



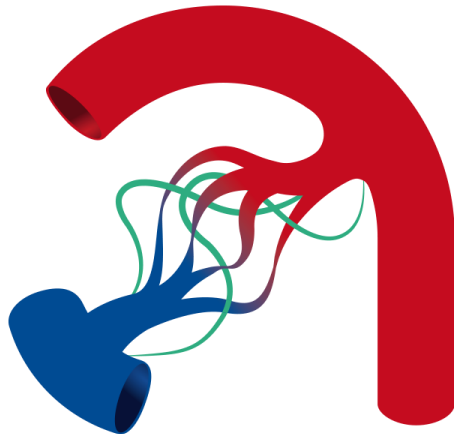
**European  
Reference  
Network**

for rare or low prevalence  
complex diseases



**Network**

Vascular Diseases  
(VASCERN)



# Clinical Patient Management System (CPMS)

- Progress reports from CPMS team on issues faced
- Referral of guests cases to VASCERN: how to handle?

<https://vascern.eu/what-we-do/cpms-discussion-of-complex-clinical-cases/>

# AGEND A

## 1) CPMS Latest Development

- Customized Datasets
- New Data Protection ringfence
- Technical Features

## 1) CPMS Upcoming Development

- Workflow Simplification

☰ **EURACAN CONSULTATION FORM**

- Consultation Request ●
- Patient Information ●
- Rare Disease Diagnosis ●
- Patient Significant Medical History ●
- Patient Comorbidities ●
- Patient Behaviours ●
- Patient Assessment ●\*
- Exams performed ●
- Primary tumour ●
- Tumour Extension ●
- Medical Documents ●

Recorded: 21/Oct/2019 15:33 (Europe/Dublin) by: Hany Mina

**CONSULTATION REQUEST**

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

\* Nickname:

Is urgency required for this panel?  Yes  No

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

\* Consultation request description short:

**PATIENT ASSESSMENT**

**Performance status - OMS/Karnofsky**

Performance Status - OMS/Karnofsky: 90 - Able to carry on normal activities. Minor signs or symptoms of disease

**BMI / BSA parameters**

Weight: 15 kg

Height: 60 cm

BMI (Body Mass Index): 41.7 kg/m<sup>2</sup>

BSA (Body Surface Area): 0.5 m<sup>2</sup>

**Menopause and pregnancy**

Pregnancy: Yes

**EXAMS PERFORMED**

**Imaging findings**

Imaging Findings: CT scan  
PET scan  
X-ray  
MRI  
Scintigraphy

Scintigraphy: 18 FDG-PET  
131IFDG-PET  
68Ga-PET

**Biology Findings - Molecular biology**

Has molecular biology analysis been conducted before the consultation? Yes

**Biopsy**

Has a biopsy been conducted before the consultation? Yes

Biopsy Type: Micro  
Open  
Cytological  
Sentinel Node

# Customized Dataset Guard-Heart

**GUARD-HEART CONSULTATION FORM** Recorded: 21/Oct/2019 15:19 (Europe/Dublin) by: Hany Mina

**CONSULTATION REQUEST**

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

Consultation Request

Patient Information

Episode Description

Rare Disease Diagnosis

Medication and current treatment

Phenotype/Genetic Features and Biobanks

Family History

Health Behaviours

Allergies and Other Adverse Reactions

Comorbidities

Medical History

Other

Medical Documents

\* 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 short:

\* Consultation request reason:  Diagnosis  Treatment  Other

\* Consultation request reason description:

\* Healthcare provider:

\* Point of care specialist:

\* ERN:  ERKNet  ERN-LUNG  ERN-SKIN  Endo-ERN  GUARD-HEART

# New Data Protection Ring-fence

**DE01 - Charité Universitätsmedizin Berlin\_EURACAN** USER: EURACAN FORM

Enrol Patient

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

## ENROL PATIENT

Enrolment

\* Patient Id: ERN-de01-euracan-025

\* Date enrolled: dd/Mmm/yyyy

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

\* 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 short:

\* Consultation request reason:  Diagnosis  Treatment  Other

\* Consultation request reason description:

