European Reference Network

for rare or low prevalence
complex diseases

Network
Neurological Diseases
(ERN-RND)

USER GUIDE
CLINICAL PATIENT MANAGEMENT SYSTEM

CPMS User Guide Summary

CPMS is:

☐ a **tool for e-consultations**, connecting experts on rare diseases from all over 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**

☐ Supported by the **ERN-RND helpdesks** to assist users anytime:

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

Additional information:

☐ Before you can enter the CPMS for the first time, you need to register.
Please refer to our **CPMS Registration guide.**

☐ Our **best practise guide** helps you to achieve faster progress for your panel.

☐ A **personal guided tour** through CPMS via videoconference is possible – just drop us an email: *cpms-helpdesk_ern-rnd@med.uni-tuebingen.de*

☐ The **CPMS training platform** is the easiest way to get familiar with CPMS. We can provide you with login details.

I CPMS General

Before starting:

☐ Use as a web-browser Google Chrome.
It is recommended to have a minimum dedicated 350kb/s down per download stream as well as 350kb/s up per uploaded stream to maintain a stable video connection.

☐ 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 '🛈' icon 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 guid on the go.
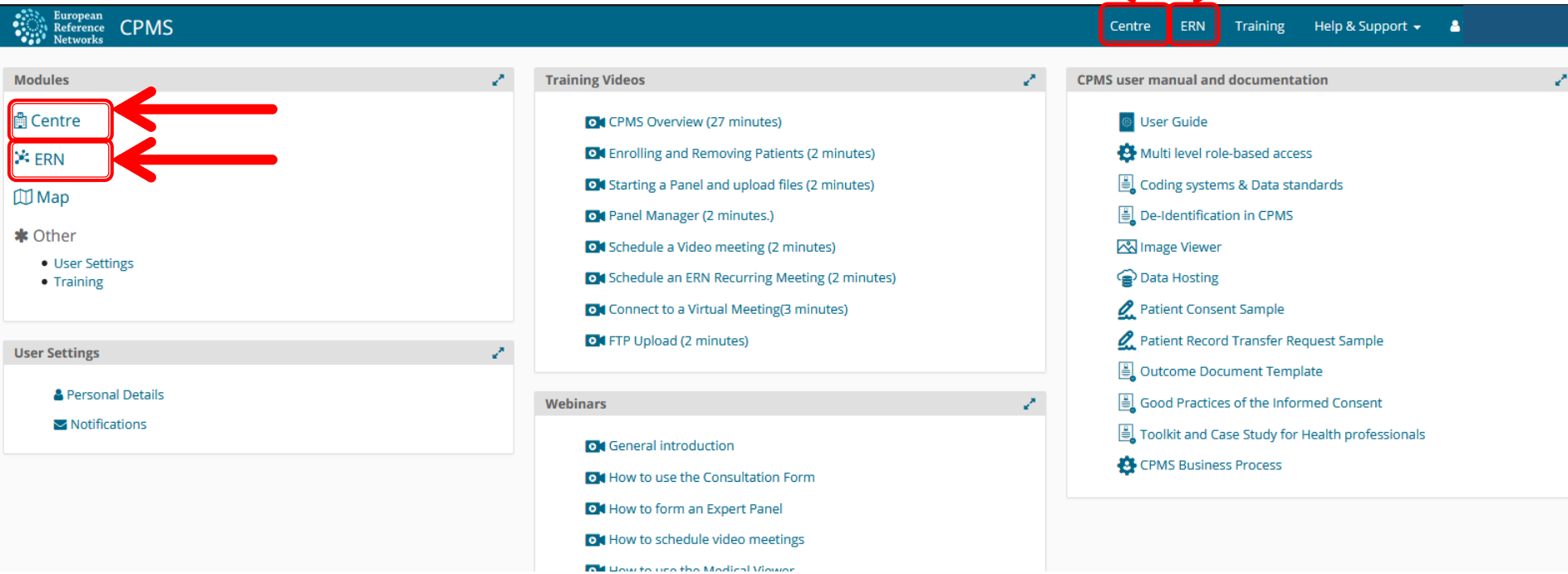
I CPMS General

