

CPMS User Guide

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Table of Contents

1. Welcome to the CPMS.....	4
CPMS Made for ERN.....	4
2. Getting Started.....	5
2.1. Access to CPMS.....	5
2.2. Request Access to CPMS.....	5
2.3. Logging In.....	11
2.4. Network.....	12
3. Accessing Your Applications within the CPMS.....	13
4. CPMS system navigation.....	14
4.1. Medical Centre (Hospital) Dashboard.....	14
4.2. ERN Dashboard.....	15
4.3. Preferences.....	16
4.4. Guest Dashboard.....	16
5. Patient Enrolment.....	16
5.1. Consent.....	18
6. Consultation Form.....	19
6.1. File Upload.....	20
Batch Upload.....	21
IHE.....	22
6.2. Medical Image Viewers.....	23
Series picker.....	23
6.3. Osimis Medical Viewers.....	24
Osimis Pro viewer background.....	24
CE-marking.....	24
Radiology Study types supported.....	25
Digital pathology viewer.....	25
6.4. Pedigree.....	25
7. Panel & Form Layout.....	27
7.1. Timeline.....	28
7.2. Data Entry.....	29
8. Panel Workflow – Virtual Consult Process.....	30
8.1. Open a New Panel.....	30
8.2. Open.....	31
8.3. Panel Selection.....	31
Setting a Panel Lead.....	32
8.4. Data Completion.....	32
8.5. Assessment.....	32
8.6. Outcome.....	33
8.7. Sign-Off.....	33
8.8. Closed.....	34
8.9. Archived.....	35
9. Meetings.....	36
9.1. Create a Meeting.....	36
9.2. Join a Meeting.....	37

9.3. Meeting Summary.....	38
10. CPMS Task-List.....	40
11. Email Notifications.....	40
12. Roles & Rights.....	40
12.1. ERN Coordinator.....	40
12.3. ERN Meetings.....	41
12.4. ERN Dispatcher.....	42
13. Webinars.....	43
14. ERN Map.....	44
15. ERN Databases/Registries.....	45
16. Appendix – Outcome Document Template.....	47

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 (EU Login) 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 Healthcare 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](#)

- 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.

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

[Help for external users](#)

First name

Last name

E-mail

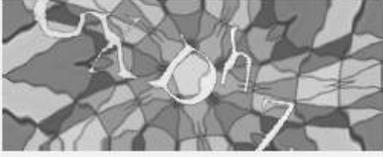
Confirm e-mail

E-mail language

English (en) 

Enter the code



By checking this box, you acknowledge that you have read and understood the [privacy statement](#)

Create an account

Once the EU Login has been created you are ready to request access to 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](#)

- 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](#).

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



SaaS - Authorization System

European Commission

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 EIPAAH 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

Please choose your Department:

Internal Organisation

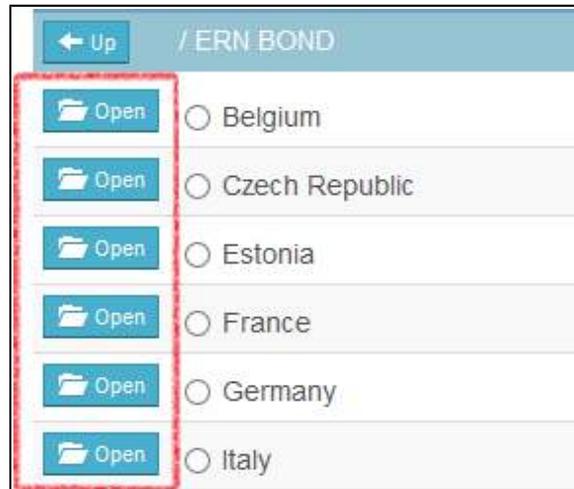
Or one of the Organisations below:

*Organisations

25 records per page

<input type="button" value="Open"/>	<input type="radio"/>	ERKNet
<input type="button" value="Open"/>	<input type="radio"/>	ERN BOND
<input type="button" value="Open"/>	<input type="radio"/>	ERN CRANIO

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

The screenshot shows the 'New application access' page with four steps: 1. Select application, 2. Select organisation, 3. Select access profile (highlighted), and 4. Recap and Submission. Under the heading '*Access Profile', there is a table with columns 'Name', 'Status', and 'Description'. A single row is visible with the name 'user' and a small circle next to it, which is highlighted with a red box.

Name	Status	Description
<input type="radio"/> user		

When done you click on **Step 4 : 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*

The screenshot shows the 'New application access' page with four steps: 1. Select application, 2. Select organisation, 3. Select access profile, and 4. Recap and Submission (highlighted). The page is divided into two main sections: 'Summary' and 'Comments'. The 'Summary' section contains a table with the following data:

Summary	
Application	CPMS
Organisation	BE01 - Universitair Ziekenhuis Antwerpen
Access Profile	user

Below the summary is a 'Comments' section with a text input field. At the bottom, there is a yellow box with the text: **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**

2.3. Logging In

The application can be accessed through web-browsers, such as Google Chrome, Mozilla Firefox and Internet Explorer (11.0) by entering the following URL in the address line:

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

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:

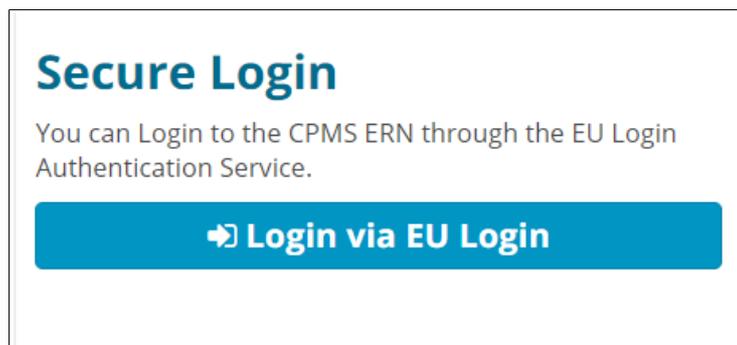


Figure 1: EU Login Link

2. The user should enter their registered email, followed by their password or use another method of authentication to sign in:

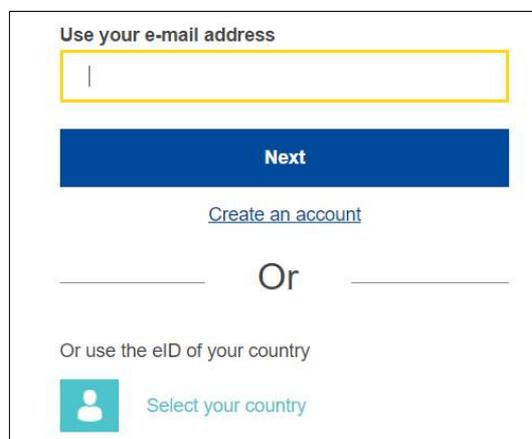


Figure 2: EU Login

Note:

- *When using devices with Mac Operating System, all users are requested to access the CPMS with the aforementioned browsers as Safari doesn't yet support the video conference technology used in the CPMS known as WebRTC.*
- *Users should not use private browsing modes such as 'Incognito' on Chrome whilst using the CPMS.*

2.4. Network

We recommend a minimum dedicated 350kb/s down per downloaded stream, as well as 350kb/s up per uploaded stream to maintain a stable video connection.

3. Accessing Your Applications within the CPMS

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

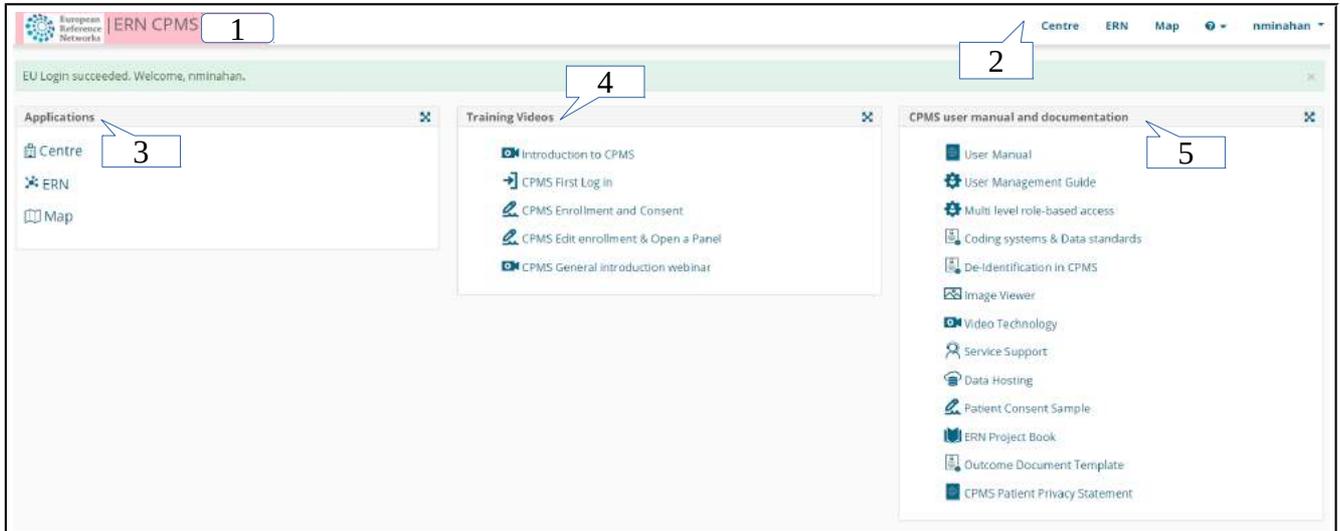


Figure 3: Home Page

1. Clicking here will direct the user always to the Global Dashboard from anywhere in the system.
2. The top menu contains links to the user's applications allowing for quick and easy navigation of the CPMS.
3. The 'Applications' section lists and links the applications (ERNs, medical centres etc) 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 documentation section contains various training materials and documents detailing 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, the user can navigate to their dashboard for that centre. An example of such a dashboard is shown in Figure 4 below:

The screenshot shows the EB-Haus Austria Medical Centre Dashboard. The top navigation bar includes 'Centres', 'ERN', 'Map', 'Research', and the user profile 'doctor1 @ AT01 - EB-Haus Austria'. The dashboard is titled 'EB-Haus Austria' and 'USER: Doctor One'. It features a side menu (1) with 'Dashboard', 'Patient List', 'Enrol Patient', and 'User Management'. The main content area has a 'Patients (ERN)' section (2) with 'Enrol Patient' and 'Patient List' buttons, both showing '48' patients. A search bar (3) is located above the 'Recent Activity' section (4), which displays a table of patient activity.