\* Healthcare provider: DE01 - Charité Universitätsmedizin Berlin\_EURACAN

\* Point of care specialist:

\* ERN:  EURACAN

New Panel

# CPMS Improvements

### Panel Selection

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

Invited Panel Members

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



**Close**   **Accept all**

# CPMS Improvements..

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

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

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


[I would like assistance](#)

[Close](#)

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

Title of meeting\*:

Description:



[Close](#) [Schedule Meeting](#)

[Date & Time](#) [Participants](#) [Summary](#) Test video [Starts in: 1 day\(s\)](#)

Invite the members of your panel

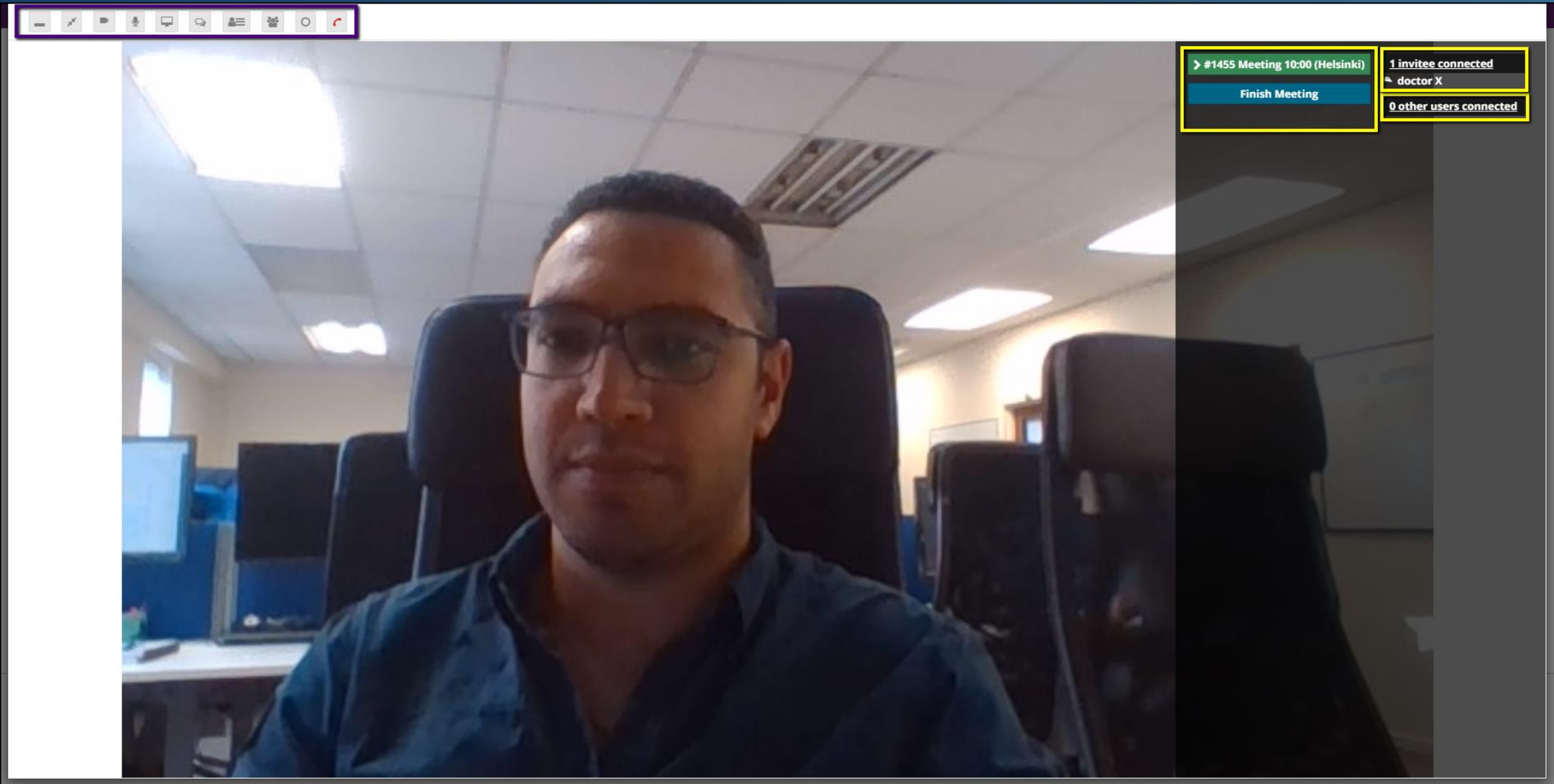
Thematic Area:

