

for rare or low prevalence complex diseases

Network
Neurological Diseases
(ERN-RND)

USER GUIDE CLINICAL PATIENT MANAGEMENT SYSTEM





CPMS User Guide Summary



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I General

page 3 – 13

Relevant for all CPMS users

- 1. About CPMS
- 2. Important Ressources
- 3. Before starting
- 4. CPMS Home: Dashboard
- 5. ERN-Board
- 6. Centre-Board
- **7. Setting Preferences**

II Panels - Basics

page 14 - 20

Relevant for if you join a panel as expert & for panel creators

- 1. Panel View
- 2. Panel interactions
- 3. Meetings
- 4. Contributions & outcome

III Leading a panel

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Relevant for panel creators

- 1. How to discuss your case
- 2. Patient list
- 3. Enrol patient
- 4. Consultation Form
- 5. Panel lead actions
- 6. Attachments
- 7. Manage Panel Members
- 8. Meetings
- 9. Contributions & Outcome
- 10. Closing & archiving panel



I CPMS General

1. About CPMS



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About CPMS – Clinical Patient Management System:

- a telemedicine platform for online-consultations, connecting
 ERN-experts across Europe
- safe for exchanging sensitive clinical data. It allows upload of all medical documents, including DICOM files.
- Funded, maintained and updated by the European
 Commission
- □ the **ERN-RND Helpdesk** can assist users anytime:



cpms-helpdesk_ern-rnd@med.uni-tuebingen.de



I CPMS General

2. Important Ressources



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Important information:

- To join CPMS you need to register (see CPMS Registration guide).
- Check out our <u>best practice guide</u>.
- Enroll a patient case together with the Helpdesk:
 <u>cpms-helpdesk ern-rnd@med.uni-tuebingen.de</u>
- □ To get familiar with CPMS you can use the <u>CPMS training platform</u>. The Helpdesk will provide you with login details.
- Use the Troubleshooting guide to find a quick-help for common issues.
- All information about CPMS is regularly updated on <u>our website</u>.



I CPMS General3. Before starting



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Before starting:

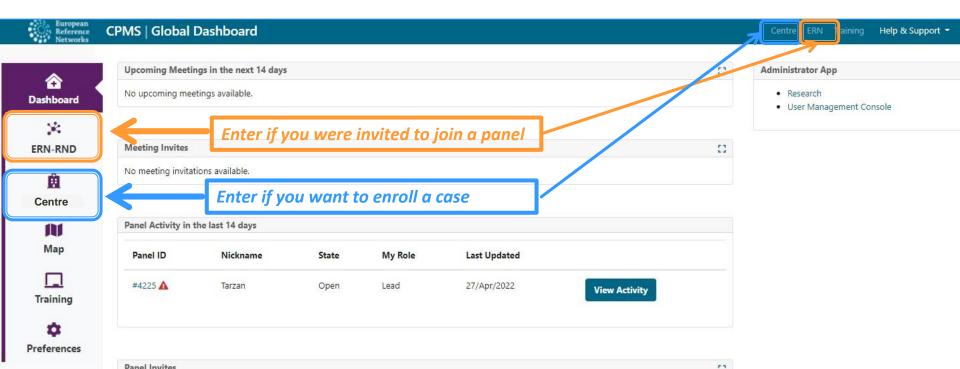
- It is recommended to use Google Chrome as a browser to be able to apply all functions.
 Recommended speed for stable video connection: 350kb/s download stream speed, 350kb/s upload stream speed.
- This guide contains information for the role of Panel member (if you are giving advice to others) and for the role of Panel lead (if you are receiving advice on a panel you created)
- Panel creation: You can fill out the consultation form in several returns if you save the sections you have already filled
- □ There will be **date pickers** ' (where you have to fill the date in the format dd/mm/yyyy, **but some** date pickers allow to write only mm/yyyy, or yyyy
- If you're not sure about the exact requirement of a box check the ' ticon for more information.
- Red boxes and red arrows in this guide will help you navigate within the CPMS.
 Recommended: log into CPMS and compare the guide on the go.



I CPMS General 4a. CPMS home: Navigation



- □ Login into CPMS: https://cpms.ern-net.eu/login/
- □ CPMS Home Dashboard:
 - ✓ CPMS opens at your Dashboard (individualized due active panels or set up meetings)
 - ✓ 2 navigations bars: one on the top and one on the left
 - ✓ 2 main tabs (Dashboards): 'Centre' and 'ERN'
 - ✓ Each Dashboard (Centre and ERN) has it's own **colour** for easy navigation





I CPMS General

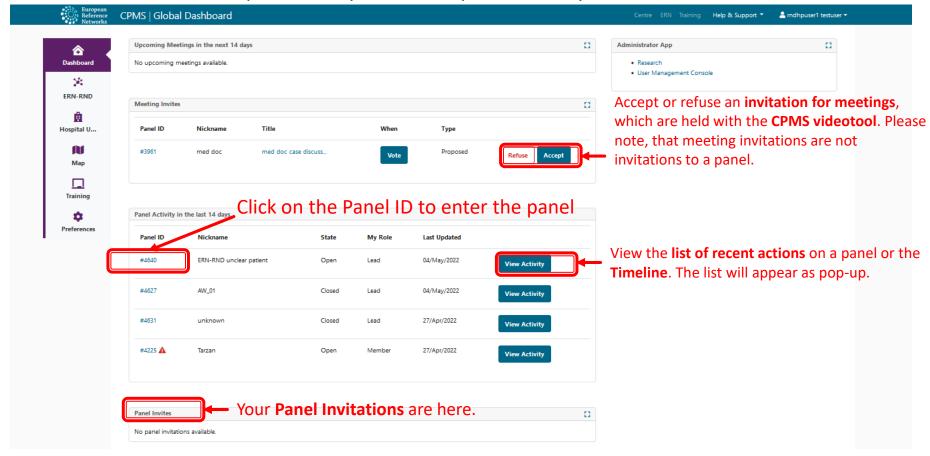
4b. CPMS Home: Dashboard



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The Dashboard gives you an overview of your Panel-Activity or current invitations to meetings or other panels, which you can accept or refuse.

✓ The Panel ID is the quickest way to enter a panel directly from the Dashboard.





I CPMS General 4c. CPMS Home: Dashboard

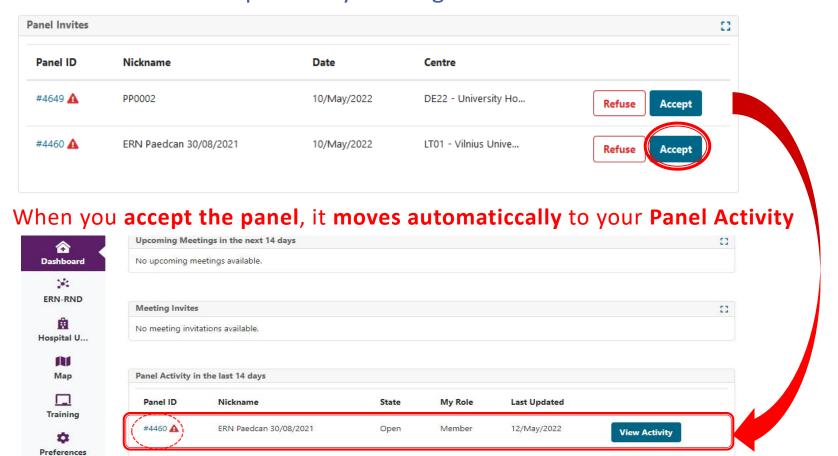


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On the bottom of the Dashboard you will find your Panel Invitations.
You can view the panels by clicking on the Panel ID.