CPMS Id	Date
ERN-at01-109	17/05/2017 13:40
ERN-at01-108	17/05/2017 10:50
ERN-at01-107	17/05/2017 09:32
ERN-at01-002	16/05/2017 12:01
ERN-at01-006	15/05/2017 13:49
ERN-at01-001	12/05/2017 13:50
ERN-at01-106	11/05/2017 15:58
ERN-at01-104	11/05/2017 15:52
ERN-at01-038	11/05/2017 15:29
ERN-at01-105	11/05/2017 08:52

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' section contains links for the user to enrol a new patient to the system (see Section 4) and to view their current patients.
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, that is 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:

The screenshot shows the ERN Dashboard for 'Doctor One'. The interface includes a top navigation bar with 'Centres', 'ERN', 'Map', and 'Research' menus, and a user profile 'doctor1 @ AT01 - EB-Haus Austria'. A left sidebar contains a 'Side Menu' with links to Dashboard, Tasklist, Preferences, Webinars, My Panels, Contributing Panels, My Meetings, Performance Indicators, and Meeting groups. The main content area is divided into several panels:

- Request Inbox (3):** A table with columns 'Code', 'Date', and 'Centre'.

Code	Date	Centre
#121	28/04/2017	Hospital One
#113	02/05/2017	EB-Haus Austria
#123	04/05/2017	Guest HPs
#154	10/05/2017	EB-Haus Austria
- Panel Invitations (4):** A message: 'You have no unanswered invitations at this time.'
- My Meetings (5):** A table with columns 'When', 'Title', and 'Status'.

When	Title	Status
22/11/2017	Consult	Host
31/05/2017	hjhj	Host
29/05/2017	a	Host
22/05/2017	s	Host
- Member Tasklist (2):** A table with columns 'Nickname' and 'Task'.

Nickname	Task
#185	You have been invited to join this panel. Please A...
- My Panels (6):** A table with columns 'Code', 'Date', and 'Nickname'.

Code	Date	Nickname
#61	07/04/2017	kik
#70	10/04/2017	22/11/1990 (male)
#72	10/04/2017	sdf, dasd DOB: 02/02/2008 (male)
#77	10/04/2017	01/07/2016 (male)a
#79	11/04/2017	Kerry 20/10/1990 (male)
#80	11/04/2017	Jim20/10/1990 (male)
#82	11/04/2017	TEST AGAIN 01/04/1966 (male)
#83	18/04/2017	20/10/1990 (male)
#104	20/04/2017	12124334
#71	10/04/2017	22/11/1990 (male)
- Contributing Panels (7):** A table with columns 'Code', 'Date', and 'Nickname'.

Code	Date	Nickname
#69	10/04/2017	22/11/1990 (male)
#140	08/05/2017	GUEST INE, TEST DOB: 04/05/2000 (male)

Figure 5: ERN Dashboard

1. **Side Menu:** Contains links to the features of the ERN to allow for quick and easy navigation.
2. **Member Tasklist:** Contains a list of pending tasks awaiting the user's interaction.
3. **Request Inbox:** Contains the requests for assistance sent to the user (as ERN Coordinator or Dispatcher only). Discussed further in Section 9.
4. **Panel Invitations:** Lists the invitations the user has to join different panels. The invitations can be accepted or declined by clicking on the link.
5. **My Meetings:** Lists the meetings the user is scheduled to participate in.
6. **My Panels:** Contains links to the panels on which the user is the Panel Lead.
7. **Contributing Panels:** Contains links to the panels that user contributes to, but does not lead.

4.3. Preferences

In the ‘Preferences’ tab, Healthcare Professionals can dictate which thematic areas they are interested in within the ERN. This is an important step to ensure that user is listed as an available Health Professionals during the Panel Selection phase (discussed in Section 7). Figure 6 below shows an example of a preference list.

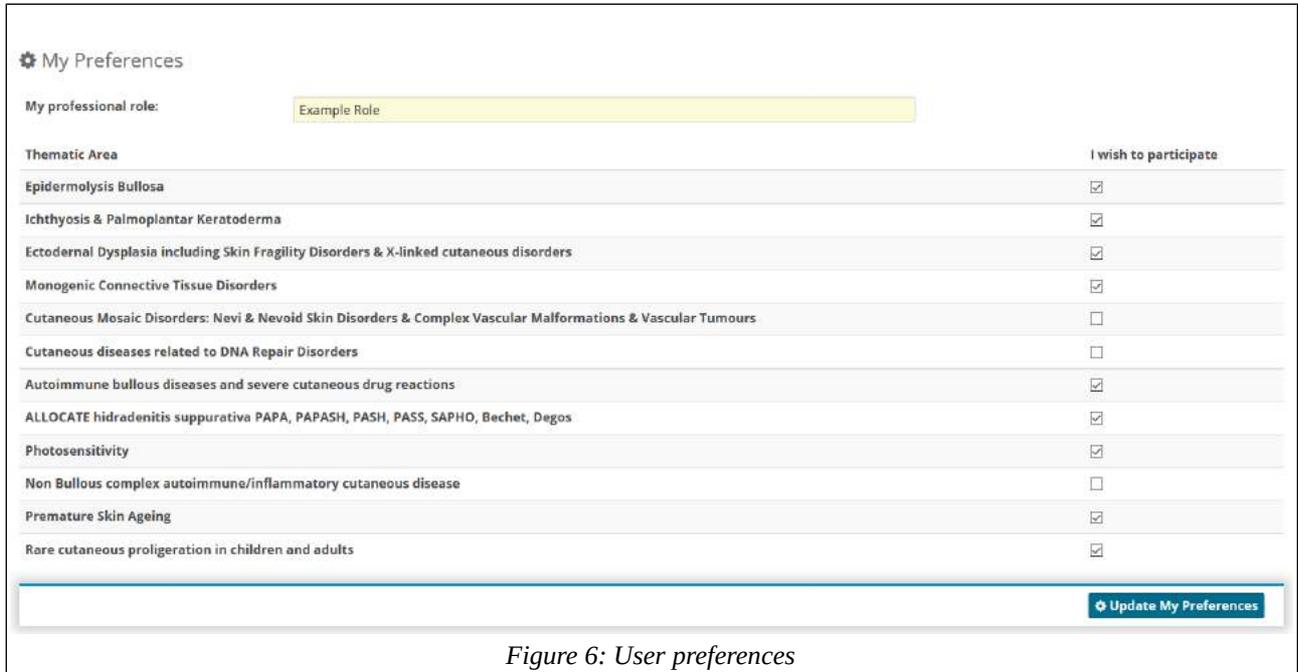


Figure 6: User preferences

The health professional ticks the checkboxes of the thematic areas that they are interested in, and leaves blank the areas which do not interest them.

4.4. Guest Dashboard

The ‘Guest’ Dashboard allows guest users to enrol their patients and participate in panels they create themselves or are invited to take part in.

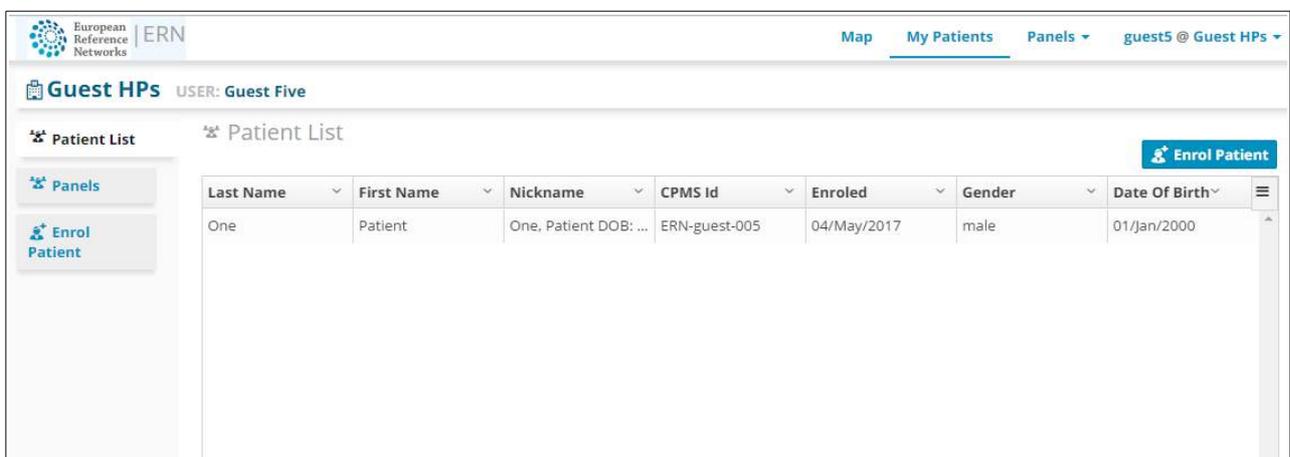


Figure 7: Guest Dashboard

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.



