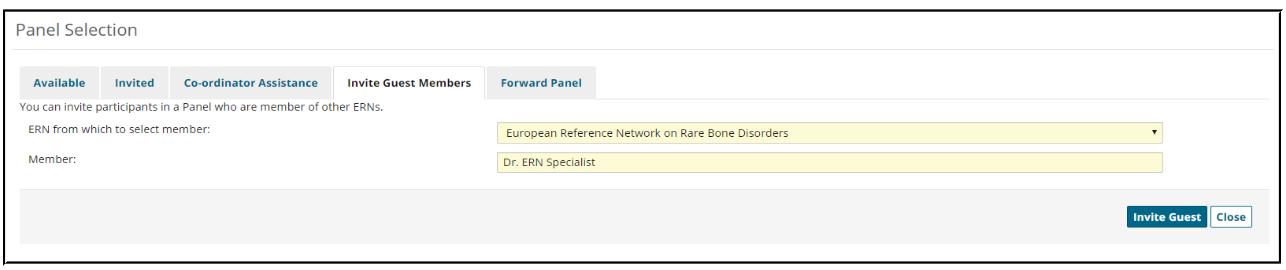
12.1. ERN Coordinator

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.

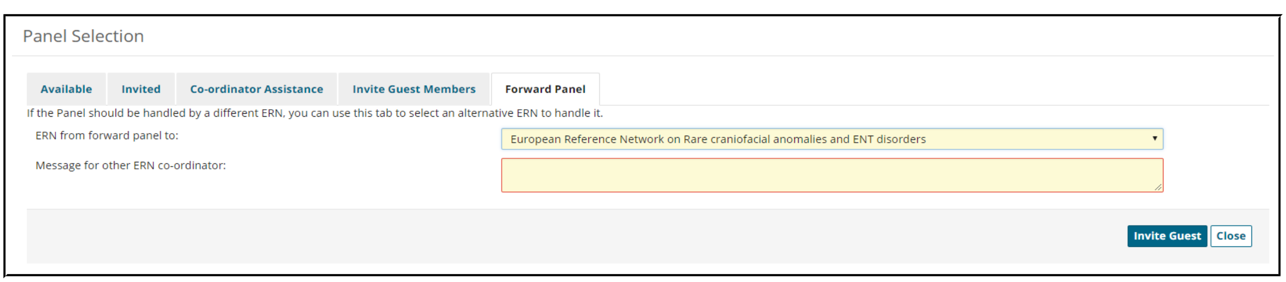


Inviting members from another ERN is an exclusive action to be done though the ERN Coordinator's assistance.



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.



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 if 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.

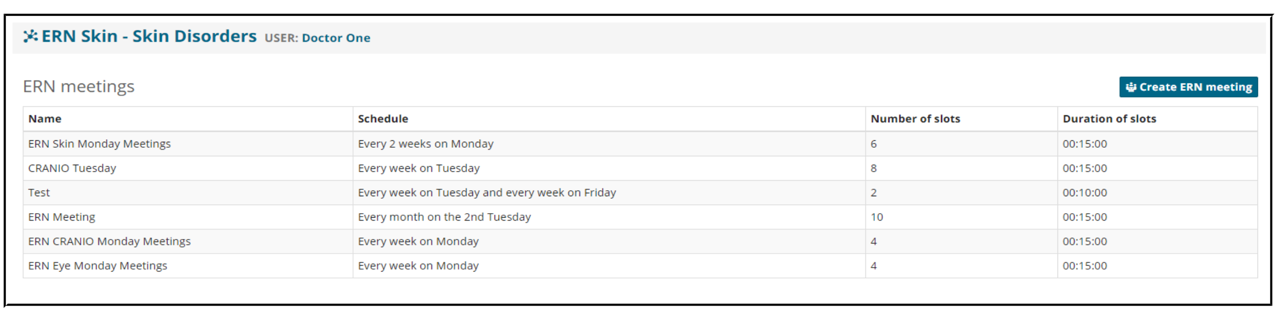
Use-case 4: Panel Member who is HP in the referring ERN but NOT the receiving ERN

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.



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

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.