□ Login into CPMS: https://cpms.ern-net.eu/login/

□ **CPMS Home – *Global Dashboard:***

2 main applications/dashboards: **'Centre'** and **'ERN'**

Enter if you want to enroll a case
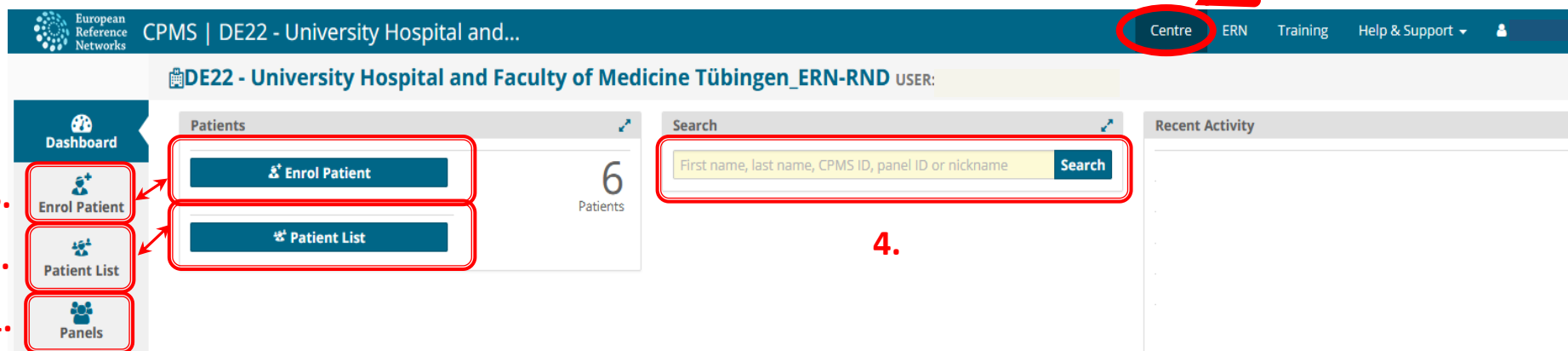
Enter if you were invited to join a panel

I Centre Dashboard

Here you can:

☐ see **all panels** of your **institution**

☐ **enroll** a **new patient**

☐ **view** the **current patients** of the **centre**

☐ **search** patients by their nickname, first or last name, CPMS ID, panel ID

✷Remember: All authorized users from this centre can see all patients enrolled within this centre regardless of enrolling user.

1. Panels

☐ See all panels of your institution

2. Patient list

□ See all enrolled patients of your centre

Access via Dashboard or via 'Patient list'

3. Enroll Patient

Start enrolling a new patient via Dashboard or via 'Patient list'

🏛 **DE22 - University Hospital and Faculty of Medicine Tübingen_ERN-RND** USER:Tamara Martin ROLE:HP

Patients

🗗

👥 **Enrol Patient**

👥 **Patient List**

6 Patients

Search

🗗

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

Enrol Patient

Patient Id: ERN-de22-005

* Date enrolled: dd/Mmm/yyyy   📅   ← Choose „today"-button from the picker

Pre-qualification check

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

See next page (p.11) for details   →   ⬇ **Download Model 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	

Required fields are **red** and marked with *

Identifying data

* First name

* Last name

* Gender:

* Date of birth: dd/Mmm/yyyy   📅

* Record Label

ℹ

Click to finalise enrollment

Cancel   👥 **Enrol Patient**

3a. Patient consent forms

✳ Obtaining **consent for care** before enrollment 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)

The CPMS patient consent form: Available in 25 different languages

Download Consent Forms

Download Consent Forms (pdf format)

- BG (20/11/2017)
- CS (04/05/2018)
- DA (20/11/2017)
- DE (05/03/2018)
- EL (20/11/2017)
- EN (20/11/2017)
- ES (04/05/2018)
- ET (20/11/2017)
- FI (20/11/2017)
- FR (04/05/2018)
- GA (20/11/2017)
- HR (20/11/2017)

- HU (20/11/2017)
- IT (04/05/2018)
- LT (20/11/2017)
- LV (21/11/2017)
- MT (20/11/2017)
- NL (20/04/2017)
- NO (05/12/2017)
- PL (04/05/2018)
- PT (20/11/2017)
- RO (20/11/2017)
- SK (20/11/2017)
- SL (20/11/2017)
- SV (04/05/2018)

Reference

Guidelines Toolkit Case Study

Good Practices Informed Consent Data Management

⬇ Download Model Consent Forms

Consents

Consent for care is **mandatory**

Here you can just write 'OK'

Consent Requested	Consent Given	Date	
Consent for care	◉ Yes ○ No X	23/May/2018 📅	
Consent for ERN databases/Registries	◉ Yes ○ No X	23/May/2018 📅	Please specify
Consent contact for research	◉ Yes ○ No X	23/May/2018 📅	Please specify