There are no more available Healthcare Professionals

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



# CPMS Improvements..



# CPMS Improvements..

Patient ID: ERN-AT01-010 EGF, RFE DOB: 30/12/1980 (M) Enrolled: 26/Aug/2019

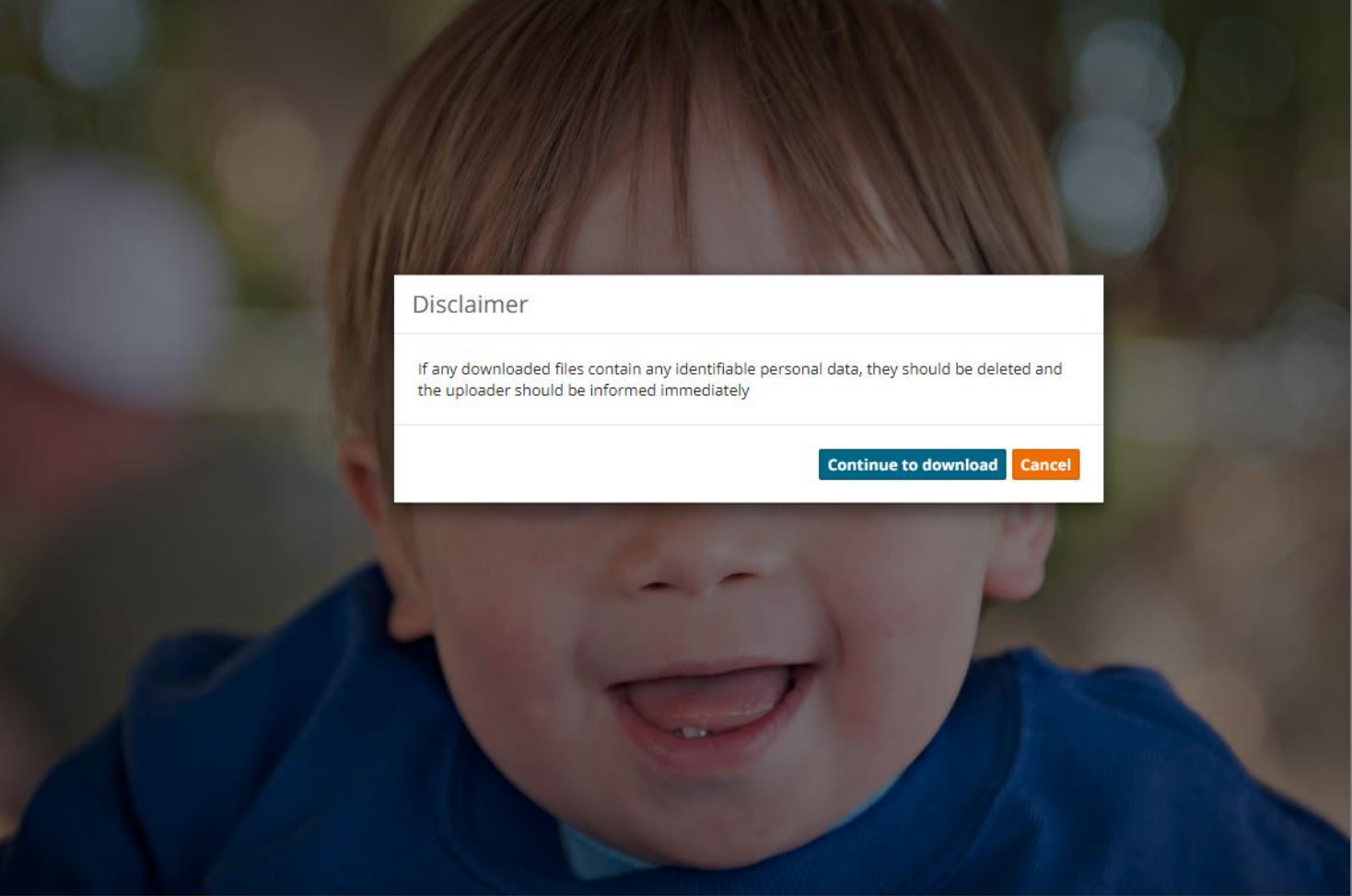
image

This viewer is only for visualisation purposes and is not a diagnostic tool.