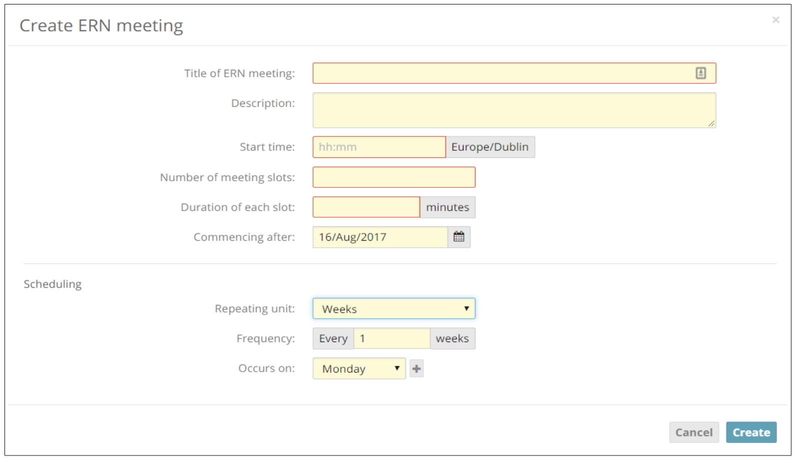


Figure 38: Create ERN Meeting

12.2. 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. 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, however, this role has to be requested by the ERN Coordinators directly to the CPMS support team.

13. Webinars

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

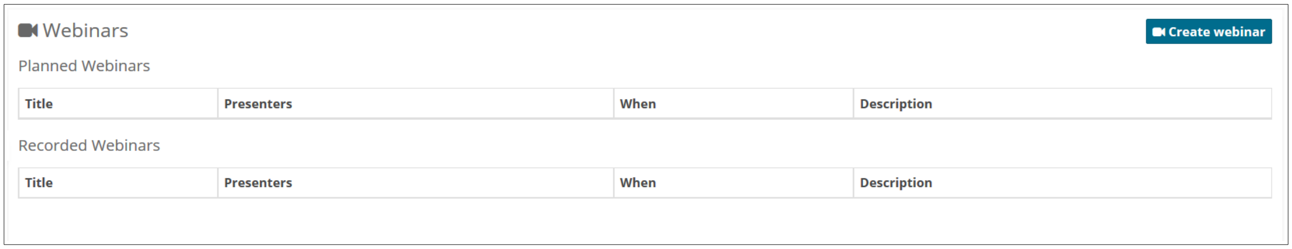


Figure 39: Webinar Section

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.

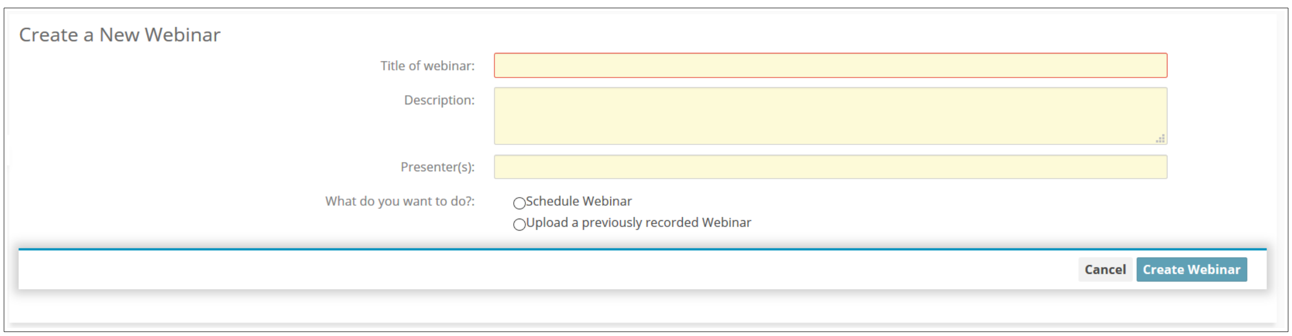


Figure 40: Create a New Webinar

14. 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.