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.

 The image shows the 'Enrol Patient' form. At the top, it displays 'Patient Id: ERN-at01-114' and 'Date enrolled: dd/Mmm/yyyy' with a calendar icon. Below this is a 'Pre-qualification check' section with the question 'Have you sought advice on this patient at a national healthcare provider organisation?' and a 'Required' tag. The 'Consent' section includes 'Consent for Care:' with a 'Required' tag, a 'Download Consent Forms' button, 'Consent contact for research:', 'Consent for ERN databases/Registries:', and 'Date of consent: dd/Mmm/yyyy' with a calendar icon. The 'Identifying data' section contains 'First name', 'Last name', 'Gender:' with a dropdown menu, 'Date of birth: dd/Mmm/yyyy' with a calendar icon, and 'Record Label'. At the bottom right, there are 'Cancel' and 'Enrol' buttons.

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 can be downloaded by clicking the ‘Download Consent 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 a consultation panels on a particular patient.
- Consent for ERN databases and registries: This consent is linked directly to authorize Panel Leads make the clinical data available for ERN researchers 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 by outside ERN research projects (e.g. clinical trials)

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.

Patient ID: ERN-be04-001 One, emma DOB: 02/05/2003 (female) Enrolled: 29/Jun/2017

Error: This patient has not consented to share their data with ERN members. If you have open Panels, you must abort them. If you do get consent from the patient, you must update the enrolment page.

Panels

Enrolment

Panel ID	Nickname	Started	Lead	ERN	Thematic Area
<input type="checkbox"/> #330	mo	19/07/2017	Mr. Emma Jackson	ERN LUNG - Respiratory Diseases	Interstitial Lung Disease

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. The form can be edited only in the "Edit view" to allow doctors record patient data into the form. 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.

The data model running onto the CPMS conforms with European standards, nomenclatures and strategies to share health data syntactically and semantically in the eHealth sector.

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. The following coding and terminology systems have been used to build the Basic Data-Set in the consultation form. (scroll in the form up and down after you picked several sections)

- ICD
- Orphanet Rare Disease Ontology (ORDO)
- ICC3 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

Search widget: Please note that a search widget is provided in some sections to help health professionals select a medical condition without prior knowledge to the coding systems such as ICD-10, Orphanet and ICC3 in the diagnosis section.



The screenshot shows a web interface titled "Consultation Form". It features a list of sections, each with a checkbox and a green indicator dot. The sections are: Consultation Request (checked), Patient Information, Episode Description, Rare Disease Diagnosis, Comorbidities, Phenotype/Genetic Features and Biobanks, Family History, Health Behaviours, Allergies and Other Adverse Reactions, History of Past Illness and Disorders, Special Treatment Intervention, Surgical Procedures, Transplantation History, Medication Summary, Medical Documents, and Others.

Multi-check coding systems: Health professionals, can pick one or more coding systems 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 some data fields to indicate structure or type in information in certain format e.g. RNA Nucleotide variant description. Additionally, general attachments can be uploaded in some sections or the medical document section particularly the those documents needed to be viewed in the radiology or pathology viewer.

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

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.

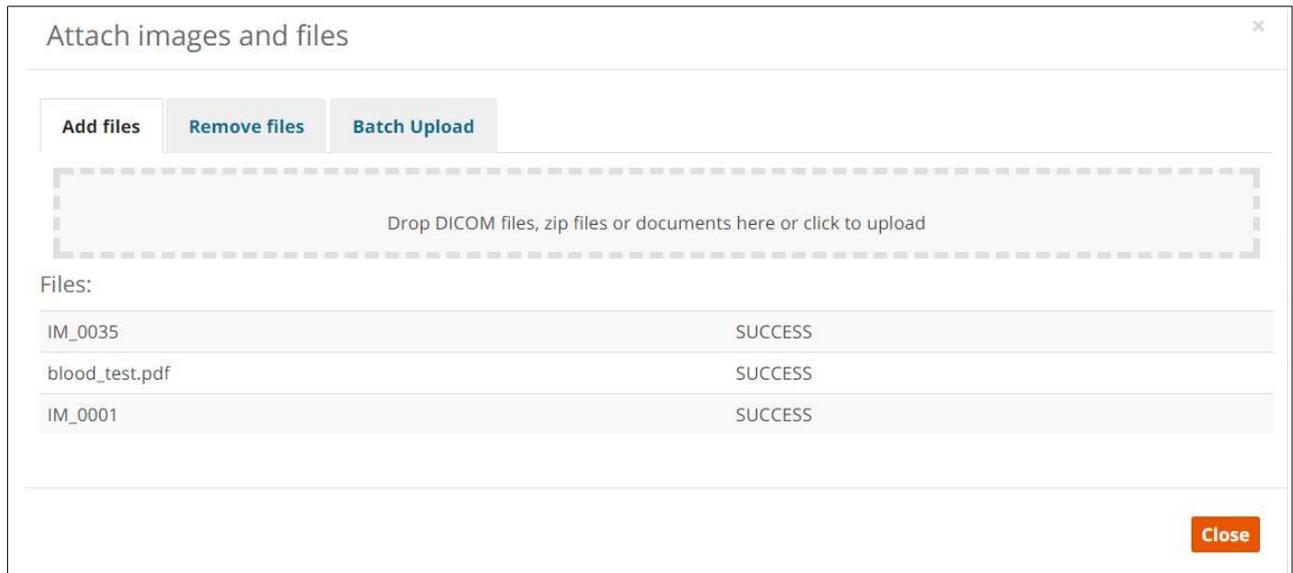


Figure 12: Drag or Browse Files to Upload

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	

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

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.

Attach images and files ×

Add files **Remove files** **Batch Upload**

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:	ftp	Encryption	TLS/SSL Explicit Encryption
Host name:	78.46.49.179	Port number:	1990
User name:	Your login username	Password:	Your FTP password that you provided previous Change 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 'Batch Upload' in the Medical Documents section.

Attach images and files
✕

Add files
Remove files
IHE
Batch Upload

* Patient first name(s):

* Patient last name(s):

* Patient Date of Birth:

6.2. Medical Image Viewers

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. Clicking on a link for the images on the consultation form opens the viewer as shown in Figure 13 below:

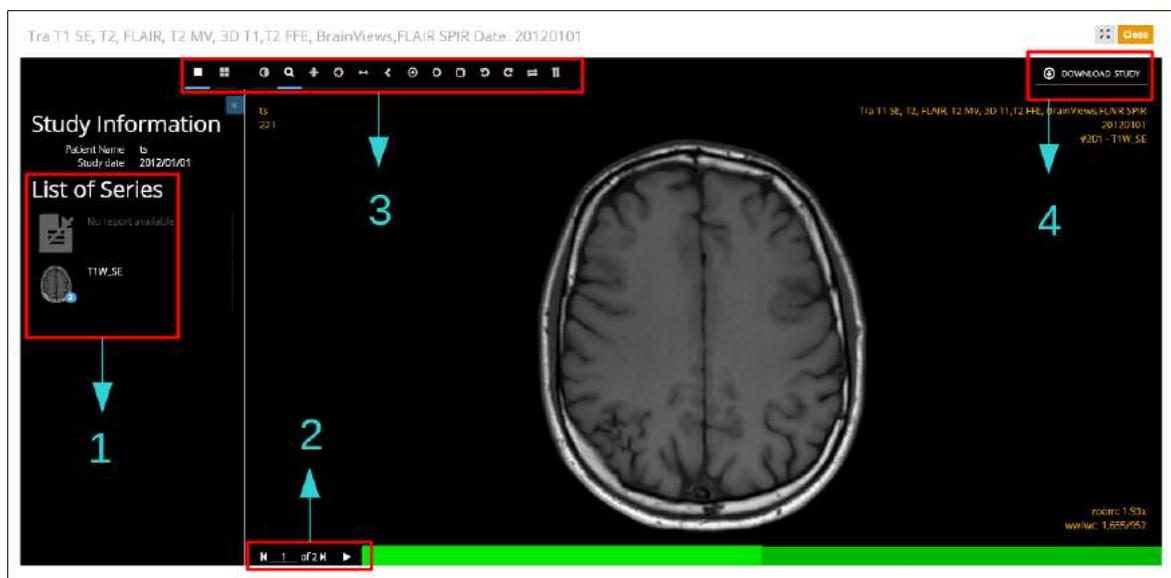


Figure 13: DICOM Viewer

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're assigned a colour that's 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 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:
 - Zoom
 - Invert colour
 - Annotations to measure length, area and angles (See Figure 14 below)
 - Flip image – vertically and/or horizontally
 - Rotate image
4. Allows the user to download the series.