Risunok6  
Attachment - Medical Documents

Down-syndrome-1140x757  
Attachment - Medical Documents

Down-syndrome-1140x757 Uploaded by: doctor X Date: 21/Oct/2019 Size: 107.0 kB [Download](#)



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# CPMS Improvements..

- Support Safari Browser to run video meetings
- Export DICOM images in JPEG
- CPMS notification Management
- Downtime banner in CPMS
- Record Guest HCP


# CPMS Roadmap

The image displays a Kanban board with columns representing different stages of a project. The columns are: New Concepts, Requests/Features to EXPLORE, Researching Requirements, Estimating, Sprint Candidate, Sprint - Tasks in Dev., Delivered to UAT, and Delivered to CPMS Live. Each column contains several task cards with titles, dates, and status indicators. Overlaid on the board are several text labels: 'HCP Admin Role' (yellow), 'Workflow Changes' (white), 'Next Gen. Path Viewer' (green), 'Vascern Dataset' (green), 'Data Role Manager' (white), 'Family Enrollment' (white), 'Video Meetings outside Panels' (purple), and 'Dial In Functionality' (white).

# Workflow Changes


ERN AT01 - EB-HAUS AUSTRIA
CENTRES   ERN   MAP   DOCTORT WO ▾

←
PATIENT ID: ERN-AT01-005   DOB: 05/04/2017 (UNDETERMINED)   ENROLLED: 04/APR/2017



PANELS


---




ENROLMENT



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ACCOUNT DETAILS

 Panels

1  Open New Panel
Copy Panel
Cancel or Restart Panel

State: All ▾

Panel ID	Nickname	Started	Lead	ERN	Thematic Area	Stage
<input type="radio"/> #1314	Eric	22/07/2019	Doctor One	ERN-SKIN - Skin Disorders	Epidermolysis Bullosa	Data Completion
<input type="radio"/> #1327	nickname	09/08/2019	Doctor One	ERN-SKIN - Skin Disorders	ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos	Panel Selection
<input type="radio"/>  #1331	zsdfdsd	15/08/2019	Doctor One	ERN-SKIN - Skin Disorders	ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos	Sign-off
<input type="radio"/> #1334	dggdsdsgfs	15/08/2019	Doctor One	ERN-SKIN - Skin Disorders	ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos	Panel Selection
<input type="radio"/>  #1340	KJLHK	15/08/2019	Doctor One	ERN-SKIN - Skin Disorders	ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos	Open

# Workflow Changes..

ERN AT01 - EB-HAUS AUSTRIA CENTRES ERN MAP DOCTOR TWO

PATIENT ID: ERN-AT01-005 DOB: 05/04/2017 (UNDETERMINED) ENROLLED: 04/APR/2017

#501 PANEL

PANELS OPEN PANEL SELECTION ASSESSMENT OUTCOME SIGN-OFF

2 CONSULTATION REQUEST CANCEL CREATE PANEL

ENROLMENT ACCOUNT DETAILS

2. The correct ERN form is loaded completely from the start.

CONSULTATION FORM Recorded: 22/Jul/2019 16:16 (Europe/Berlin) by: Doctor One Edited: 22/Jul/2019 17:16 (Europe/Berlin) by: Doctor One

- 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 identify the patient, including his/her first name or last name.

\* Nickname: Eric

Is urgency required for this panel?