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

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
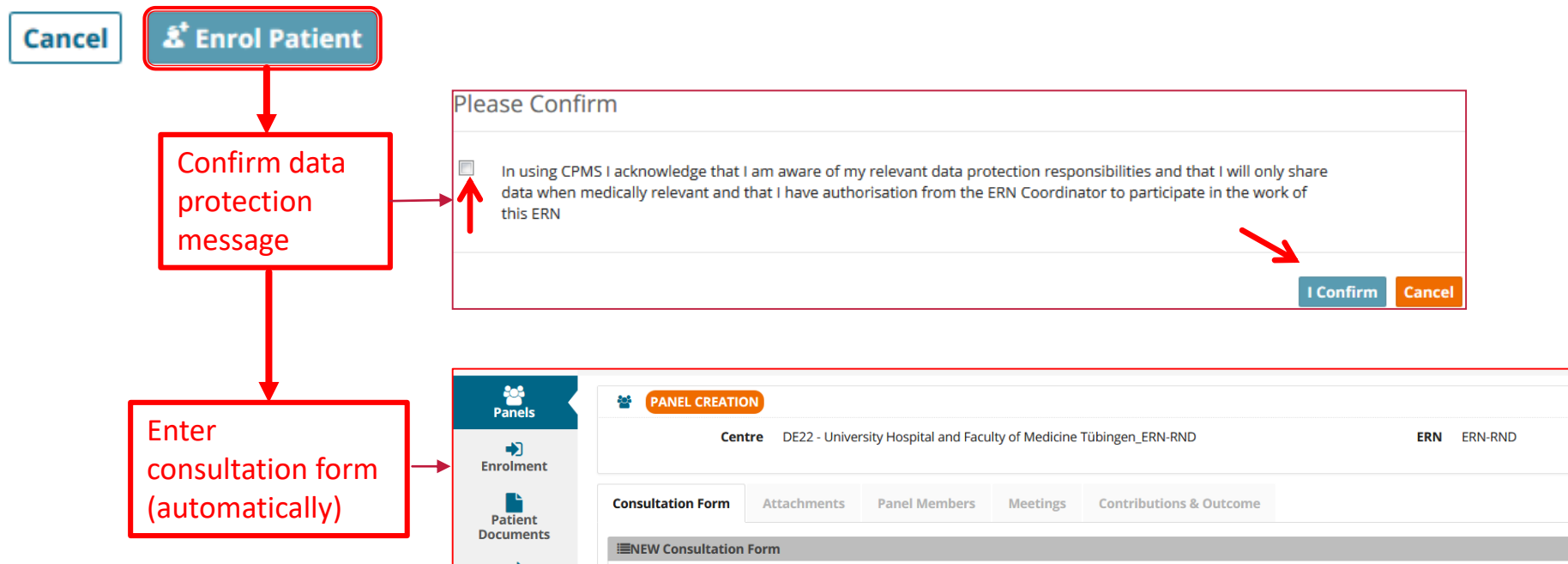
Cancel

Enrol Patient

Confirm data protection message

Enter consultation form (automatically)

Please Confirm

In using CPMS I acknowledge that I am aware of my relevant data protection responsibilities and that I will only share data when medically relevant and that I have authorisation from the ERN Coordinator to participate in the work of this ERN

I Confirm   Cancel

Panels

Enrolment

Patient Documents

PANEL CREATION

Centre   DE22 - University Hospital and Faculty of Medicine Tübingen_ERN-RND   ERN   ERN-RND

Consultation Form   Attachments   Panel Members   Meetings   Contributions & Outcome

NEW Consultation Form

👤 Patient ID: **ERN-DE22-ERN-RND-009** lalala, lala DOB: 10/Oct/2018 (F) Enrolled: 11/Apr/2021

👥 **PANEL CREATION**   **Cancel Panel Creation**

Centre DE22 - University Hospital and Faculty of Medicine Tübingen_ERN-RND   **ERN** ERN-RND

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

≡ **NEW Consultation Form**

- ☑ Consultation Request 🟢
- ☐ 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

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

* Nickname: nickname ⓘ

Is urgency required for this panel? ☐

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

* Consultation request description: Contradictory indications: WES vs. phenotype

* Consultation request reason: ☑ Diagnosis ☑ Treatment ☐ Other

* Healthcare provider: DE22 - University Hospital and Faculty of Medicine Tübingen

* Point of care specialist: [current user] ⓘ

* ERN: ERN-RND

* Panel lead: rndhpuser5 testuser ▾

Save

Red annotations:

Different sections of consultation form, only 'Consultation Request' and 'Patient Information' are mandatory

Nickname of the patient is visible for users external to your centre; it is one of the searchable items in CPMS

In these settings Panel Lead = Point of Care Specialist

Save the consultation form every time you fill a new section.

Consultation form-
4b. Patient Information

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

Consultation form-
4c. Re-enter consultation form

👤 Patient ID: **ERN-DE22-ERN-RND-009** lalala, lala DOB: **10/Oct/2018 (F)** Enrolled: **11/Apr/2021**

👥 **#4308 nickname** **PANEL IN PROGRESS**

Centre	DE22 - University Hospital and Faculty of Medicine Tübingen_ERN-RND	**ERN**	ERN-RND - Neurologica
Lead	rndhpuser5 testuser	**Thematic Area**	Cerebellar Ataxias and :
		Date created	11/Apr/2021

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

☰ **Consultation Form**   Recorded: 11/Apr/2021 20:39 (Europe/Berlin) by: rndhpuser5 testuser
Edited: 11/Apr/2021 20:59 (Europe/Berlin) by: rndhpuser5 testuser   ⬇Download ☑Edit

CONSULTATION REQUEST   ❶

* Nickname:	nickname
* Is this a repeat of a previous panel for the same patient but a different episode?	No
* Consultation request description:	Contradictory indications: WES vs. phenotype
* Consultation request reason:	Diagnosis, Treatment
Healthcare provider:	DE22 - University Hospital and Faculty of Medicine Tübingen

If you want to re-enter the consultation form, click **'edit'**

- 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.