Member

Open

12/May/2022

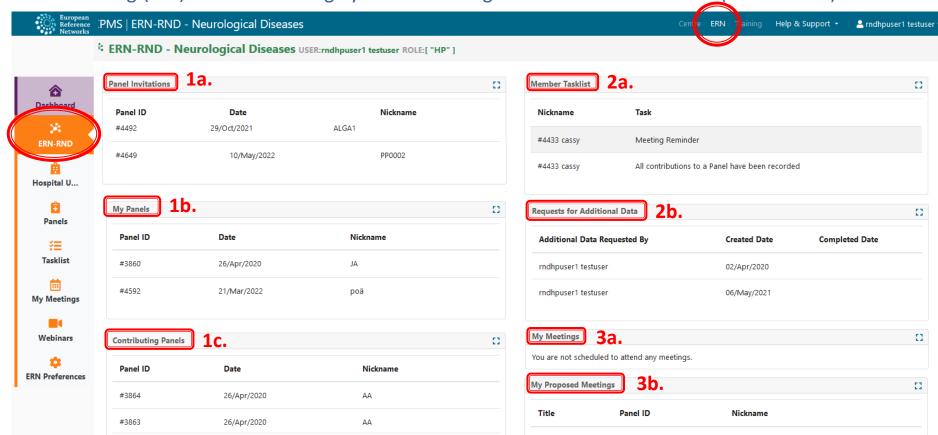
View Activity



I General 5. ERN-Dashboard



- Contains an overview of all panels you were invited to (1a.), you are leading (1b.) and you are contributing to (1c.)
- See all the tasks associated with any panel or meeting you are participating in (2a) or leading (2b.) and all meetings you are hosting or have been invited to (3a. and 3b.)



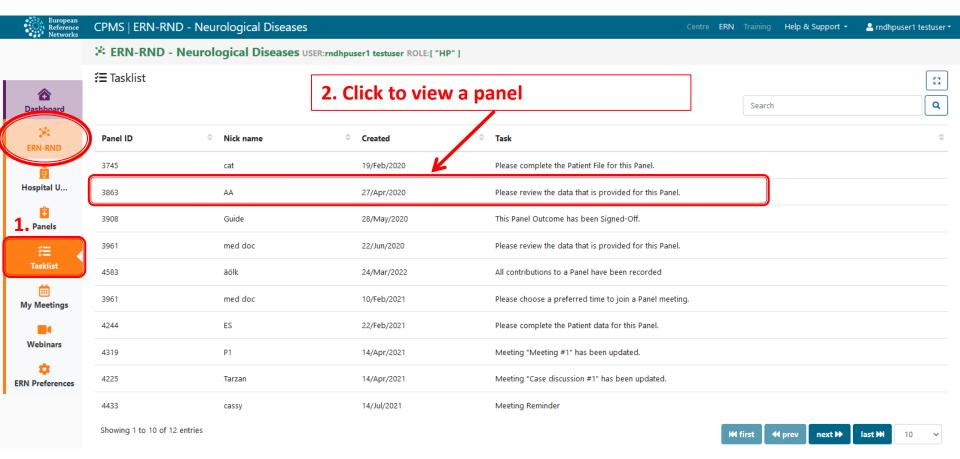


I General 5a. ERN-Dashboard: 'Task List' View



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 Here you can see all the tasks associated with any panel or meeting you are participating in or leading (e.g. Accept/Refuse a panel invitation, Accept/Refuse a meeting invitation, provide requested additional information on the patient)



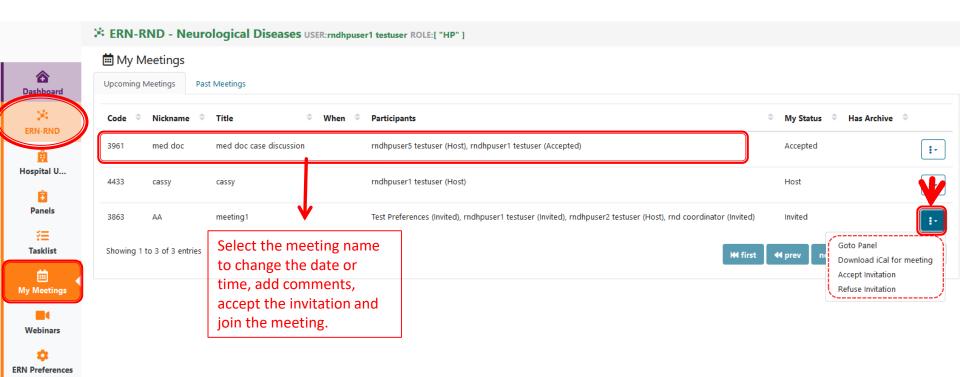


I General 5b. ERN-Board: 'My Meetings' View



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□ See all meetings you were invited to, manage your invitations and go to the panels in order to join the meeting.





I CPMS General

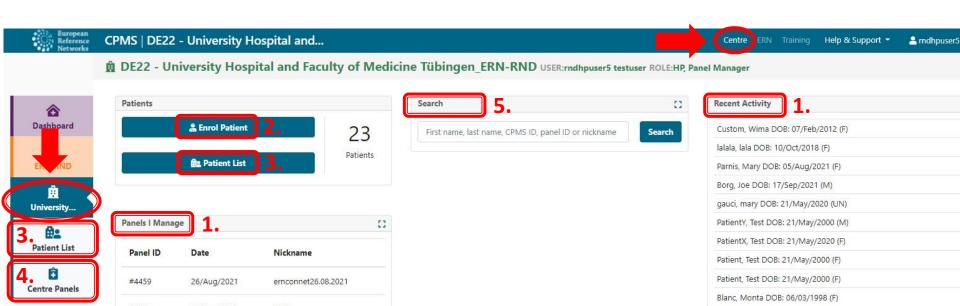
6. Centre-Dashboard



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Here you can:

- 1. see all panels you manage or were recently active in
- 2. enroll a new patient
- 3. See all patients of your institution
- 4. See all panels of your institution
- 5. search patients by their nickname, first or last name, CPMS ID, panel ID
- *Remember: All authorized users from your institution can see all patients enrolled within the centre