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

\* Consultation request description short: AFWFHW

\* Consultation request reason: Treatment

\* Consultation request reason description: DFJ

\* Healthcare provider: AT01 - EB-Haus

\* Point of care specialist: poc

\* ERN:  ERN-SKIN

\* Panel lead: Doctor One

Panel Manager:

\* Primary thematic area:  ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO, Bechet, Degos  Autoimmune bullous diseases and severe cutaneous drug reactions

# Workflow Changes..

ERN AT01 - EB-HAUS AUSTRIA    CENTRES    ERN    MAP    DOCTOR TWO ▾

←    PATIENT ID: ERN-AT01-005    DOB: 05/04/2017 (UNDETERMINED)    ENROLLED: 04/APR/2017

#501 PANEL

OPEN > PANEL SELECTION > ASSESSMENT > OUTCOME > SIGN-OFF

CONSULTATION REQUEST

PANEL MEMBERS

Available    Invited    Invite Guest Members    Forward Panel

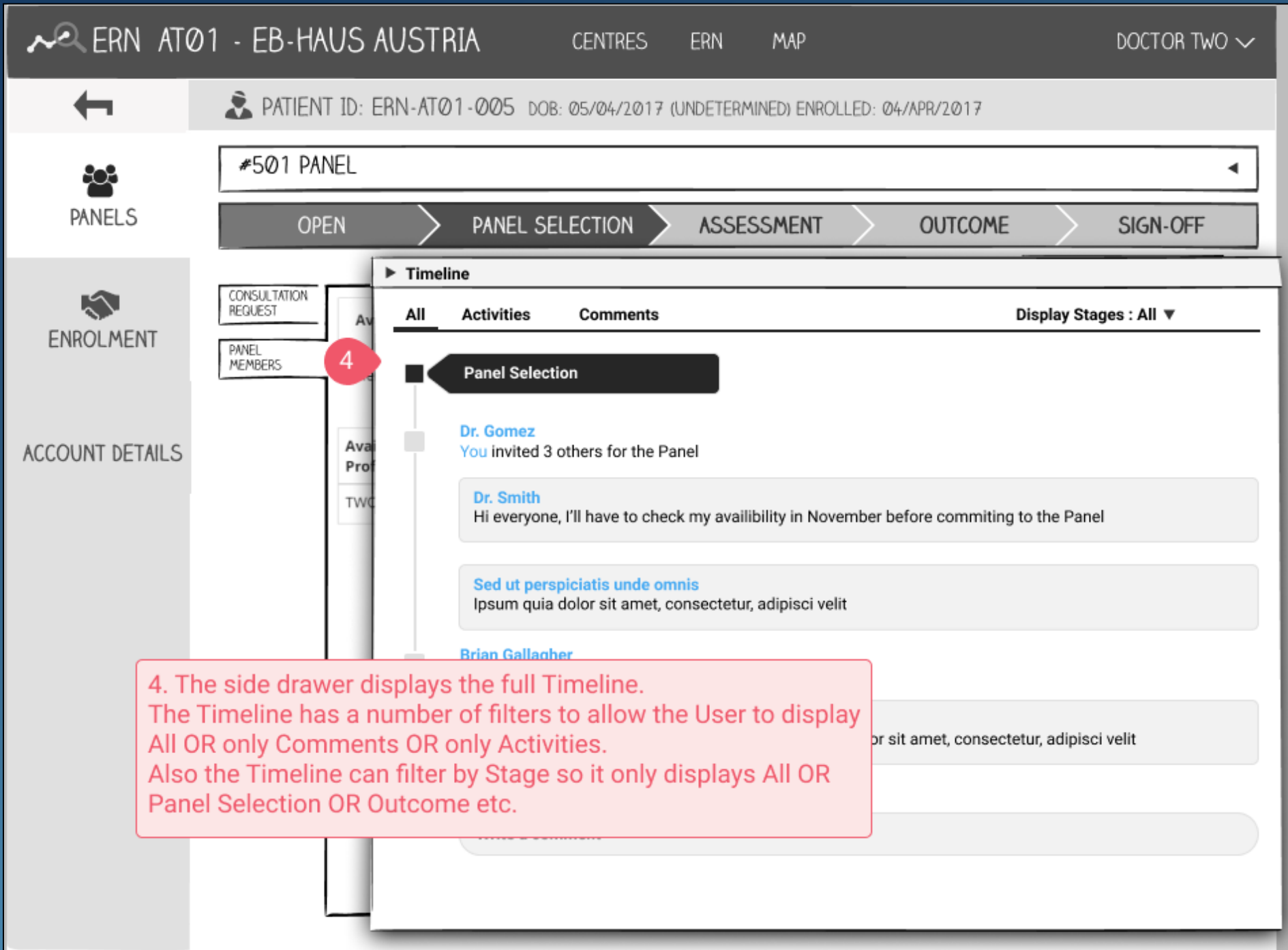