OPTIONAL

Anything uploaded here will also appear in the attachment tab

☑ Consultation Request	🟢
☑ 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	🟠

5. 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

Choosing „Task" produces an **action** button for the panel lead

Patient ID: **ERN-DE22-ERN-RND-007** Doe, Jane DOB: 04/07/2000 (F) Enrolled: **11/Feb/2021**

⚠ #4225 Tarzan **PANEL IN PROGRESS**   🗎 Request Additional Data

Centre	DE22 - University Hospital and Faculty of Medicine Tübingen_ERN-RND	**ERN**	ERN-RND - Neurological Diseases
Lead	rndhpuser5 testuser	**Thematic Area**	Cerebellar Ataxias and Spastic Paraplegias
Manager	rndhpuser5 testuser	**Date created**	11/Feb/2021
Panel	rndhpuser1 testuser (Neurologist)		

Panels

Enrolment

Patient Documents

Transfer

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

⏱ TIMELINE

Panel Members

You can freely switch between these tabs anytime

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

Edit and view **Patient information**

Here you can **upload files** and **view all uploads**; also contains uploads from „medical documents section (consultation form)

Invite and **view** panel members

Schedule, **edit** and **enter** meetings

View the contributions of other panel members and **write contributions** and **outcome**. **Sign-off** and **close** the panel.

7. 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.

- ✳ Attention: once uploaded, files **cannot be removed** again!

Click on attach file/image

Confirm data protection message

Drop files in square ,then press "**attach**" for upload
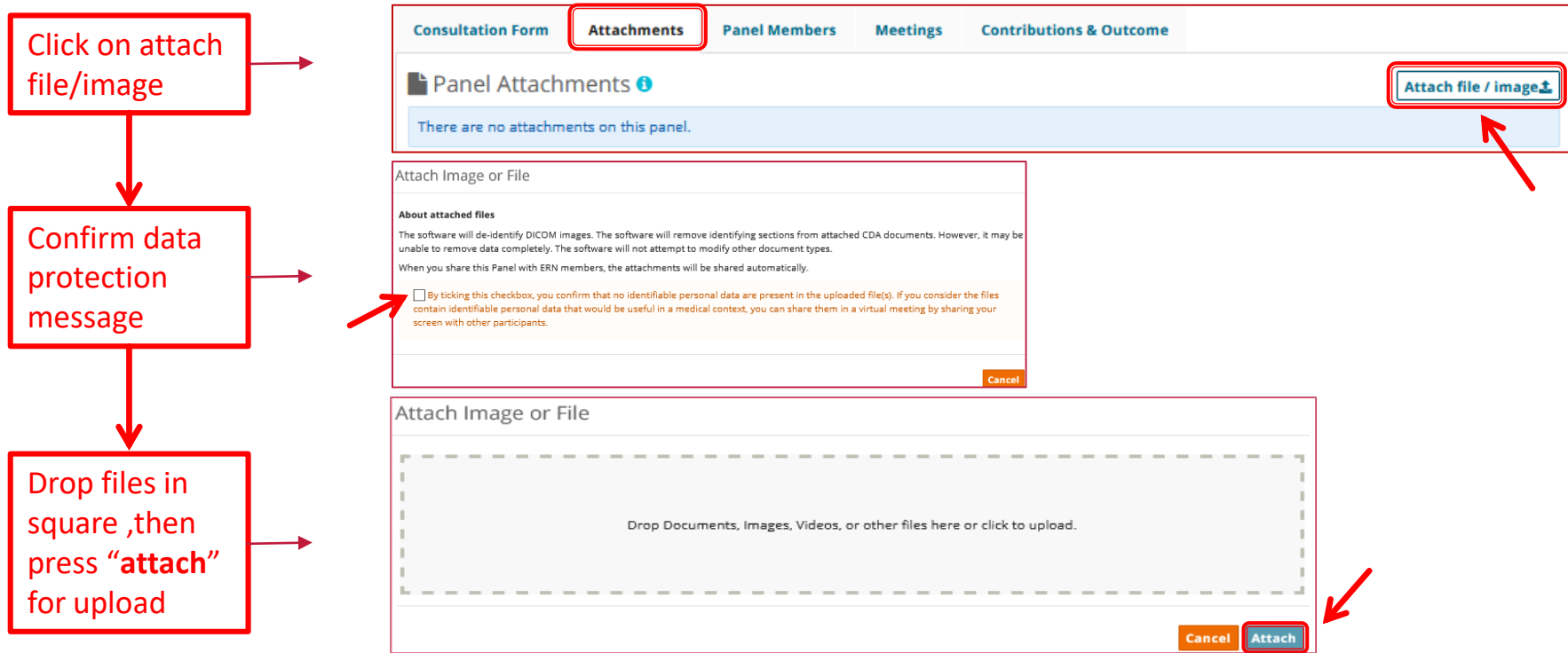
8a. Manage Panel members –
Panel Selection

☐ Form the panel by inviting other Health Professionals to join.

☐ ✳ **Notify ERN-RND helpdesk** via mail about your new panel; they will invite suitable panel members for you!

In this case, you can **skip this section** of the guide entirely.

You can click 'Co-ordinator Assistance' but **always notify CPMS helpdesk via Email** about entering a new case, too.