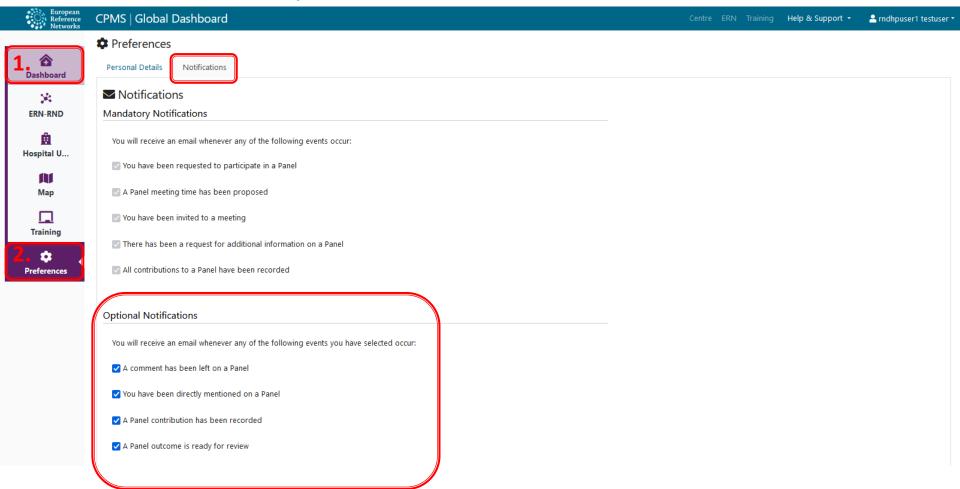
I CPMS General

7a. Setting Notifications Preferences



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When logging in for the first time, it is recommended to set your preferences for notifications, which you will receive via email.

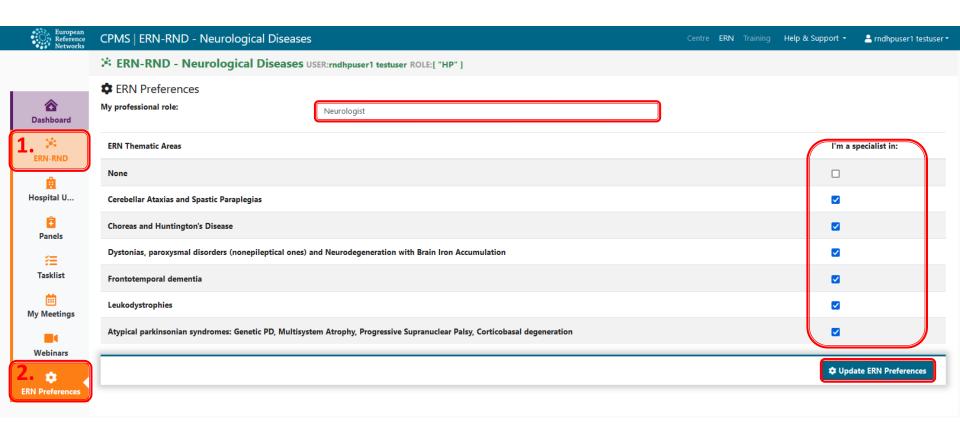




I CPMS General7b. Setting ERN Preferences



- When logging in for the first time, please enter your professional role and specialization.
- Panel leads can view this information and invite you more targeted to panels.

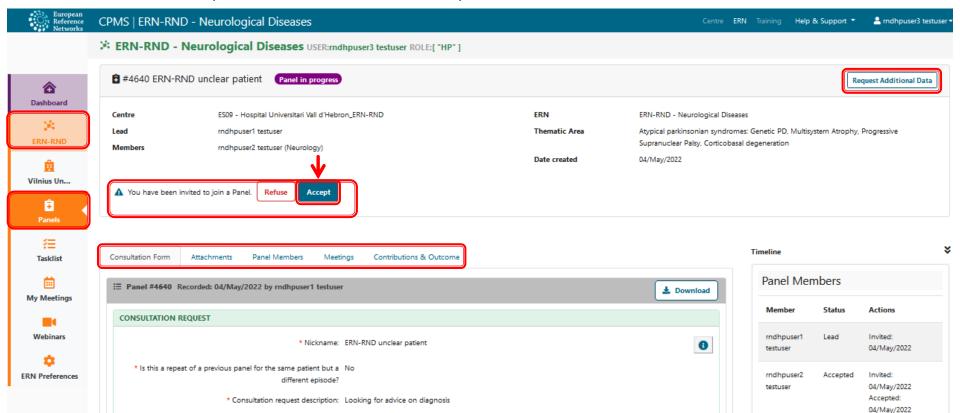




II Panels - Basics 1.'Panel' View



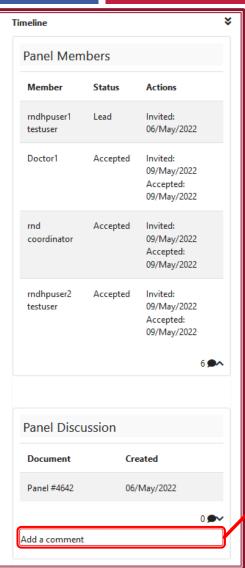
- You can select a panel in 2 ways: 1. from the ERN-Dashboard via "Panels" or 2. from the Centre-Dashboard via "Centre Panels" (only if panel was created by your centre)
- By opening a panel you can view all the panel activities including the consultation request, attachments, other panel members, meetings and contributions & outcome.
- You need to accept or refuse an invitation to a panel.



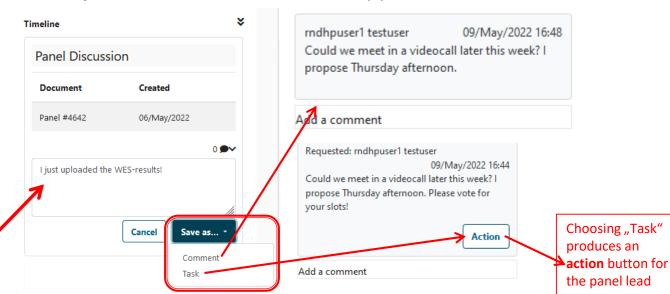


II Panels - Basics 1a. 'Panel' View: Timeline





- **Shows all actions** triggered by a Panel member or Lead in real-time
- Is a **chatting tool** AND allows panel members to make comments on images, contributions and outcome documents
- Can be seen by all panel members
- All requests for additional data appear here

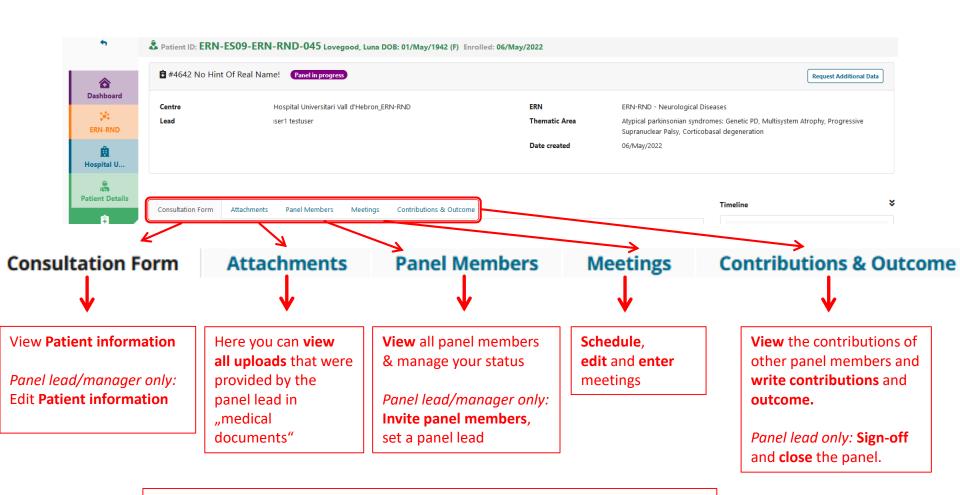




II Panels - Basics 1b. 'Panel' View: Panel Tabs



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You can freely switch between these tabs anytime