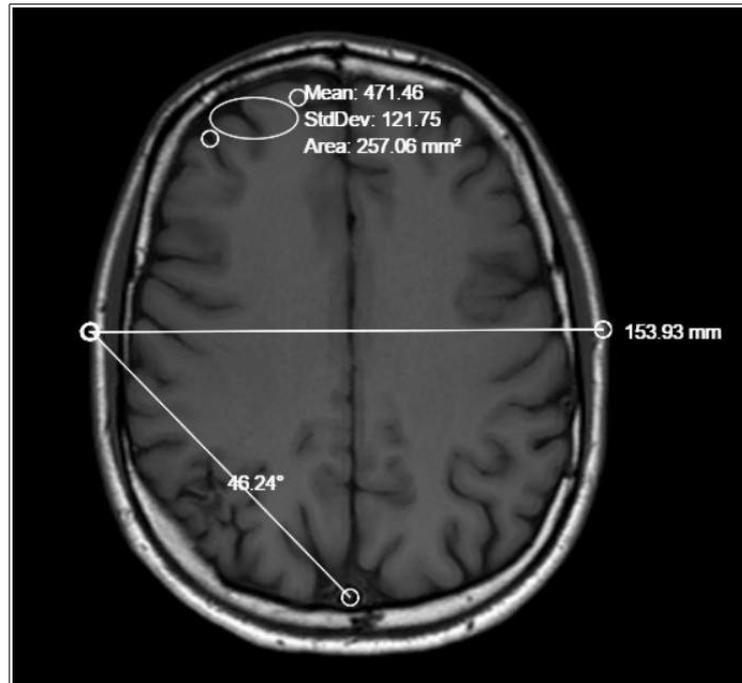


Figure 14: Annotations on a DICOM Image

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

6.3. Osimis Medical 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. The viewer supports both mouse and multi-touch (gesture) input and has been optimised for visualisation on mobile devices.

CE-marking

Osimis is an ISO 13485 certified organisation with BSI as certification body (file reference: MD655957).

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>

Radiology Study types supported

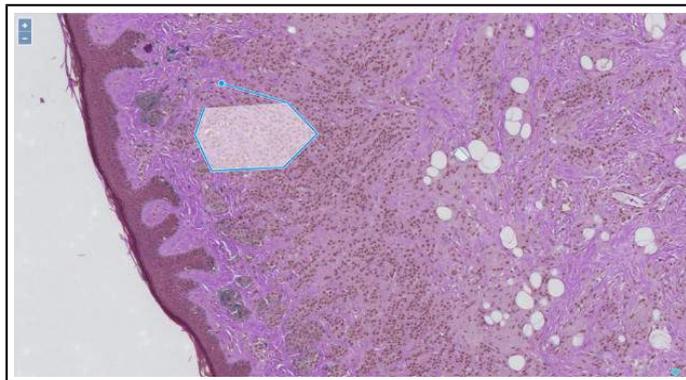
The following types of exams are supported by the viewer:

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

The 'Osimis Pro Web Viewer' is a certified Class I medical device. For more information please go to: <http://www.osimis.io/en/blog/2016/10/14/plugin-osimis-pro-viewer.html>

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. A command-line tool called "DicomToTiff" that converts some whole-slide image stored in an Orthanc server, into a standard hierarchical TIFF image. This tool can be used to export DICOM images to any post-processing framework.



6.4. Pedigree

The pedigree tool is located in the Family History section of the Consultation Request. 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 the pedigree chart. 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.

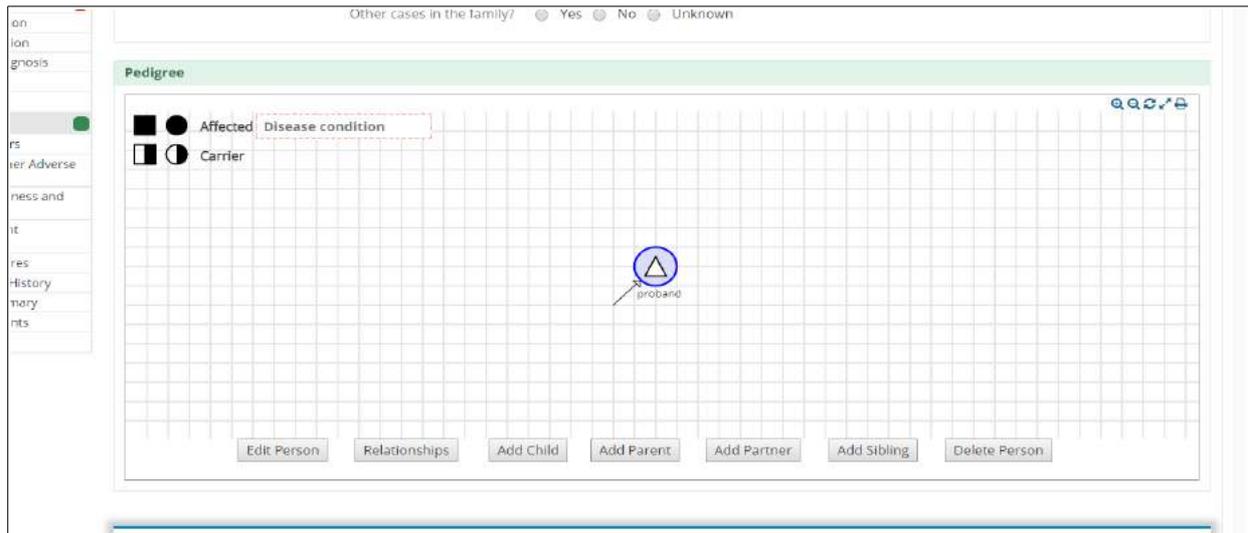
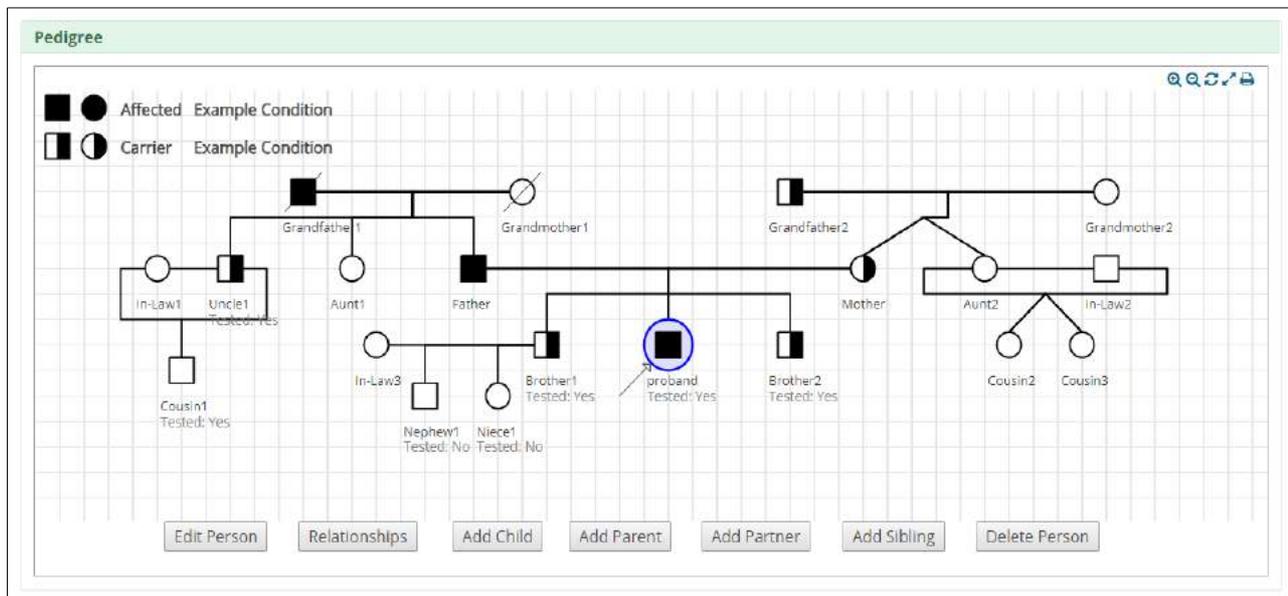


Figure 15: Pedigree Chart

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:



16: Example of a Pedigree Chart

Figure

7. Panel & Form Layout

All the interactions and communication happening between Health Professionals on a particular case can be seen within the Panel view. 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 screenshot displays the 'Panel Home Page' for a consultation request. At the top, a progress bar shows the current state as 'Panel Selection' (indicated by a green checkmark). Other stages include Open, Data Completion, Assessment, Outcome, Sign-off, Closed, and Archived. A 'Next »' button is visible on the right.

Below the progress bar, the following information is displayed:

- Centre Lead:** AT01 - EB-Haus Austria, Doctor One
- ERN Thematic Area:** ERN Skin - Skin Disorders, Cutaneous diseases related to DNA Repair Disorders

Buttons for 'Invite Members' and 'Schedule Meeting' are located below this information.