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

Invited   **Available**   **Co-ordinator Assistance**

Invited Panel Members

Name	Specialisation	Status	When
rndhpuser5 testuser		Lead	Invited: 11/Apr/2021

Here you can see all panel members and their status (lead/invited/accepted/refused)

8b. Manage Panel members – *Panel Selection*

□ You can invite members to your panel from your thematic area, from other thematic areas or from whole ERN.

□ ✱ Remember: they should have chosen the same thematic area as you (s. page ERN - 'Preferences') in order to appear in your list as possible invitees.

Panel Selection

| **Available** | **Invited** | **Co-ordinator Assistance** |

Thematic Area: Cerebellar Ataxias and Spastic Paraplegias ▾

Available Healthcare Professionals	Role	☑ Invite All
rnd coordinator	surgeon	Invite
rnd database	surgeon	Invite
rndhpuser4 testuser	surgeon	Invite

| **Available** | **Invited** | **Co-ordinator Assistance** |

Invited Panel Members

Name	Role	Status
rndhpuser5 testuser		Lead
rnd database	surgeon	Invited ▾
rndhpuser4 testuser	surgeon	
rnd coordinator	surgeon	

Accept
Refuse
Set As Lead

You can accept the panel invitation on behalf of the invited panel members in the tab 'Invited'
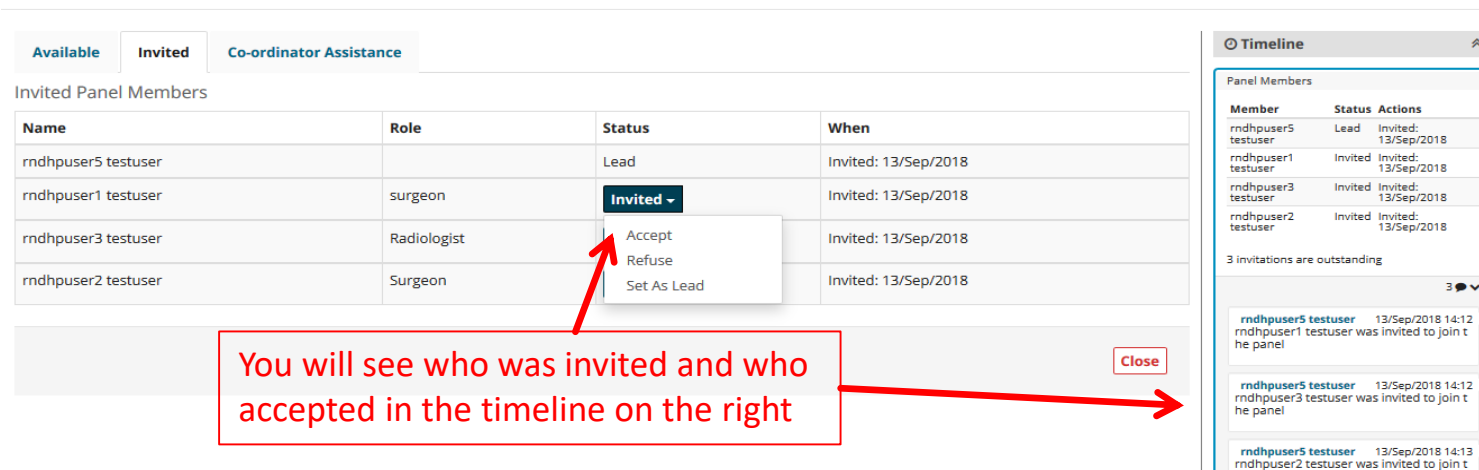
8c. Manage panel members – *Panel Lead*

Options for Panel Lead:

☐ As a panel lead you can accept or refuse the invitation for the others on behalf of your self, or set another panel member to be a panel lead.

☐ Setting panel lead:

- Use case 1: the panel lead is from the originating /enrolling centre of the patient, ALL users from this centre can edit the consultation form and transition the workflow.

- Use case 2: the panel lead is from another centre but within the same ERN, ONLY panel members from the enrolling centre and the panel lead can edit the consultation form, the panel lead can transition the workflow and sign-off the outcome.