Thematic Area:    Cystic Fibrosis ▾

Available Healthcare Professionals	HCPs	Specialisation	Invite All
TWO, Bermingham		wfafwawf	Invite

3

3. Supplementary functionality is provided by by a slide in drawer

# Workflow Changes..



ERN AT01 - EB-HAUS AUSTRIA CENTRES ERN MAP DOCTOR TWO

PATIENT ID: ERN-AT01-005 DOB: 05/04/2017 (UNDETERMINED) ENROLLED: 04/APR/2017

#501 PANEL

OPEN PANEL SELECTION ASSESSMENT OUTCOME SIGN-OFF

PANELS

ENROLMENT

ACCOUNT DETAILS

CONSULTATION REQUEST

PANEL MEMBERS

Timeline

All Activities Comments Display Stages : All

Panel Selection

Dr. Gomez  
You invited 3 others for the Panel

Dr. Smith  
Hi everyone, I'll have to check my availability in November before committing to the Panel

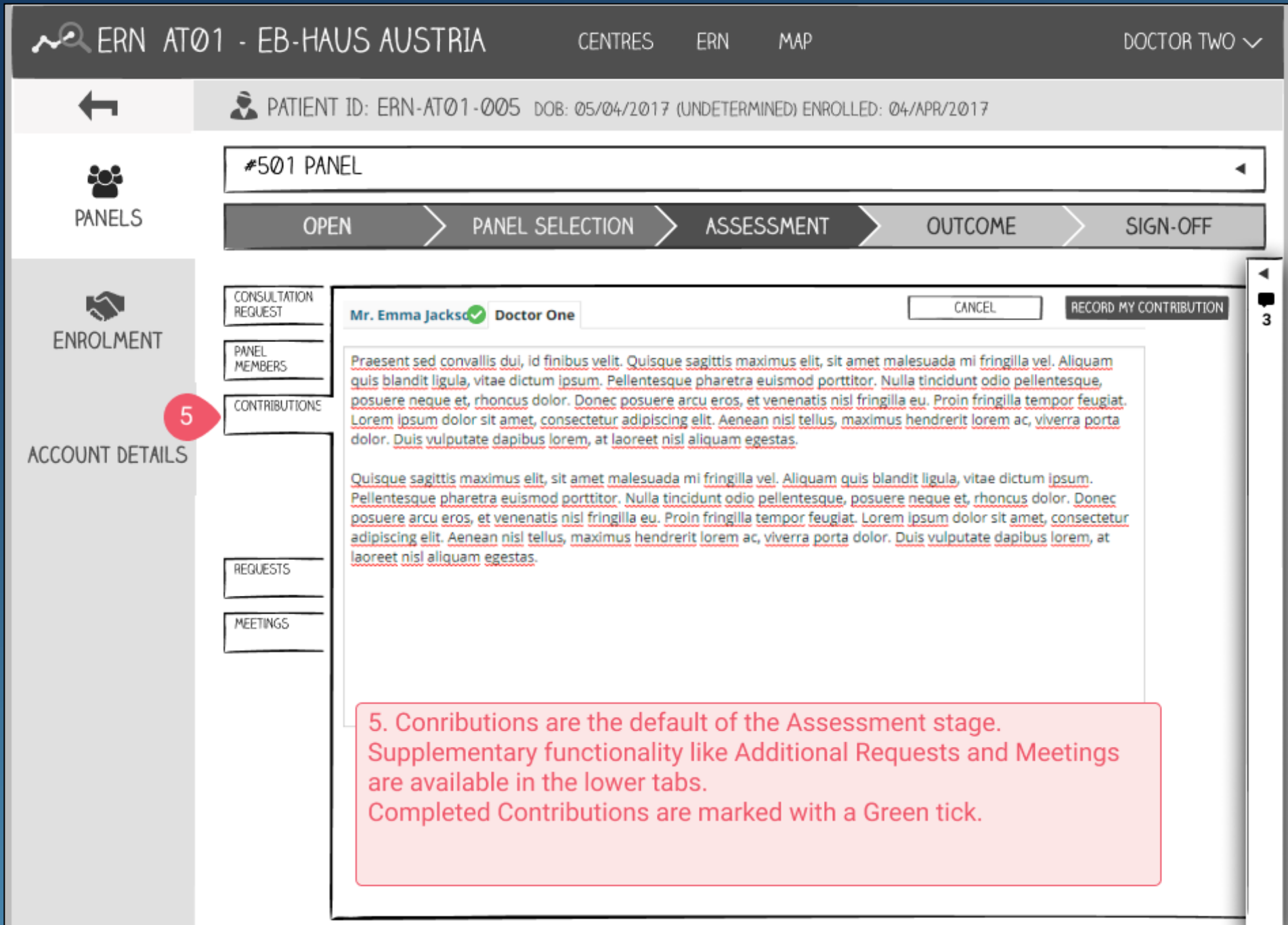
Sed ut perspiciatis unde omnis  
Ipsum quia dolor sit amet, consectetur, adipisci velit