The main content area is divided into two sections:

Consultation Form

Recorded: 27/Jul/2017 15:09 (Europe/Dublin) by: Doctor One

Consultation Request

- Nickname: UserGuideDemo
- Is this a repeat of a previous panel for the same patient but a different episode?: No
- Consultation Request Description Short: Treatment plan required for patient
- Consultation Request Reason: Treatment
- Consultation Request Reason Description: As above
- Healthcare Provider: AT01 - EB-Haus Austria
- Point of care specialist: Dr. Example
- ERN: ERN Skin
- Panel Lead: Doctor One
- Primary Thematic Area: Cutaneous diseases related to DNA Repair Disorders

Patient Information

- Birth complications:
- Gender: Male
- Country of Residence (ISO 3166-1): Belgium
- Country of birth (ISO 3166-1): Belgium
- Education Level (ISCED 2011): ISCED 6: Bachelor's or equivalent level
- Occupation: Employee working full-time

Timeline

Meeting: Demo

Description: demo
Invited: Doctor One (Host)
Scheduled: 29/Jul/2017 15:30 (Europe/Dublin) for 20 minutes

Starts in: 1 day(s)

add a comment

Panel Members

Member	Status	Actions
Doctor One	Lead	Invited: 27/Jul/2017

There are no outstanding invitations.

add a comment

27/Jul/2017: The Panel is now in state "Panel Selection"

Patient Documents

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.

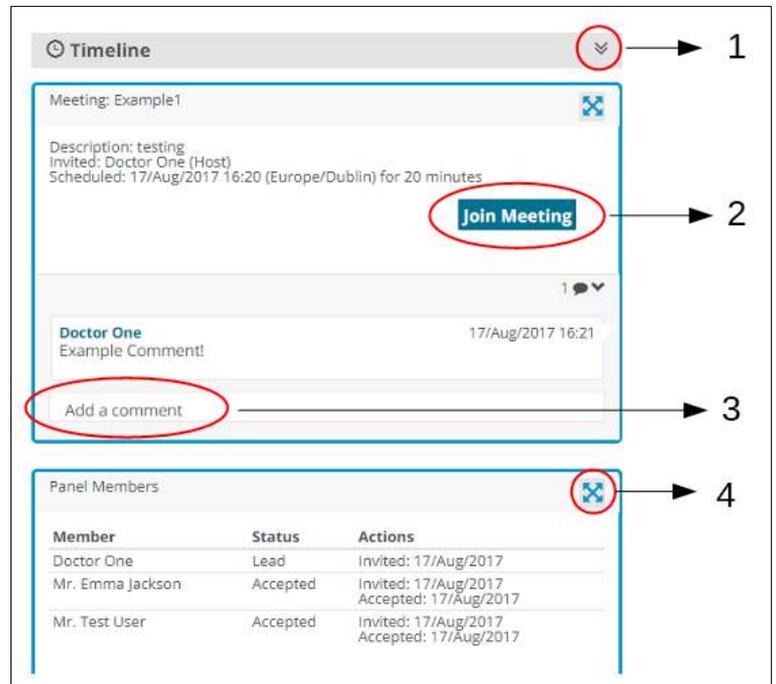


Figure 18: Timeline of Panel

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 make comments on images, contributions and outcome documents.

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.

The image shows a data entry form with several fields. A date picker is open over the 'Date of current Diagnosis' field, displaying a calendar for April 2017. The date '06' is selected. To the right, a dropdown menu titled 'Status of diagnosis' is open, showing options: 'Relapse', 'Resolved', 'In Remission', and 'Active'.

Mon	Tue	Wed	Thu	Fri	Sat	Sun
27	28	29	30	31	01	02
03	04	05	06	07	08	09
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
01	02	03	04	05	06	07

Status of diagnosis

- Relapse
- Resolved
- In Remission
- Active

Figure 19: Date 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 the ‘Enrol Patient’ form from Section 4.

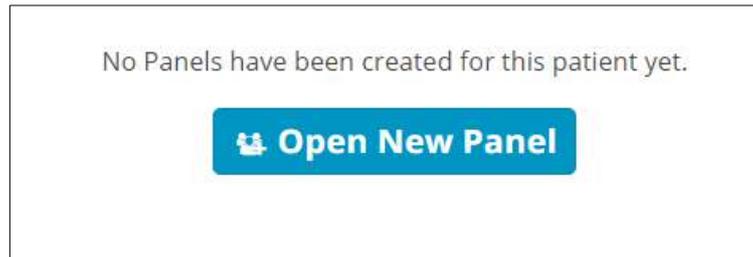


Figure 20: New Panel – New Patient

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. The user will also have the option to cancel or restart any panels on which they are the panel lead.

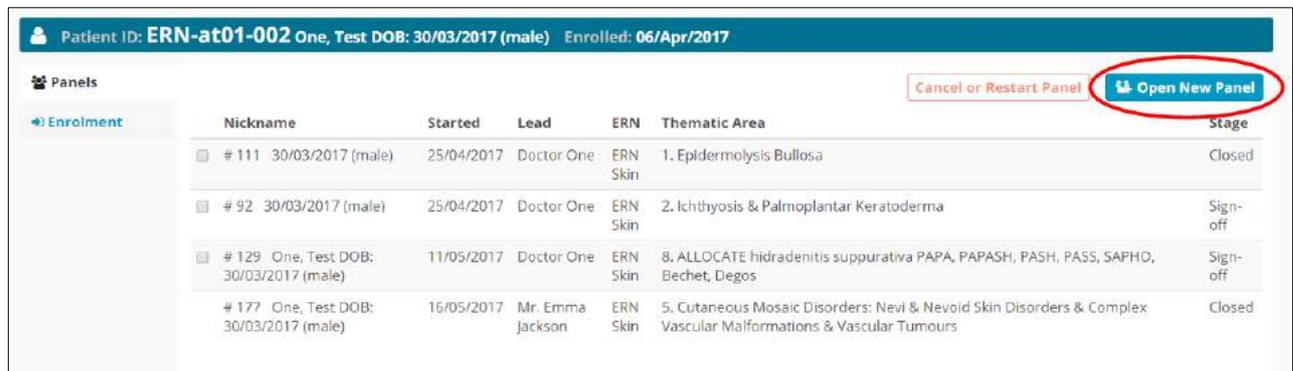


Figure 21: New Panel - Existing Patient

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.

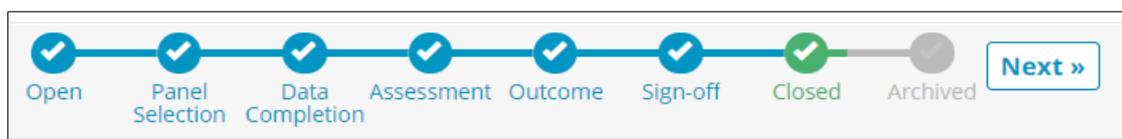


Figure 22: Stages of the consult process

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 healthcare professional in that particular medical centre.

8.3. Panel Selection

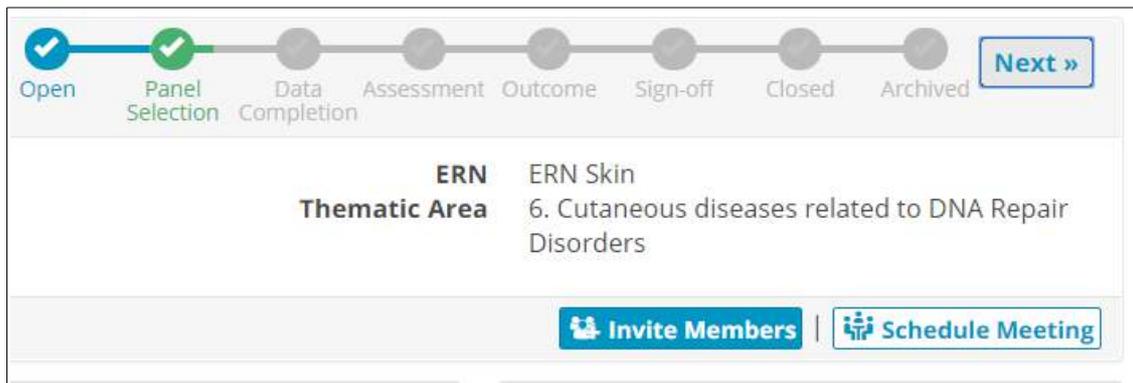


Figure 23: Invite Members and Schedule Meeting

In the 'Panel Selection' stage the Panel Lead at this stage, 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.

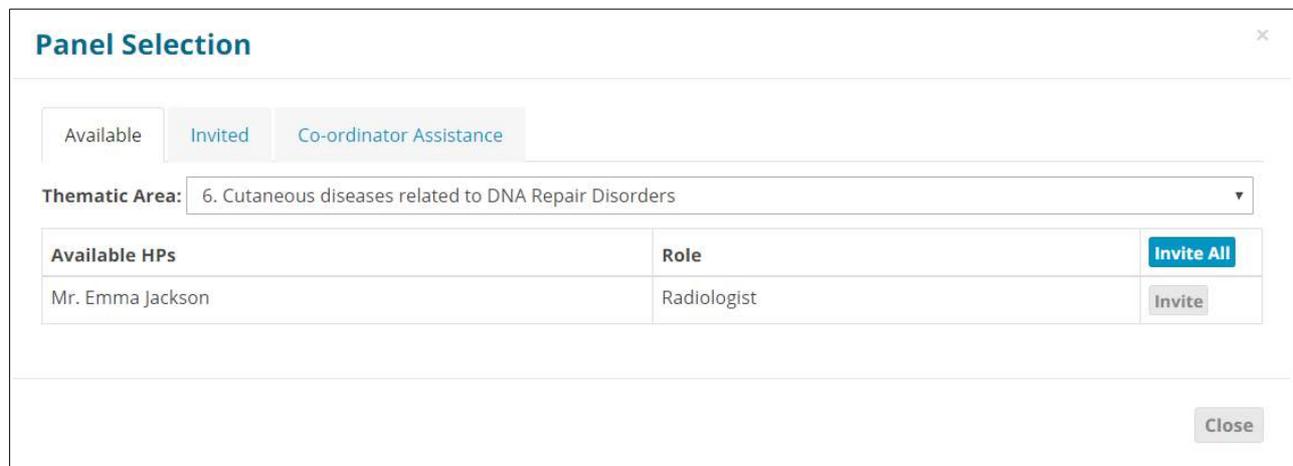


Figure 24: Panel Selection

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 has 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.