You will see who was invited and who accepted in the timeline on the right
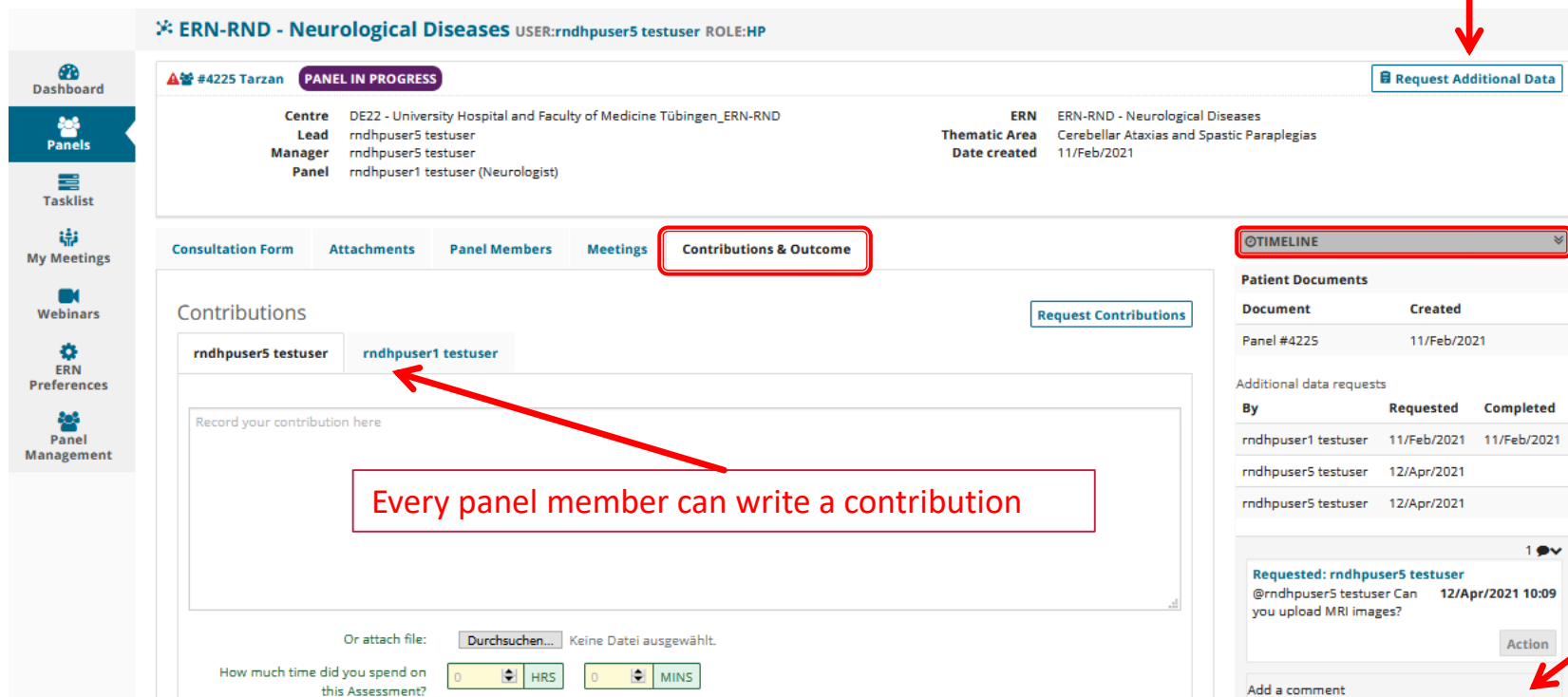
9. Interactions in the panel

Panel members can

☐ **request additional data**

☐ provide **comments** or **ask questions** in the **timeline**

☐ **write contributions**

Panel members can 'Request Additional Data'

Every panel member can write a contribution

Chatting tool integrated in Timeline

10. Meetings

☐ **Highly recommended:** after informing the **ERN-RND helpdesk**, they will compose a panel and schedule a meeting for you.

   In this case, you can **skip this section** of the guide entirely.

☐ Advice: If you entered **multiple panels** in CPMS, discuss all cases **in one meeting**

10a. 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

□ **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)

Use these options as preparation for the meeting and/or for writing conclusions afterwards

Invite all your panel members

Can't find someone?
Try changing 'Thematic area' to **'Entire ERN'**

Still cant find them?
Notify **ERN-RND Helpdesk** via Email.

□ Once accepted, the invited meeting member can join the meeting *via* ERN-Dashboard (s. page 38): 'My Meetings' or by selecting the Meetings-tab when viewing the Panels

Click on the 'Join Meeting' button

10d. Meetings –
In & after the meeting

□ Attention: The conferencing tool is sometimes blocked by hospital firewalls

□ During the meeting you can:

• Hide panel

• Toggle full screen, camera, microphone

• Share screen

• Show chat and users

• Start recording

rndhpuser5 testuser
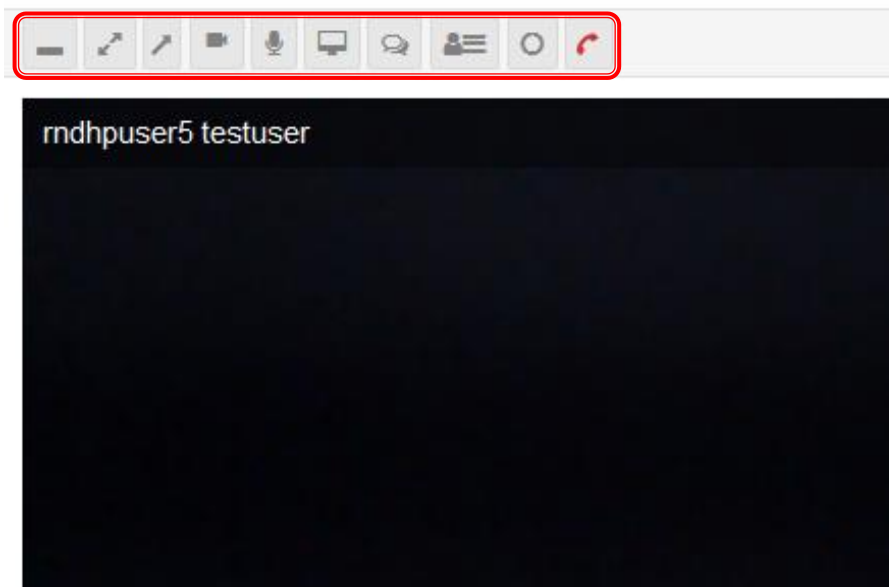
Meeting: Case discussion #1