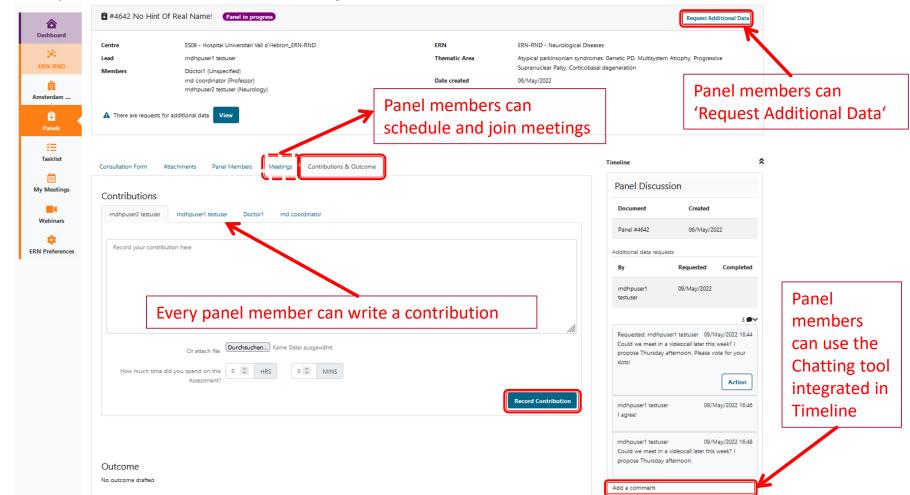
II Panels - Basics

2. Interactions in the panel



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Panel members can see consultation form and attachments, request additional data, provide comments or ask questions in the timeline and write contributions.



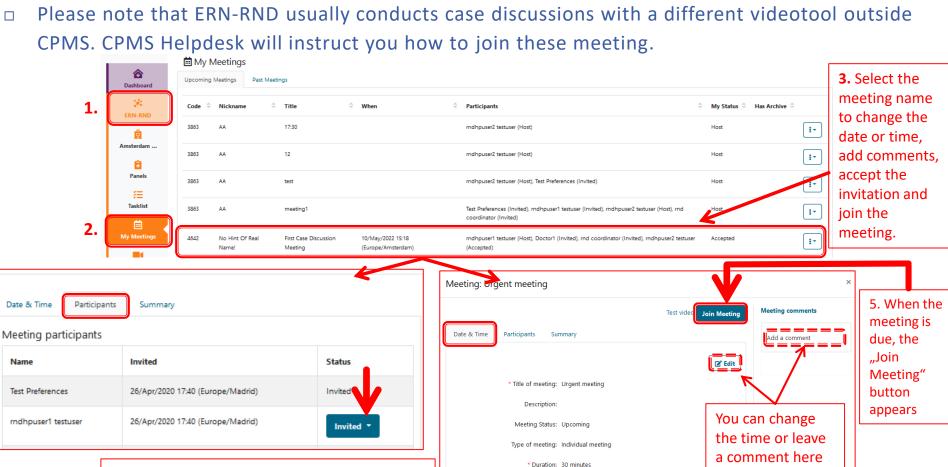


II Panels - Basics 3a. Meetings - how to join

4. Make sure you accepted the meeting invitation!



- Once accepted, the invited meeting member can join the meeting via ERN-Dashboard 'My Meetings' or by selecting the Meetings-tab when viewing the Panels.

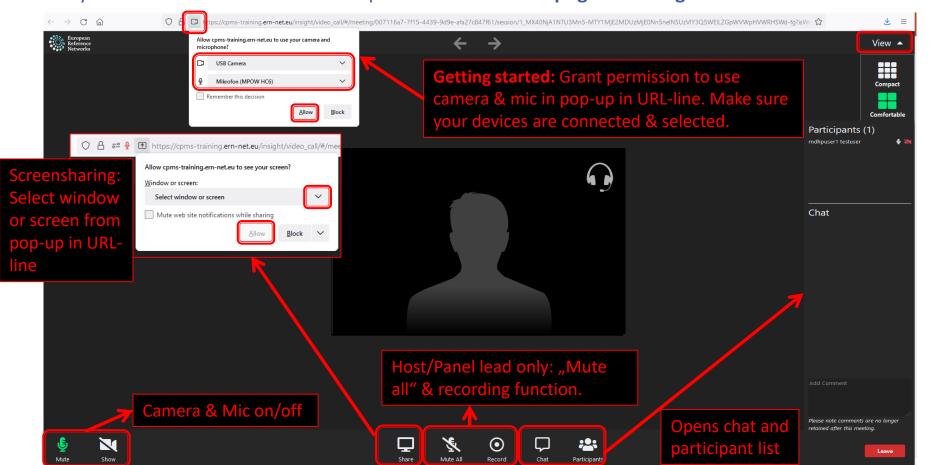




II Panels - Basics 3b. The CPMS videotool



- Attention: The conferencing tool is sometimes blocked by hospital firewalls
- Once you click "join meeting", the video call will open in a new tab in your browser. A pop-up will ask you to select camera and microphone. **Re-load the page to change selected devices**.



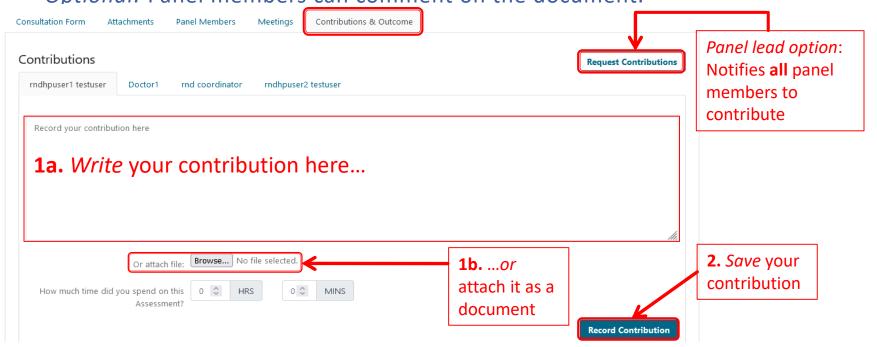


II Panels - Basics

4. Contributions & outcome



- Panel members can write contributions anytime. We recommend especially for those experts who cannot join a meeting to provide their advice here.
- If contributions of panel members are provided in a meeting instead, the panel lead should document these in 'outcome'.
- After consultation, the **outcome** is written by the panel lead only.
 Optional: Panel members can comment on the document.