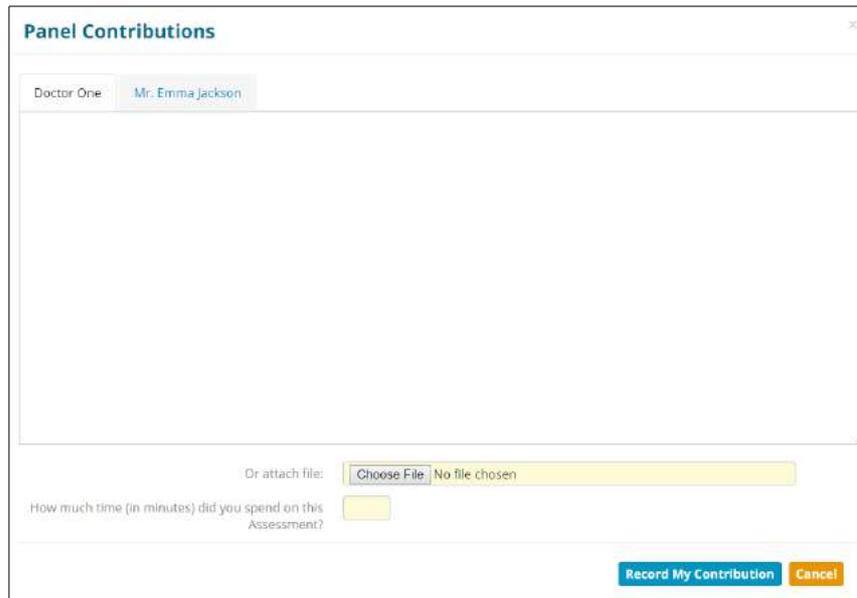


Figure 25: Panel Contributions

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

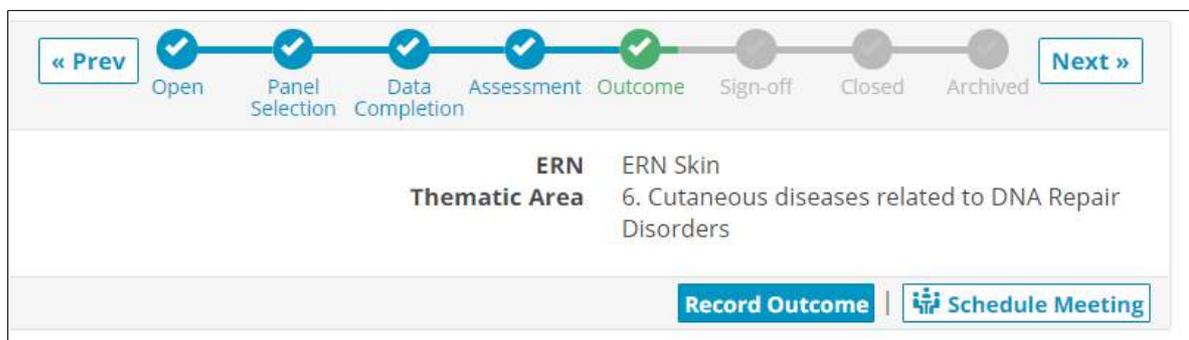


Figure 26: Outcome

Assessment stage if he/she deem it necessary, as shown in Figure 26.

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 Panel Lead, can export the outcome as PDF document for personal record or sending it over to POC specialist or patient themselves.

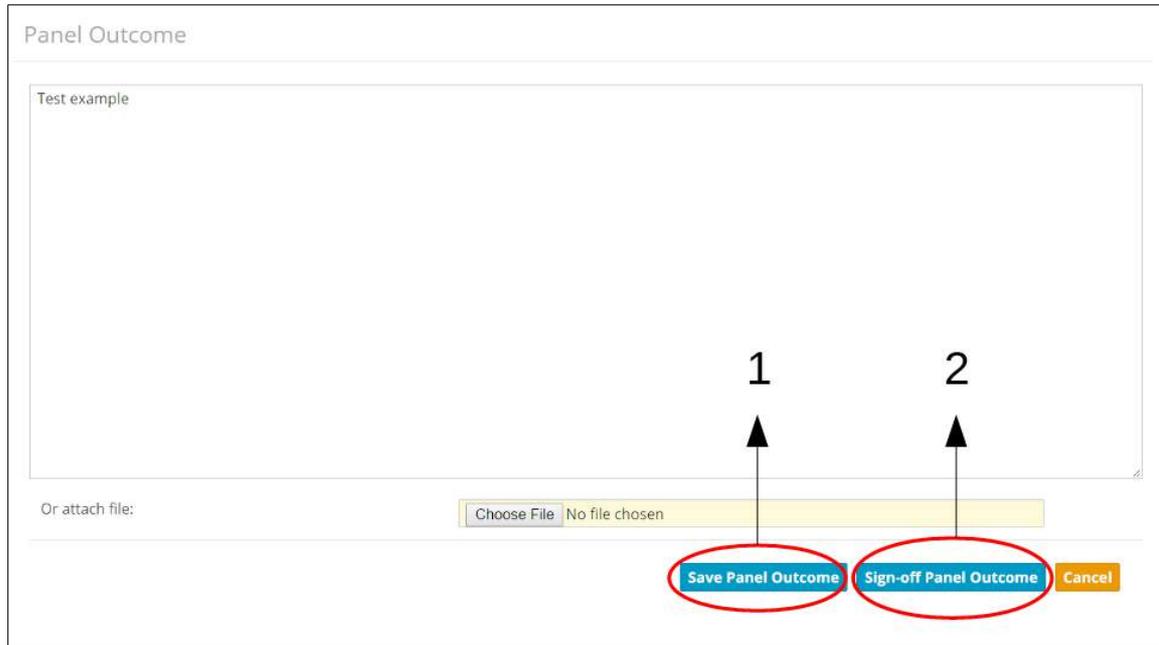


Figure 27: Panel Sign-Off

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:

Transition to Closed ✕

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

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
 Other

Search All Coding Systems:

Diagnosis Coding System: ICD-10 i
 ICC-3
 Orphanet
 Other

Orphanet nomenclature:

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.

Outcome
 Sign-off
 Closed
 Archived
Next »

Disorders

Ageing

Figure 29: A Closed Panel

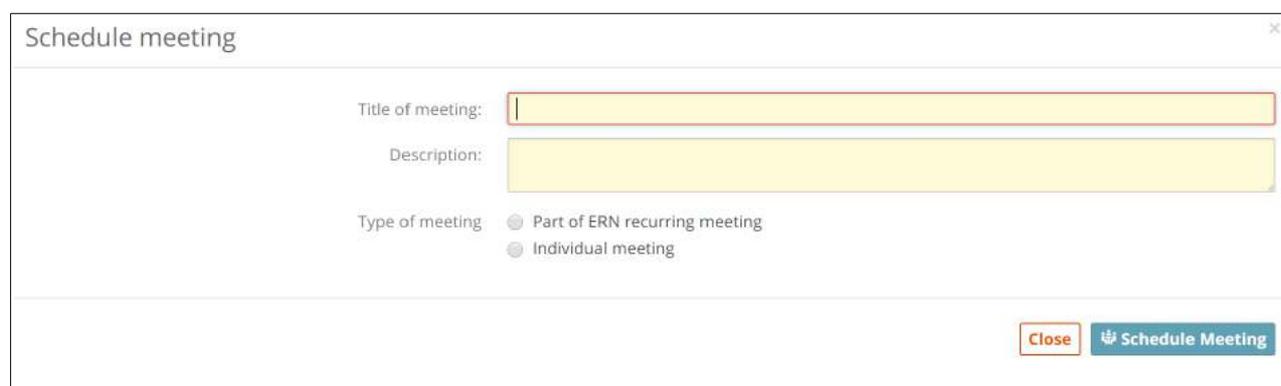
8.9. Archived

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.

9. Meetings

9.1. 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 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.

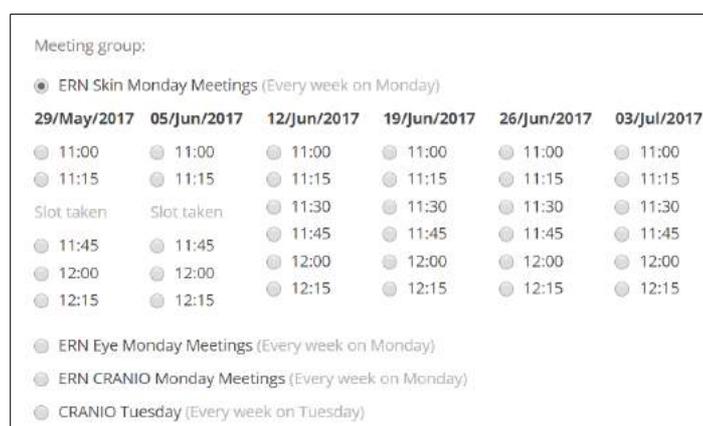


The screenshot shows a 'Schedule meeting' dialog box. It has a title bar with 'Schedule meeting' and a close button (X). The form contains the following elements:

- Title of meeting:** A text input field with a yellow background.
- Description:** A larger text input area with a yellow background.
- Type of meeting:** Two radio buttons:
 - Part of ERN recurring meeting
 - Individual meeting
- Buttons:** A 'Close' button (orange) and a 'Schedule Meeting' button (blue).