Brian Gallagher

4. The side drawer displays the full Timeline.  
The Timeline has a number of filters to allow the User to display All OR only Comments OR only Activities.  
Also the Timeline can filter by Stage so it only displays All OR Panel Selection OR Outcome etc.



# Workflow Changes..




ERN AT01 - EB-HAUS AUSTRIA CENTRES ERN MAP DOCTOR TWO

PATIENT ID: ERN-AT01-005 DOB: 05/04/2017 (UNDETERMINED) ENROLLED: 04/APR/2017

#501 PANEL

OPEN > PANEL SELECTION > ASSESSMENT > OUTCOME > SIGN-OFF

Mr. Emma Jacksc  Doctor One [CANCEL] [RECORD MY CONTRIBUTION]

CONTRIBUTIONS

Præsent sed convallis dui, id finibus velit. Quisque sagittis maximus elit, sit amet malesuada mi fringilla vel. Aliquam quis blandit ligula, vitae dictum ipsum. Pellentesque pharetra euismod porttitor. Nulla tincidunt odio pellentesque, posuere neque et, rhoncus dolor. Donec posuere arcu eros, et venenatis nisl fringilla eu. Proin fringilla tempor feugiat. Lorem ipsum dolor sit amet, consectetur adipiscing elit. Aenean nisl tellus, maximus hendrerit lorem ac, viverra porta dolor. Duis vulputate dapibus lorem, at laoreet nisl aliquam egestas.

Quisque sagittis maximus elit, sit amet malesuada mi fringilla vel. Aliquam quis blandit ligula, vitae dictum ipsum. Pellentesque pharetra euismod porttitor. Nulla tincidunt odio pellentesque, posuere neque et, rhoncus dolor. Donec posuere arcu eros, et venenatis nisl fringilla eu. Proin fringilla tempor feugiat. Lorem ipsum dolor sit amet, consectetur adipiscing elit. Aenean nisl tellus, maximus hendrerit lorem ac, viverra porta dolor. Duis vulputate dapibus lorem, at laoreet nisl aliquam egestas.

5. Contributions are the default of the Assessment stage. Supplementary functionality like Additional Requests and Meetings are available in the lower tabs. Completed Contributions are marked with a Green tick.