III Leading a panel

1. How to discuss your case



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Best practices for CPMS virtual discussions







1) Obtain patient consent form for CPMS



2) Enter the patient case in CPMS**



3) Provide the ERN-RND CPMS helpdesk* with the following data:

- Type of expertise you would need e.g. pediatrician, geneticist
- Recommend experts as panel members OR state if the CPMS Helpdesk should choose
- State your focus for the case discussion/outcome? e.g. treatment options
- Propose suitable time slots for a discussion



4) CPMS Helpdesk organizes a virtual discussion



5) Panel lead performs the recommended tests /investigations (if any)

Optional: another case discussion to present the new results (with the same or other panel members)



6) Write an outcome



7) Sign off and close the panel

*Email: cpms-helpdesk_ern-rnd@med.uni-tuebingen.de

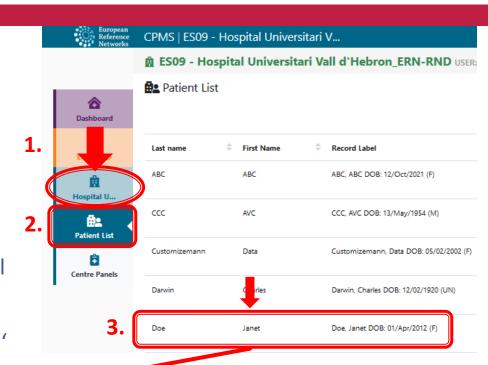
** Make sure to upload MRI data (DICOM) & patient videos!

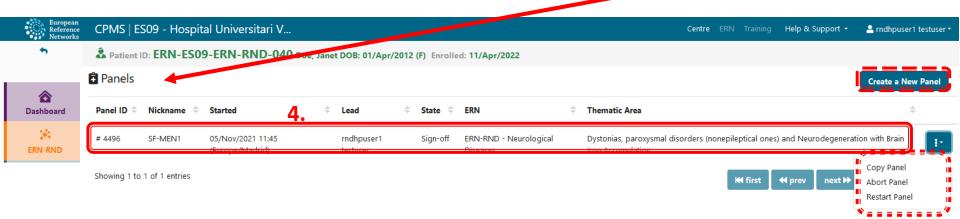


III Leading a panel 2. Patient List



- The patient list allows you to view all enrolled patients of your institution.
 Please do not enroll the same patient twice.
- Click on a patient to view and manage/restart panel(s) for this patient.
 Please do not open more than one panel per patient at a time.
- Click on a panel to enter the ,panel view'





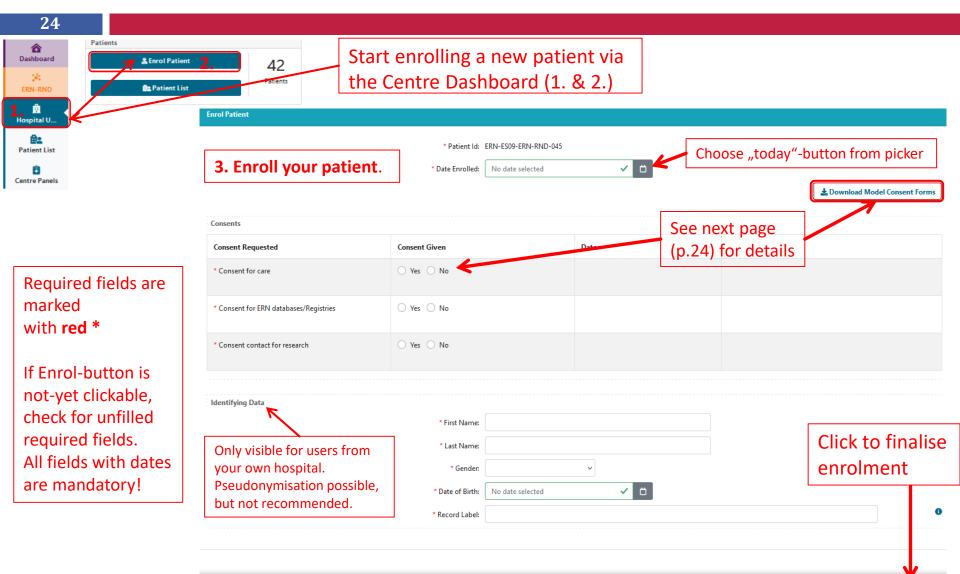


III Leading a panel

* * * * * * * Co-financed by the Connecting Europe Facility of the European Union

Cancel & Enrol Patie

3. Enrol Patient

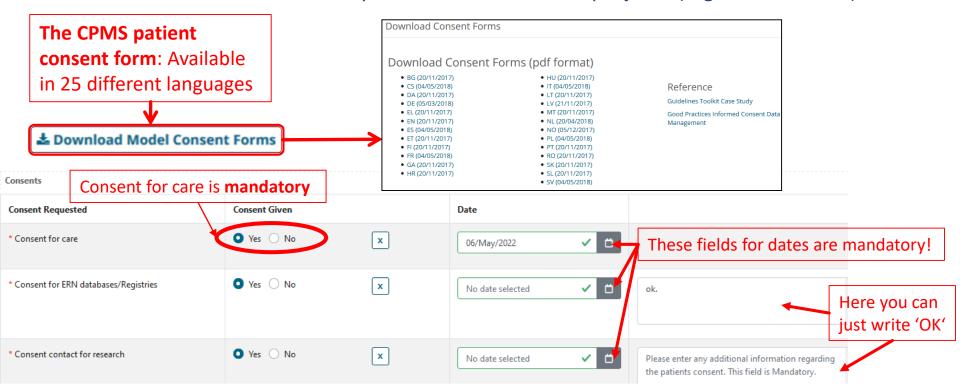




III Leading a panel 3a. Patient consent forms



- * Obtaining consent for care before enrolment is mandatory in order to use CPMS!
- Consent for ERN databases/Registries: Not mandatory. If 'Yes' it authorizes Panel leads to make the clinical data available for ERN researchers after an outcome has been signed-off. Name and Date of Birth will still not be visible for them!
- Consent contact for research: Not mandatory. If 'Yes' it states that patients are interested to be contacted by outside ERN research projects (e.g. clinical trials)

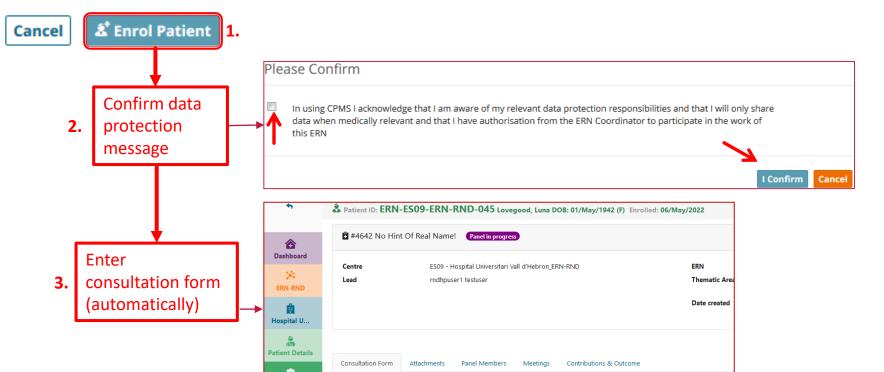




III Leading a panel 4. Consultation form



- The consultation form: heart of the case discussion (consultation process), necessary to reach a consensus for diagnosis and treatment
- Composed of multiple sections; you can decide which of them and how detailed you will fill
- Several coding systems available (e.g. ICD, ICCC-3/10, HPO, ORDO, LOINC etc.), pick one or more of them
- Search widget: type first letter of a phenotype to get suggestions