Date & Time	Participants	Summary		Test video **Join Meeting**

☞ Edit

Summary has not been recorded yet
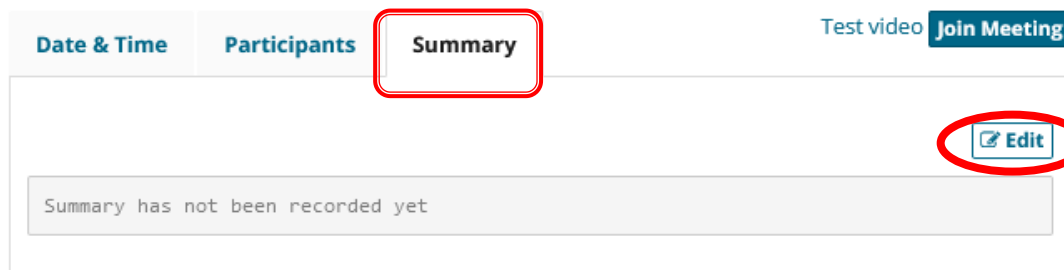
Please write a summary once the meeting is over!

☐ **Panel members** can **write contributions** anytime. We recommend especially for those 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'**.

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

Contributions

Request Contributions

Notifies **all** members to contribute

| rndhpuser5 testuser | rndhpuser1 testuser | rnd coordinator |

Record your contribution here

1a. *Write* your contribution here…

Recorded: 11/Apr/2021

Or attach file: Durchsuchen... Keine Datei ausgewählt

1b. …*or* attach it as a document

How much time did you spend on this Assessment? 0 HRS 0 MINS

2. *Save* your contribution

Record Contribution

☐ **Panel** has to consider and decide an outcome (recommended: in a meeting)

☐ **Only Panel Lead can** (and has to) record the outcome

☐ **Other panel members** can view and comment on the draft. They **cannot** edit it.

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

Outcome
No outcome drafted

1. *Start* recording outcome → Edit Sign-off

Outcome

Et harumd dereud facilis est er expedit distinct. Nam libe soluta nobis eligent optio est congue nihil impedit doming id Lorem ipsum dolor sit amet, consectetur adipiscing elit, set eiusmod tempor incidunt et labore et dolore magna aliquam. Ut enim ad minim veniam, quis nostrud exerc. Irure dolor in reprehend incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse molestaie cillum. Tia non ob ea soluad incommod quae egen ium improb fugiend. Officia deserunt mollit anim id est laborum Et harumd dereud facilis est er expedit distinct. Nam liber te conscient to factor tum poen legum odioque civiuda et tam. Neque pecun modut est neque nonor et imper ned libidig met, consectetur adipiscing elit, sed ut labore et dolore magna aliquam is nostrud exercitation ullam mmodo consequet. Duis aute in voluptate velit esse cillum dolore eu fugiat nulla pariatur.

Member Tasklist

Nickname	Task
#4308 nickname	Please review the draft Outcome for this Panel.

Did you find this panel useful?   Extremely Useful ▾

How satisfied are you with the outcome of this panel?   Completely Satisfied ▾

2. *Save outcome*

Cancel Save

3. Other Members will be asked to review.

12a. Closing a panel-
Sign-off

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

☐ **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

1. Proceed to Sign-off

2. Confirm

3. *Download outcome (visible to all panel members)*
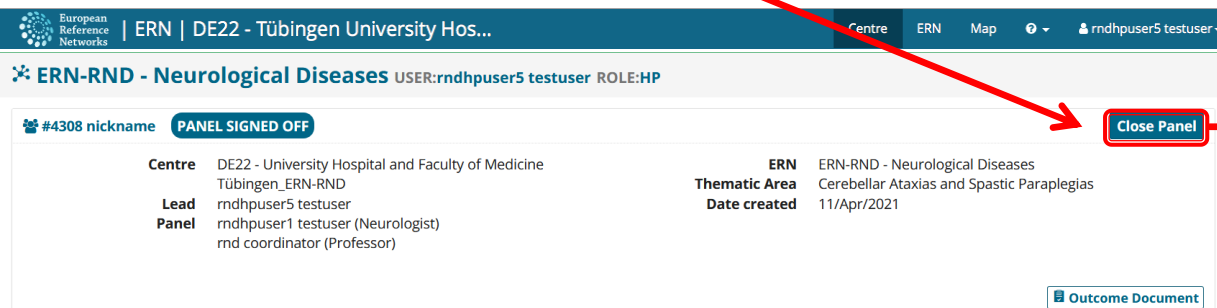
12b. Closing a Panel – *Close panel*