# Workflow Changes..

The screenshot displays the OpenApp interface for a patient named ERN AT01 - EB-HAUS AUSTRIA. The patient ID is ERN-AT01-005, DOB is 05/04/2017, and they were enrolled on 04/APR/2017. The current panel is #501. The workflow progress bar shows: OPEN > PANEL SELECTION > ASSESSMENT > OUTCOME > SIGN-OFF. The 'OUTCOME' tab is selected in the left-hand menu, which also includes CONSULTATION REQUEST, PANEL MEMBERS, CONTRIBUTIONS, REQUESTS, MEETINGS, ENROLMENT, and ACCOUNT DETAILS. A red circle with the number '6' highlights the 'OUTCOME' tab. The main content area is titled 'Write the Panel Outcome:' and contains a text editor with placeholder text. Below the text editor are three dropdown menus for 'Are you the point of care specialist, the panel lead or a panel participant?' (set to 'Panel Lead'), 'Did you find this virtual panel useful?' (set to '2'), and 'How satisfied are you with the outcome of this panel?' (set to '6'). On the right side, there are three sections for 'Panel Lead', 'Panel Member 2', and 'Panel Member 3', each with a green checkmark and a left arrow. A red circle with the number '3' is next to the 'Panel Member 3' section. At the bottom right, there are 'CANCEL' and 'SAVE PANEL OUTCOME' buttons.

6. Outcome is the default tab of the Outcomes stage. As before the previous material is accessible. The User can selectively paste in the Contributions from the different Panel members to allow them to write up the final Outcome.

# Workflow Changes..

The screenshot displays the OpenApp interface for a patient named ERN AT01 - EB-HAUS AUSTRIA. The patient ID is ERN-AT01-005, DOB is 05/04/2017, and they were enrolled on 04/APR/2017. The current panel is #501. The workflow progress bar shows the following stages: OPEN, PANEL SELECTION, ASSESSMENT, OUTCOME, and SIGN-OFF. The 'SIGN-OFF' stage is currently active, as indicated by the 'SIGN-OFF PANEL OUTCOME' button in the top right corner of the main content area. On the left sidebar, the 'ENROLMENT' and 'ACCOUNT DETAILS' sections are visible, with a red circle containing the number '7' highlighting the 'ACCOUNT DETAILS' section. The main content area contains a form for writing the panel outcome, with sections for 'Why do we use it?', 'Where does it come from?', and a satisfaction scale. The satisfaction scale is currently set to 6 out of 10.

ERN AT01 - EB-HAUS AUSTRIA CENTRES ERN MAP DOCTOR TWO

PATIENT ID: ERN-AT01-005 DOB: 05/04/2017 (UNDETERMINED) ENROLLED: 04/APR/2017

#501 PANEL

PANELS

ENROLMENT

ACCOUNT DETAILS

7

CONSULTATION REQUEST

PANEL MEMBERS

CONTRIBUTIONS

OUTCOME

REQUESTS

MEETINGS

WRITE THE PANEL OUTCOME:

Why do we use it?

It is a long established fact that a reader will be distracted by the readable content of a page when looking at its layout. The point of using Lorem Ipsum is that it has a more-or-less normal distribution of letters, as opposed to using 'Content here, content here', making it look like readable English. Many desktop publishing packages and web page editors now use Lorem Ipsum as their default model text, and a search for 'lorem ipsum' will uncover many web sites still in their infancy. Various versions have evolved over the years, sometimes by accident, sometimes on purpose (injected humour and the like).

Where does it come from?

Contrary to popular belief, Lorem Ipsum is not simply random text. It has roots in a piece of classical Latin literature from 45 BC, making it over 2000 years old. Richard McClintock, a Latin professor at Hampden-Sydney College in Virginia, looked up one of the more obscure Latin words, consectetur, from a Lorem Ipsum passage, and going through the cites of the word in classical literature, discovered the undoubtable source. Lorem Ipsum comes from sections 1.10.32 and 1.10.33 of "de Finibus Bonorum et Malorum" (The Extremes of Good and Evil) by Cicero, written in 45 BC. This book is a treatise on the theory of ethics, very popular during the Renaissance. The first line of Lorem Ipsum, "Lorem ipsum dolor sit amet..", comes from a line in section 1.10.32.

The standard chunk of Lorem Ipsum used since the 1500s is reproduced below for those interested. Sections 1.10.32 and 1.10.33 from "de Finibus Bonorum et Malorum" by Cicero are also reproduced in their exact original form, accompanied by English versions from the 1914 translation by H. Rackham.

Panel Lead

2

6

7. When the Stage has been changed to Sign-off, the User can then Sign-off the final Panel outcome