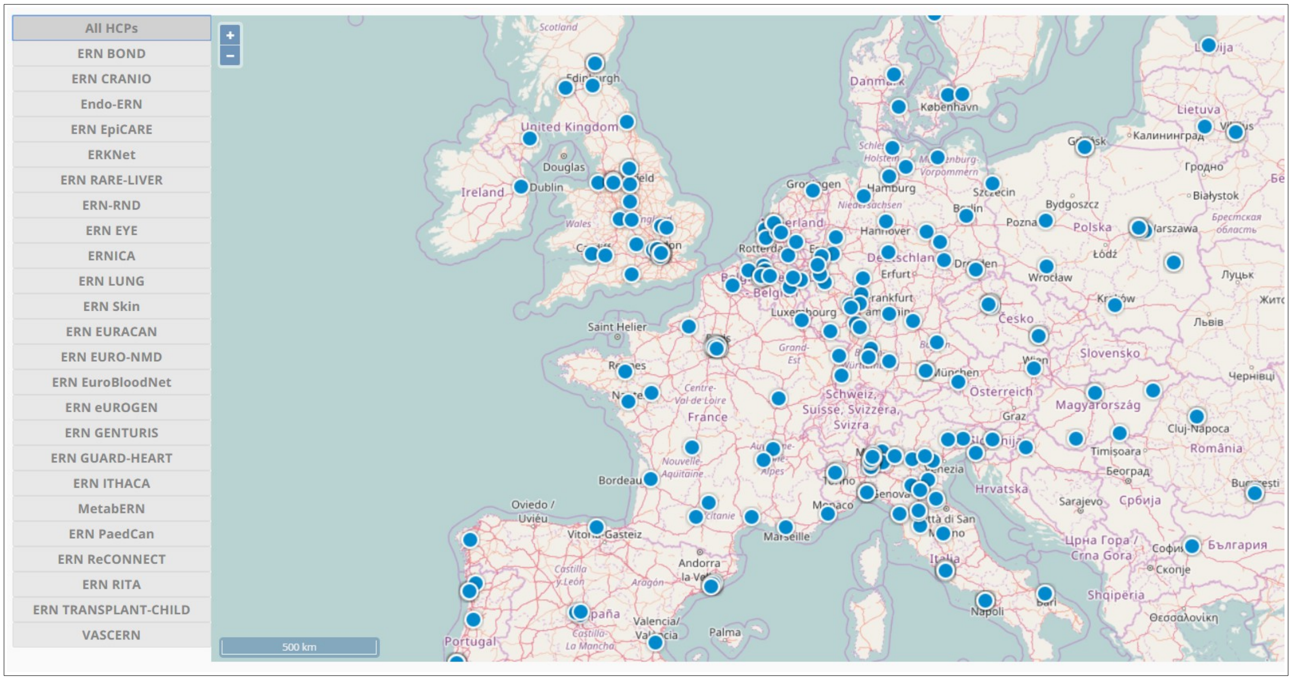


Figure 41: ERN Map

15. ERN Databases/Registries

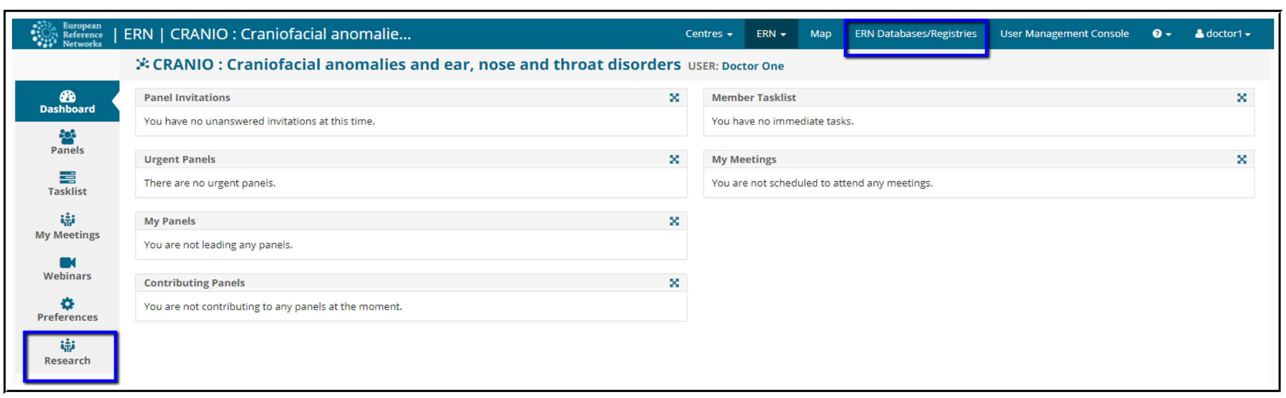
In the ERN Databases/Registries known as low accessibility database and the query builder environment in the CPMS, data are made available for authorized users (e.g. data manager, researchers) conditionally the second consent has been given by the patient (i.e. ERN Databases/Registries).

When the panel has been closed, a new patient ID is given to the Panel and the nickname is removed; the data are subsequently **anonymised**.

This database contains only clinical data collected as part of the panel, limited amount of panel admin data, decision column as the outcome of the consultation interaction. Data in the ERN database can be exported by authorized researchers in several formats with no identifiable data.

Here are two use-cases when it comes to assigning roles of “Researcher” or “Data Manager” to users:

- Researcher use-case 1: By giving access to only the ERN Databases/Registries application (from the third tab in the user management app), the user (HP or Non-HP) can have a global view of the whole data collected in the CPMS by all ERNs.
- Researcher use-case 2: Check the box of the role of Data Manager/Researcher in the ERN application to give access to a user to data only pushed by one individual ERN as requested. This role in ERN Application does not require a HP role as it works independently from the clinical tasks in CPMS.