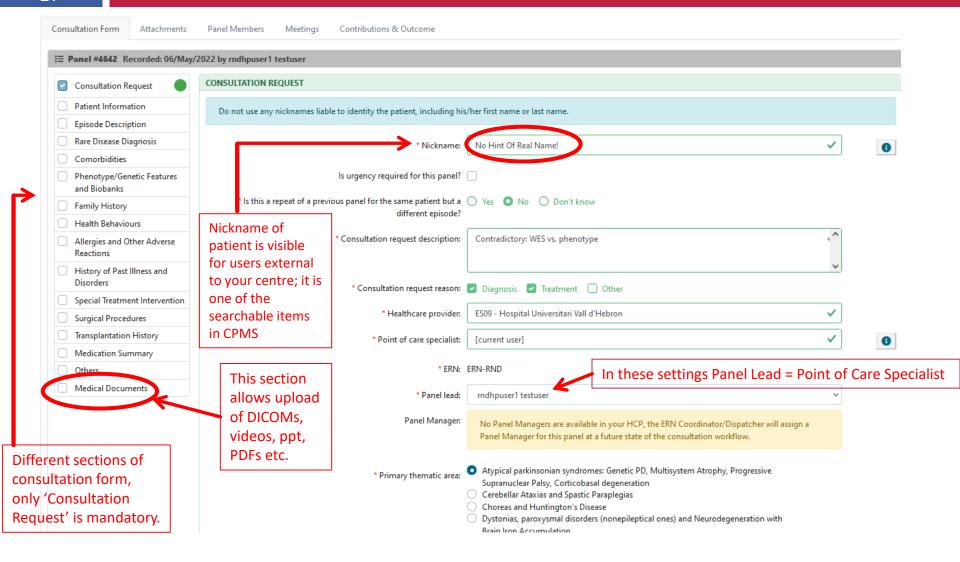




III Leading a panel 4a. Consultation Request



Co-financed by the Connecting Europe Facility of the European Union



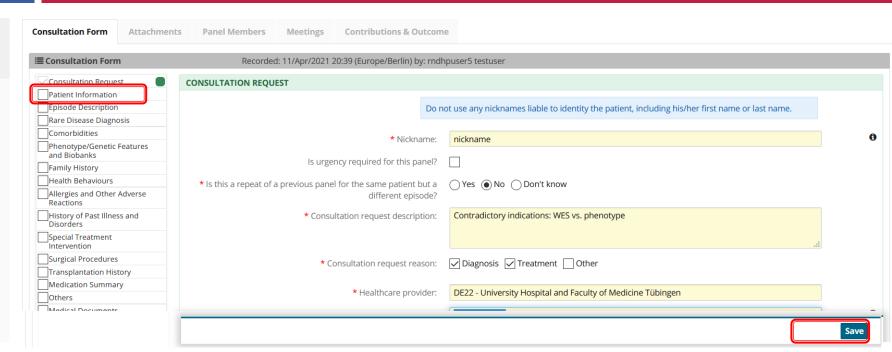


III Leading a panel 4b. Patient Information



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Documents
Transfer Request



1. After filling the minimum mandatory 'Patient Information', click **save.**

2. Now you can **close** the consultation form to access other sections of the panel







III Leading a panel 4c. Optional sections



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- You can decide which sections are most useful to describe the case in your particular situation.
- While not mandatory, maybe for your particular case they are essential.
- You can use them by ticking the box next to the heading.

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

Consultation Request

Anything uploaded here will also appear in the attachment tab



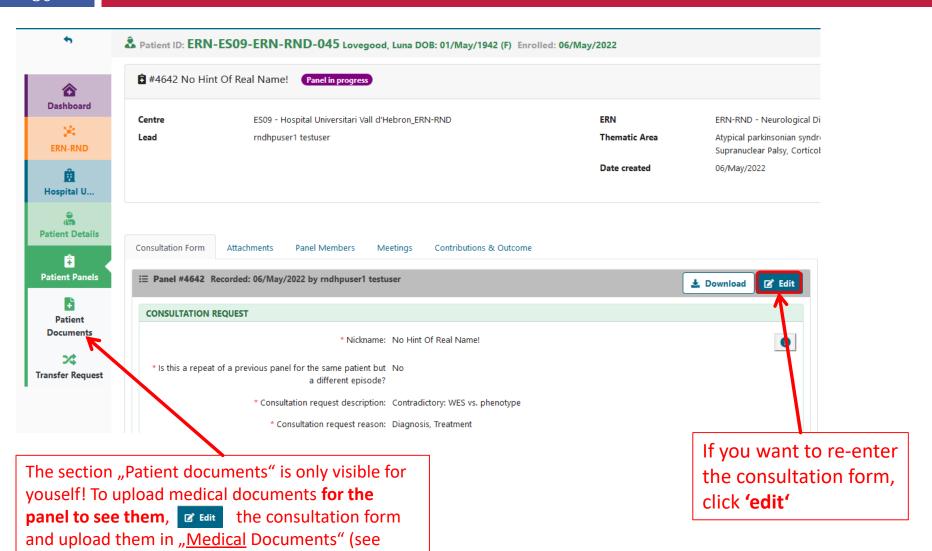


III Leading a panel 4d. Re-enter editing mode



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p.31)



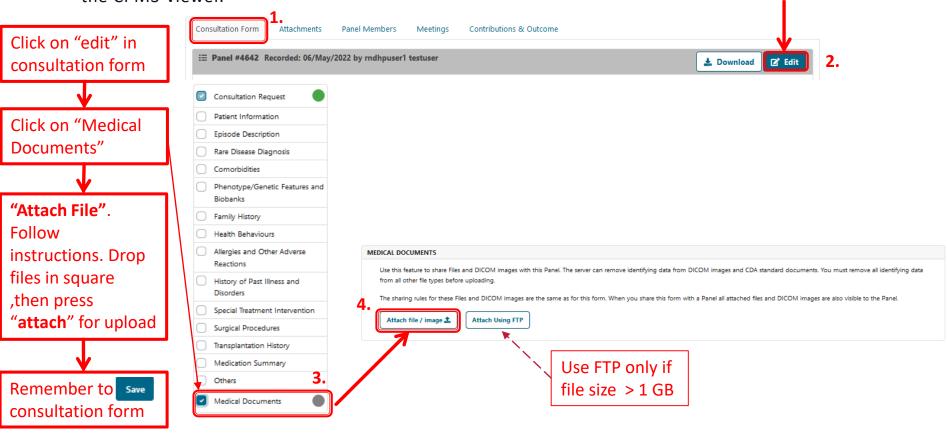


III Leading a panel

6. Attachments



- Upload attachments: make sure to remove personal data in all documents!
 Only DICOM and CDA documents are de-identified automatically.
- Convert PPT(x) files to PDF before uploading them. Only then panel members can open these within the CPMS-viewer.