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.



The screenshot shows a 'Meeting group' selection screen. It lists several meeting groups with their respective time slots:

- ERN Skin Monday Meetings (Every week on Monday)** (Selected):
 - Dates: 29/May/2017, 05/Jun/2017, 12/Jun/2017, 19/Jun/2017, 26/Jun/2017, 03/Jul/2017
 - Time slots: 11:00, 11:15, 11:30, 11:45, 12:00, 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 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.

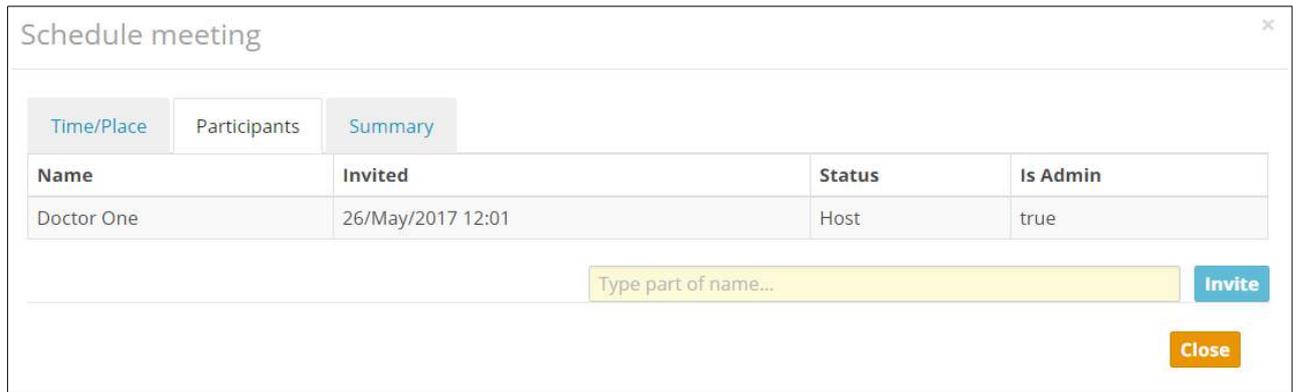


Figure 32: Invite Participants

9.2. 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 notification of the invitation in the footer of the Panel banner as

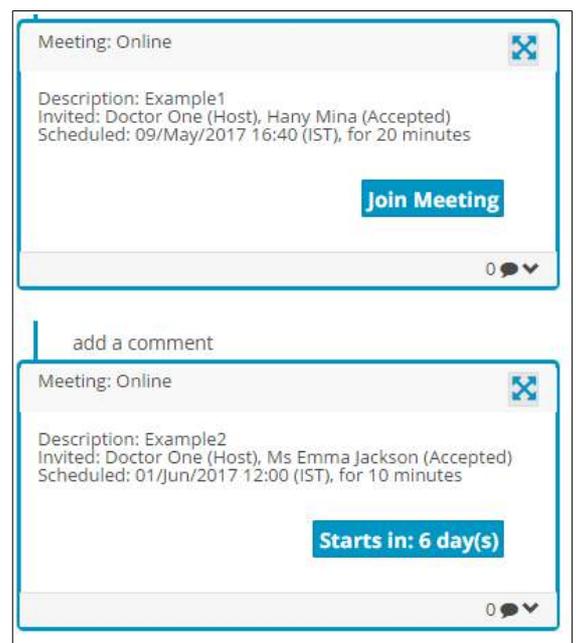


Figure 33: Meeting Notification on the main page of the Panel

seen below:

- On the ERN Dashboard, under ‘My Meetings’ and ‘Member Tasklist’.
- In the ‘My Meetings’ section of the ERN Application.
- In the ‘Tasklist’ section of the ERN Application.
- In the Panel, via a banner as shown above:

Similarly, at the designated time, the meeting invitee can join a meeting via the ‘My Meetings’ tab (where they can also view past meetings), the Tasklist and via the Timeline of the panel that the meeting belongs to, as shown.



The following features are available to use within the video environment to facilitate the interaction between participants and ensure efficient communication during the meeting:

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

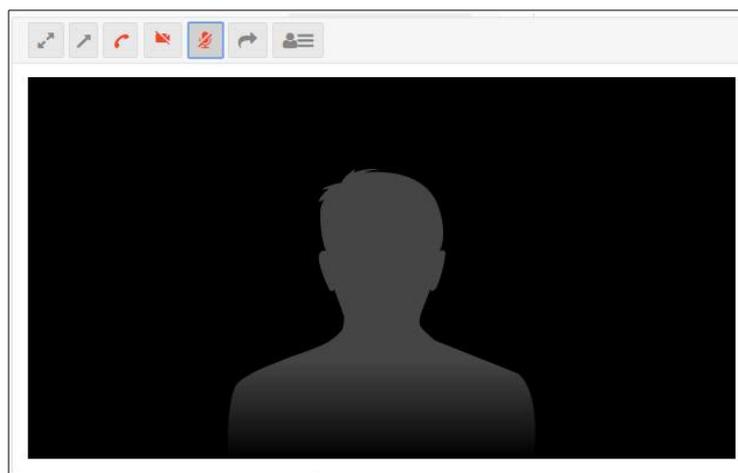


Figure 34: Meeting Interface

9.3. 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.

ERN Skin USER: Doctor One

Dashboard Tasklist Preferences Webinars My Panels Contributing Panels

311 Meeting Tester

Open Panel Selection Data Completion Assessment

Centre: EB-Haus Austria
Lead: Doctor One
Panel: Mr. Emma Jackson

ERN Thematic Area: ERN Skin - Skin Dis, ERN Skin - Skin Dis, Photosensitivity

⚠ If meeting "Summary Test" has finished please ensure meeting status is changed to finished and meeting summary is recorded.

Consultation Form recorded: 14 Jul 2017 11:16 (Europe/Dublin) by: Doctor One Edited: (Europe/Dublin) by: Doctor One

Consultation Request

Timelir 14 Jul 2017

Figure 36: Meeting Summary Reminder

10. CPMS Task-List

The Task List in the ERN dashboard contains a list of pending tasks awaiting the user's interaction. Those tasks ranges between different activities to be done by the user 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

11. Email Notifications

CPMS works in synchronization with users' emails when provided. When CPMS users are requested to do some tasks as shown 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

If the ERN Coordinator is simultaneously a coordinator and a health professional in an ERN centre, they can use both the centre and ERN dashboards. Where the ERN Coordinator is a non-medical person and not a member of an ERN centre, he/she is limited to the activities available on the ERN dashboard. ERN Coordinators will use the Key Performance Indicators of the ERN for reporting purposes based on information such as numbers of newly enrolled patients and open and closed panels.

A vital role of an ERN Coordinator will be to receive all requests made by panel leads who seek assistance in inviting suitable members into a particular panel. 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.

The ERN Coordinator is given the right to change the 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.

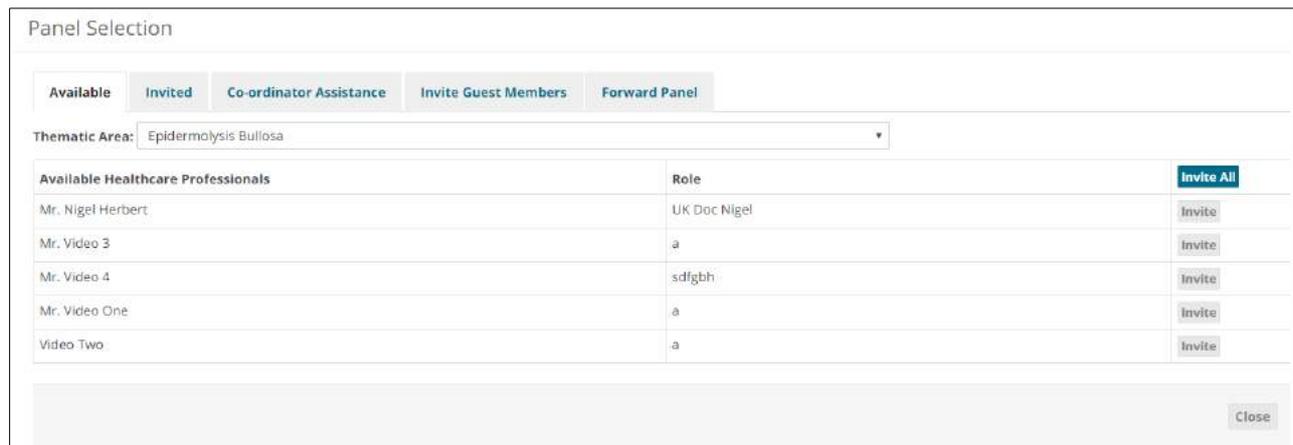


Figure 37: Additional Functionality for the Coordinator during the Panel Selection

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 Coordinator can request offline 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.

Lastly, the ERN Coordinator can upload or stream live educational videos known as Webinars onto the CPMS.

12.2.