□ After signing off, **immediately close the panel**

□ **Closing panels** is important for maintainance of the CPMS

□ The outcome document is still available for all panel members afterwards

1. Close button appears in the Panel banner after signing off

2. Fill out the mandatory questionnaire and **continue to closed**

12c. Closing a Panel – *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 the case
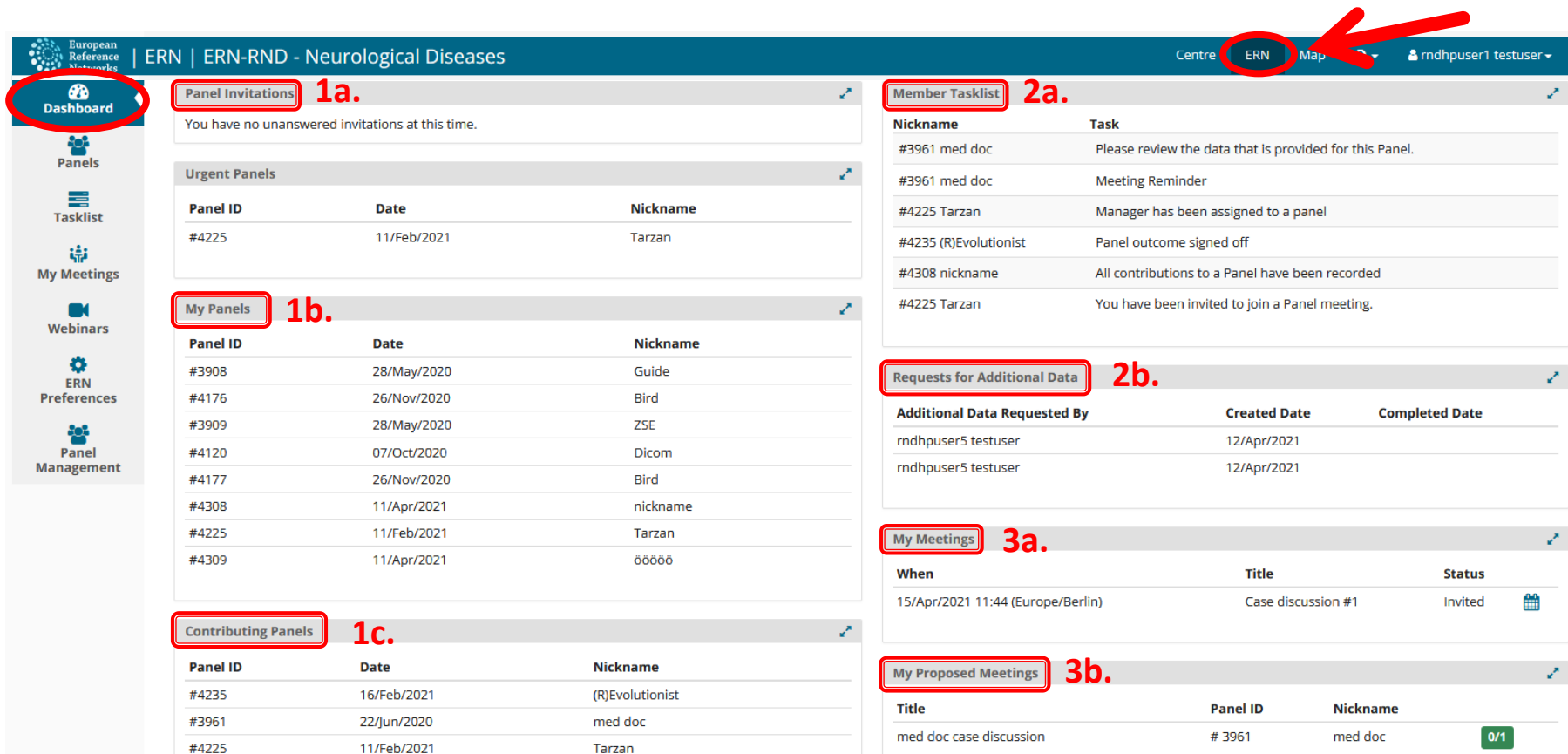
II CPMS ERN Dashboard

- ☐ 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 or leading (2a. and 2b.) and all meetings you are hosting or have been invited to (3a. and 3b.)

☐ Here you can **view all the panel** activities including the **consultation request**, **attachments**, other **panel members**, **meetings** and **contributions & outcome**.

☐ Accept or refuse the **invitation** to a panel here.

CPMS ERN Dashboard – 2.'Task List' View

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

☐ Here you can see all meetings you are hosting or have been invited to

By clicking on the meeting name you can view details, change the date or time, add comments, accept your invitation and invite others.

When the meeting is due, the „Join Meeting" button appears

Select 'Accept' from the list to join

□ Here you can enter your preferences in any of the thematic areas listed

Still having questions about how to use CPMS?

Came across any issues?
Don't hesitate to contact us:

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