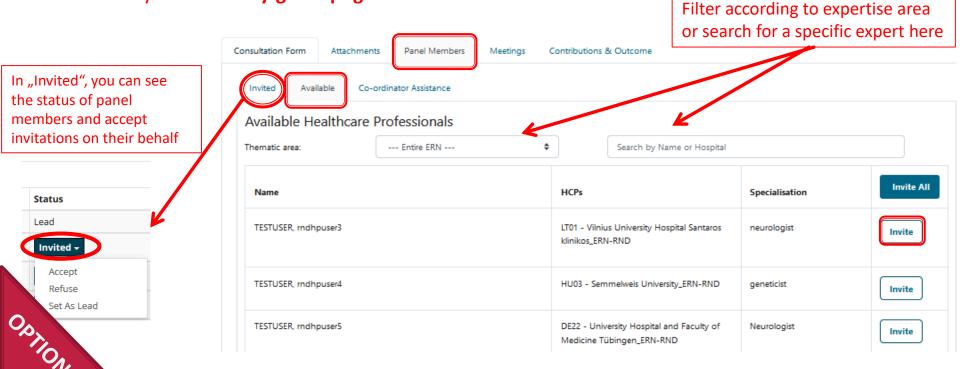




III Leading a panel7. Manage Panel members



- Form the panel by inviting other Health Professionals if you already know the most suitable experts.
- Otherwise, inform the ERN-RND helpdesk via Email & they will compose a panel according to the your needs and schedule a meeting for you. In this case, you can skip this section entirely and directly go to page 38.





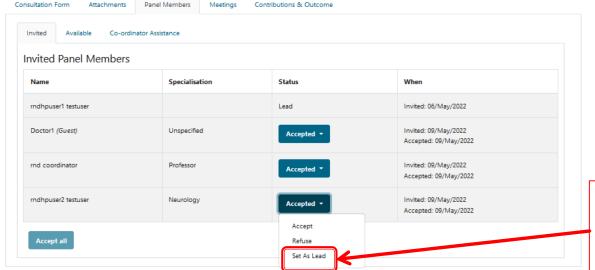
III Leading a panel7a. Changing Panel Lead



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Changing Panel Lead:

- As panel creator, you are by default the panel lead: you can invite experts, edit the panel or set another panel member to be the panel lead.
 - Only the panel lead can sign-off and close the panel!
- While panel managers (dedicated staff from your centre or the ERN) can help you invite experts on your behalf and edit consultation form and outcome, they cannot sign-off and close the panel.
- □ Changing the panel lead (e.g. in order to close the panel):



All ERN-RND members invited to the panel can be set as panel lead



III Leading a panel

8. Meetings

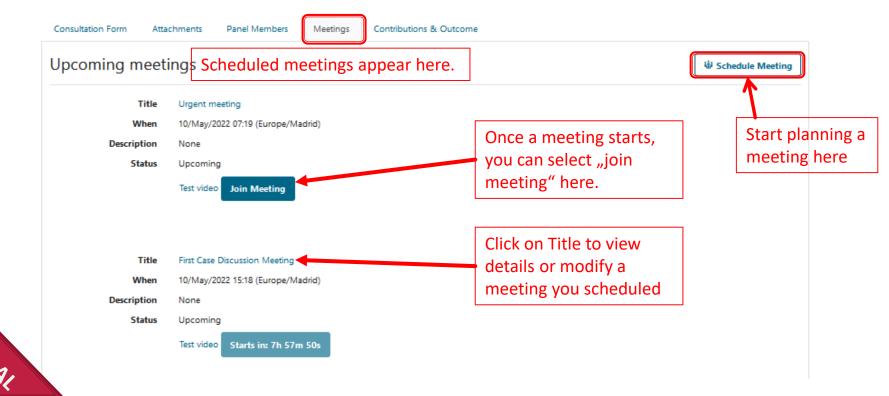


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Recommended: after informing the ERN-RND helpdesk via Email, they will compose a panel and schedule a meeting for you.

In this case, you can **skip this section** of the guide entirely & jump to p.38.

If you entered multiple panels in CPMS, discuss all cases in one meeting

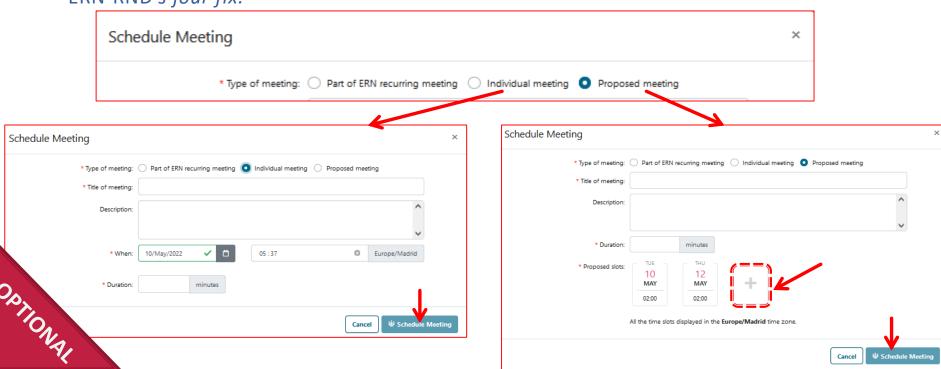




III Leading a panel 8a. Meetings - Setting a date



- Choose Individual meeting from the list if you already want to set a single, fixed date for the meeting
- Choose proposed meeting in order to propose several time slots to the panel members to find a suitable appointment
- Do not choose ERN recurrent meeting: inform ERN-RND helpdesk if you want to present in ERN-RND's jour fix.



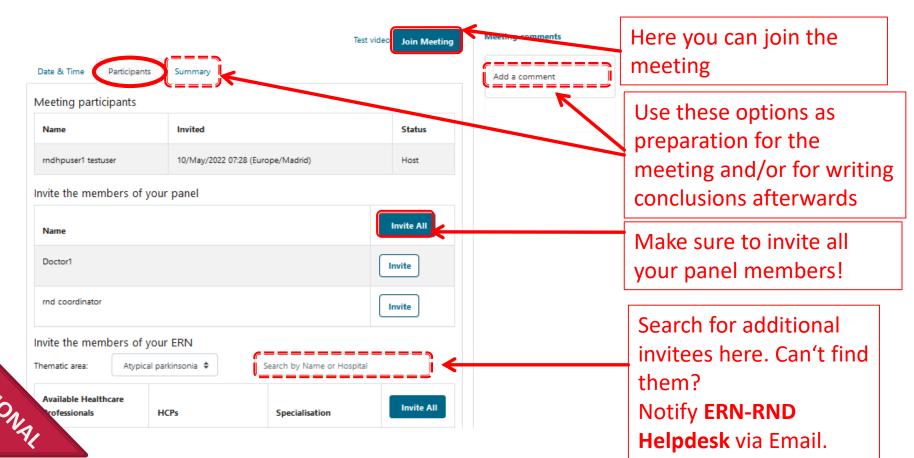


III Leading a panel 8b. Meetings - Invite participants



- Invite participants *via* the tab 'Participants'. You can invite other Health

 Professionals to join the meeting, including those who are not part of the panel.
- Invitees are notified via Email, they must first accept/decline it (s.ERN-Dashboard)





III Leading a panel 8c. In & after the meeting



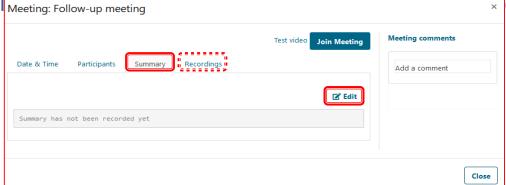
37

- Refer to pages 19 & 20 for how to join a meeting and for functions of the CPMS videotool.
- When leaving the call, CPMS will ask you if you want to save the comments (=chat). If you do not save them on your PC now, they will be lost.