The user can see the different sections of the Consultation Record. Hovering the mouse over a field name will 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 user can simply 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.

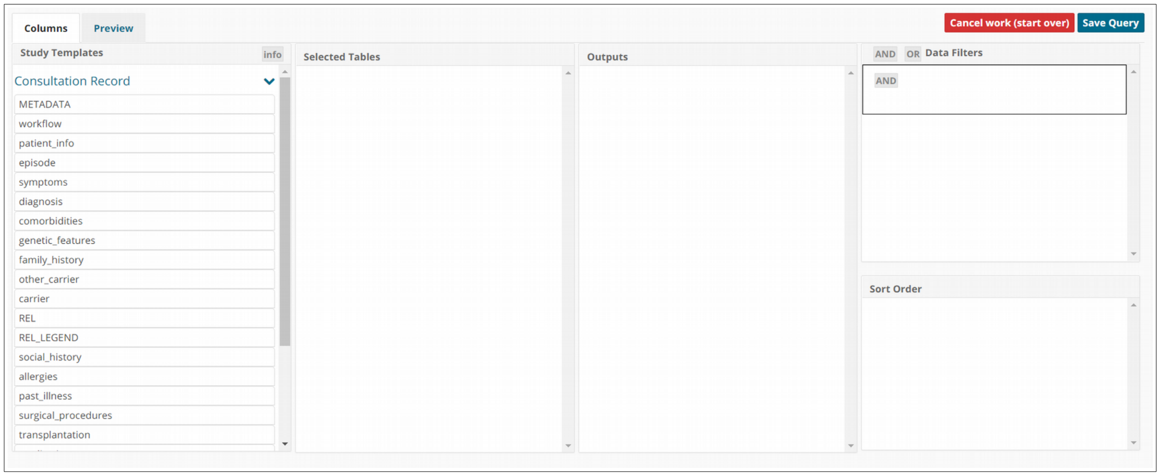
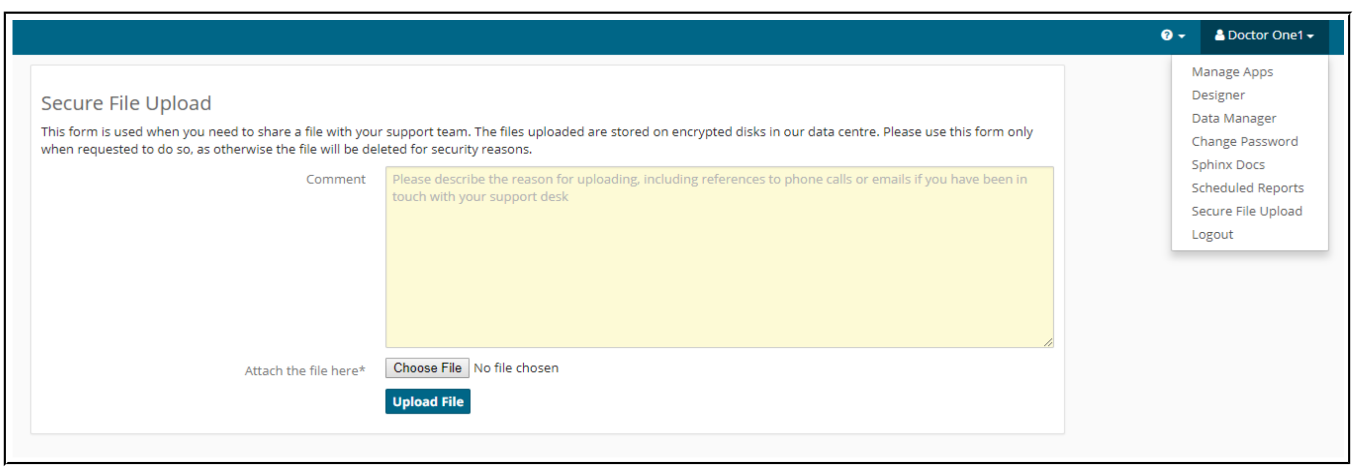


Figure 42: Blank Report Template

16. 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.



17. Appendix – Outcome Document Template

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

[ERN3 Patient ID]

[ERN9 Healthcare Provider]

Dear Dr [Point of Care Specialist]

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.

EPISODE DESCRIPTION:

RARE DISEASE DIAGNOSIS:

COMORBIDITIES:

GENETIC FEATURES:

FAMILY HISTORY:

HEALTH BEHAVIOURS:

PANEL OUTCOME

Yours faithfully

[Panel Lead Name] [Panel Lead HCP]