12.3. ERN Meetings

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
Example1	Every week on Wednesday	1	00:15:00
Example2	Every 2 months on the 1st Thursday	2	00:10:00

Figure 38: 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 screenshot shows a 'Create ERN meeting' dialog box with the following fields and options:

- Title of ERN meeting: [Text input field]
- Description: [Text input field]
- Start time: [hh:mm input field] Europe/Dublin
- Number of meeting slots: [Text input field]
- Duration of each slot: [Text input field] minutes
- Commencing after: 16/Aug/2017 [Calendar icon]

Scheduling

- Repeating unit: Weeks [Dropdown arrow]
- Frequency: Every 1 weeks
- Occurs on: Monday [Dropdown arrow]

Buttons: Cancel, Create

Figure 39: Create ERN Meeting

The established time slots are then available to be selected by Panel Leads when they are scheduling meetings for their panels.

12.4. 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. However, Dispatcher role lacks access to features such as the Key Performance Indicators (KPIs). Therefore there is no need for a case where a user is assigned the role of both Coordinator and Dispatcher for the same ERN.

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.

Please note that this role reflects the CPMS 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

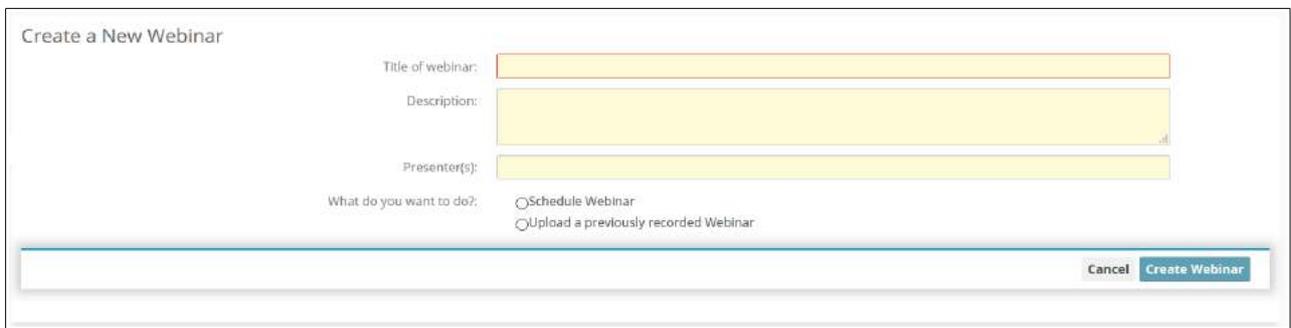
In the 'Webinars' section the user can create a new webinar or upload a previously recorded one.



The screenshot shows a web interface for managing webinars. At the top left, there is a header 'Webinars' with a small icon. To the right of the header is a blue button labeled 'Create webinar'. Below the header, there are two sections: 'Planned Webinars' and 'Recorded Webinars'. Each section contains a table with four columns: 'Title', 'Presenters', 'When', and 'Description'. The tables are currently empty.

Figure 40: 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 a form titled 'Create a New Webinar'. It contains three text input fields: 'Title of webinar:', 'Description:', and 'Presenter(s):'. Below these fields, there is a question '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, there are two buttons: 'Cancel' and 'Create Webinar'.

Figure 41: 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.

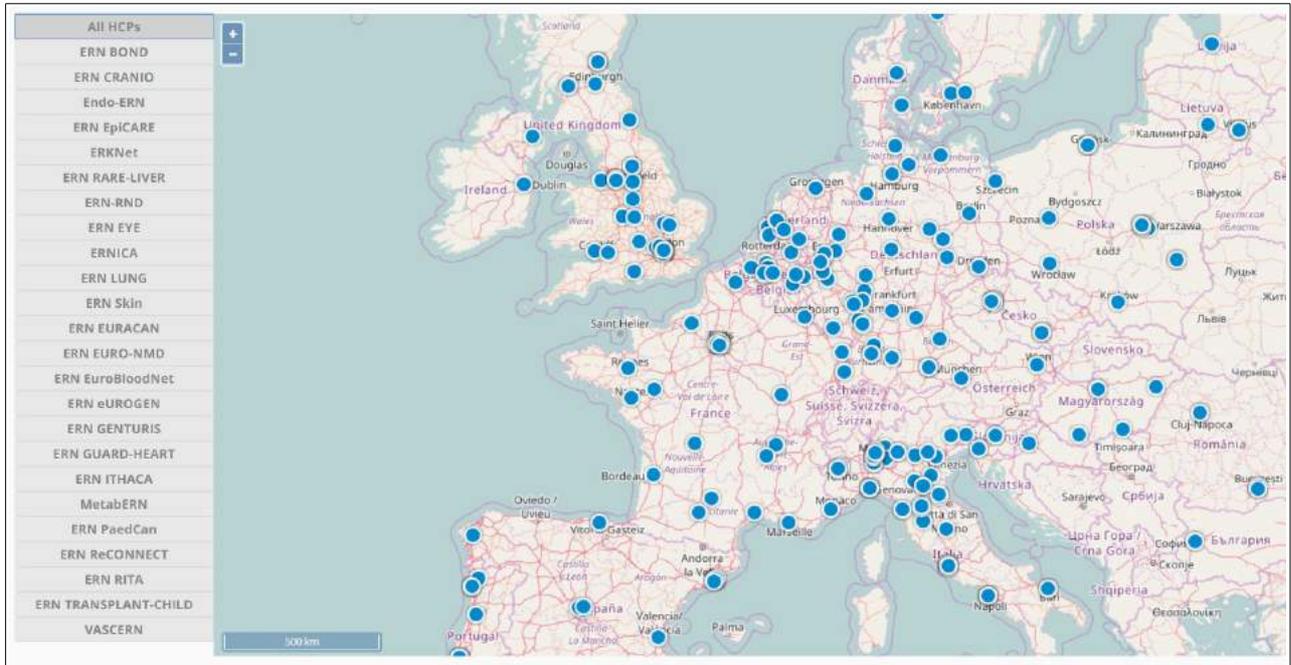


Figure 42: ERN Map

15. ERN Databases/Registries

In the ERN Database/Registries known as low accessibility database and the research environment in the CPMS, all data are made available for research once the Panel lead decides to push anonymized data to the research database when the panel has been closed. A new patient ID is given to the Panel and nickname is removed; These database contains only clinical data collected as part of the panel, small 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.

Clinical data in the low accessibility database are made available conditionally the second consent has been given by the patient (i.e. ERN Databases/Registries). ERN authorized users will have an access to the research environment in the CPMS to conduct research activities and export data.

The ERN Database contains a Query Builder which allows the user to generate customised reports. Authorised users can access the app by clicking on the 'Research' link in their top menu. To create a new query, select the 'Research Dataset' and click 'Go'.

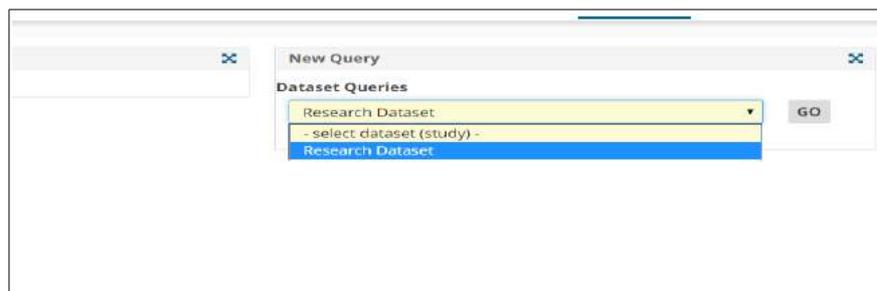


Figure 43: New Query - Select 'Research Dataset', click 'Go'

This opens a blank report template as shown below.

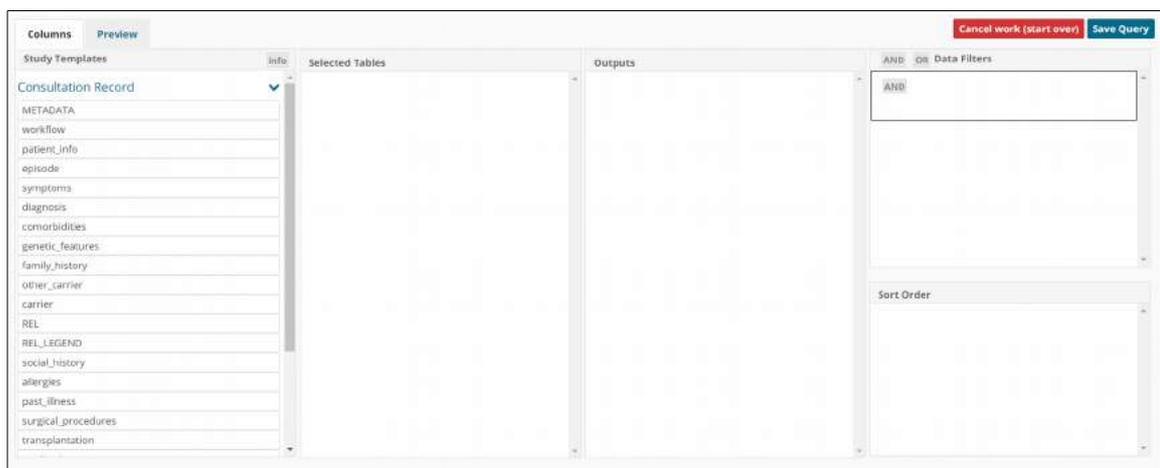


Figure 44: Blank Report Template

Under 'Study Templates', 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.

16. 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

[Signature Line or "**Dictated But Not Read**"]

[Panel Lead Name] [Panel Lead HCP]