• As panel lead, you should write a **meeting summary** once the meeting is over. Select the respective meeting from the "meeting" tab of the panel.

• If you recorded the meeti_{Meeting: Follow-up meeting} meeting details:

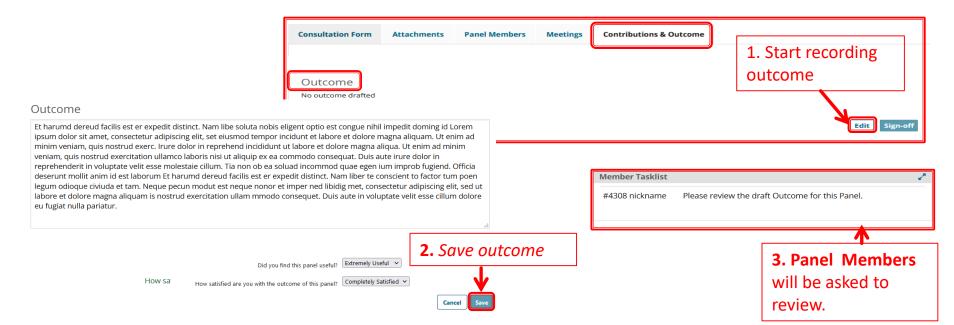




III Leading a panel 9. Contributions & Outcome



- Written contributions of panel members, esp. of those who cannot join the meeting to provide advice, can be viewed in the panel's 'Contribution & Outcome' tab.
- If contributions of panel members are provided in a meeting instead, you as the panel lead should document these in 'outcome'.
- Taking together advice from timeline, contributions and meetings, Panel Lead has to write the outcome in CPMS
- Other panel members can view and comment on the draft. They cannot edit it.

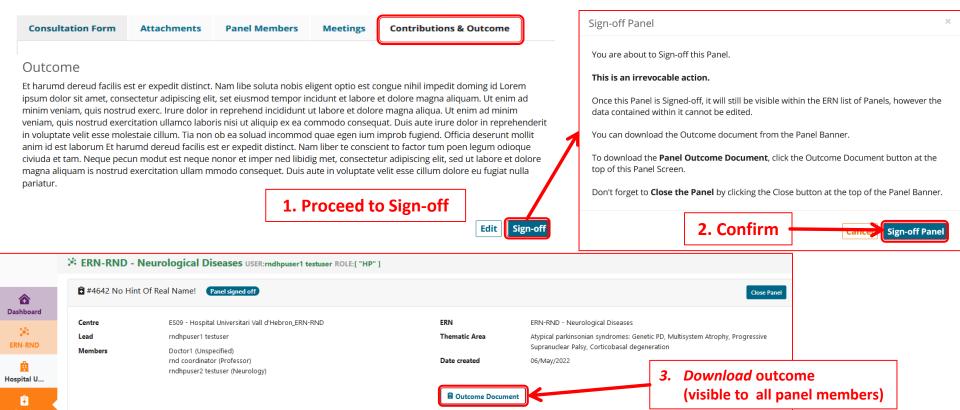




III Leading a panel 10a. Closing a panel: Sign-off



- Panel Lead confirms the outcome, and signs it off
- This means that the outcome can no longer be edited
- Panel members can export the outcome as pdf document for personal record or the Panel Lead can send it to the Point-of-Care specialist or the patient themselves

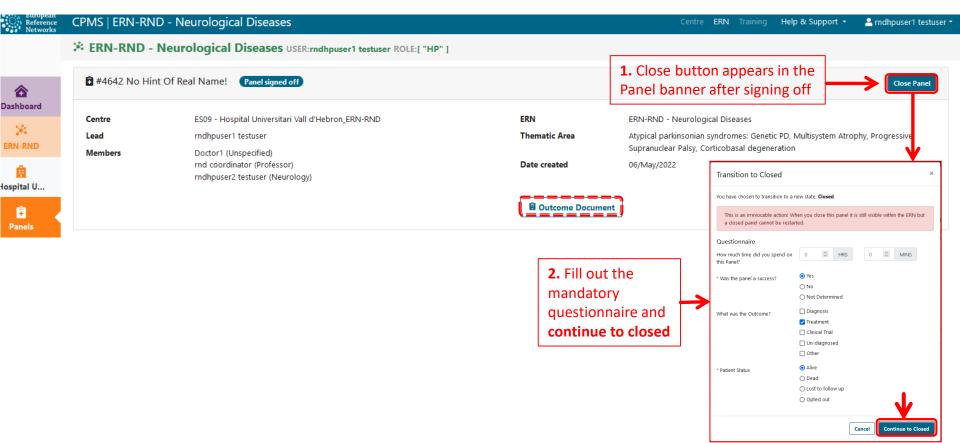




III Leading a panel 10b. Closing the Panel



- After signing off, immediately close the panel (on top of page)
- Closing panels is important for maintainance of the CPMS
- ☐ The outcome document is still available for all panel members afterwards

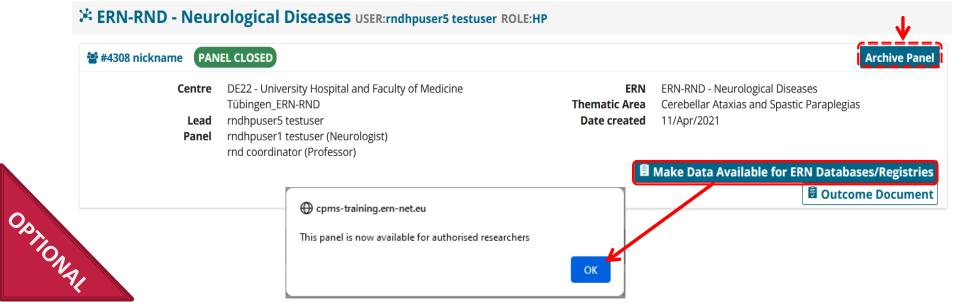




III Leading a panel 10c. Archive Panel



- □ The panel lead has the option to make the panel available for research (only available if patient consent was given and confirmed, see p.11)
- If the panel has been archived, it can **only** be viewed from the 'Centre' application by **members of the centre** where the patient was enrolled and not from the 'ERN' application.
- □ We recommend **not archiving** to allow all ERN users to view a case outcome.





Questions?



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Don't hesitate to contact us:

cpms-helpdesk_ern-rnd@med.uni-tuebingen.de