



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network

Hematological
Diseases (ERN EuroBloodNet)

Clinical Patient Management System (CPMS)

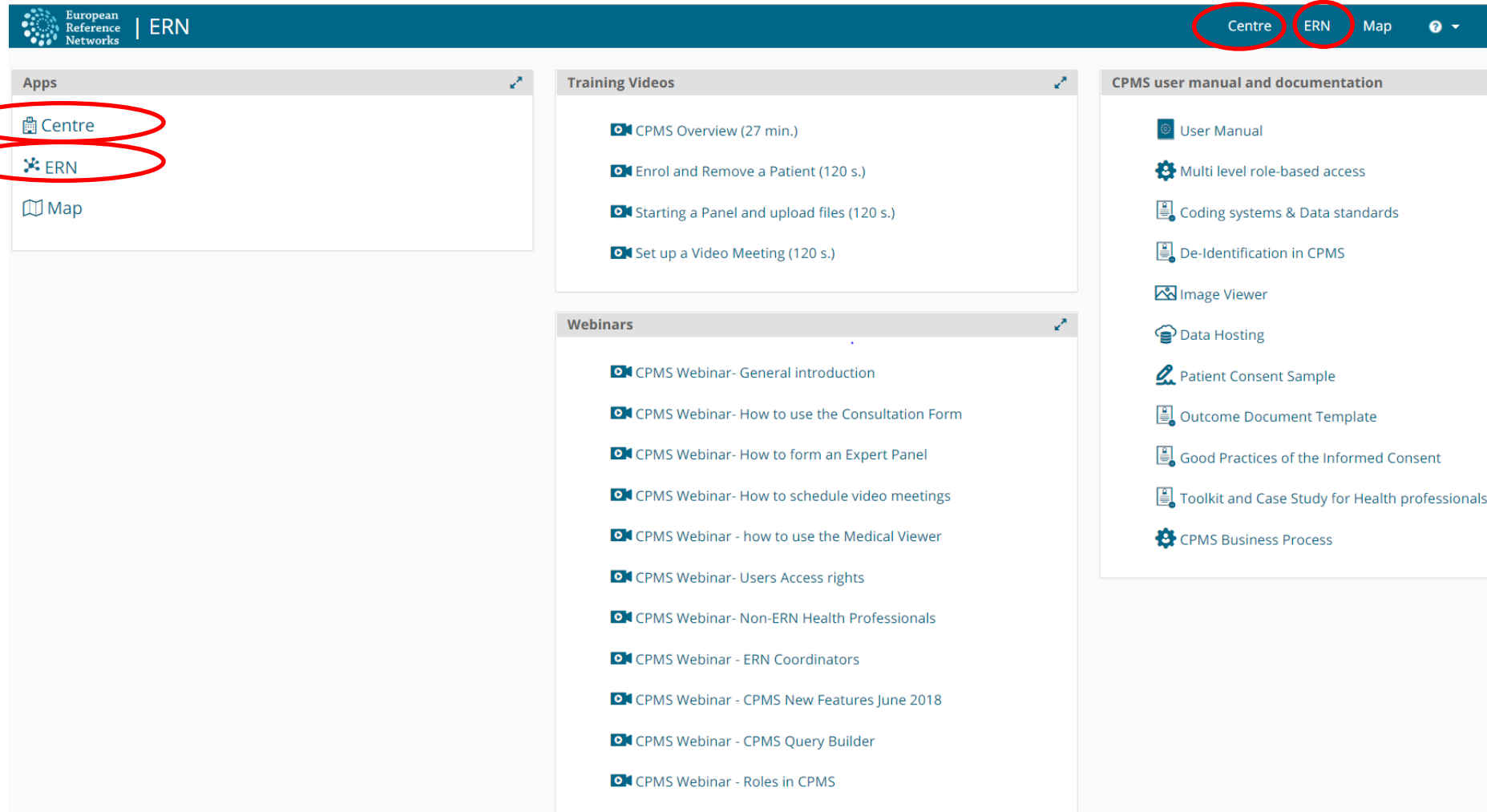
USER GUIDE

CPMS: Things to know

- **Strong recommendation to use Google Chrome with the CPMS.**
- Date fields should be entered in the format dd/mm/yyyy however some dates can be entered as mm/yyyy or yyyy.
- Data can be entered in the consultation form in several times (you should save your entry at each time).
- The consultation form has to be customised but can be used as such for the moment.

CPMS Homepage

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



The screenshot shows the CPMS homepage with a dark blue header. The header contains the European Reference Networks logo and the text 'ERN' on the left, and 'Centre', 'ERN', 'Map', and a help icon on the right. The 'Centre' and 'ERN' links in the header are circled in red. Below the header, there are three main sections: 'Apps', 'Training Videos', and 'CPMS user manual and documentation'. The 'Apps' section is on the left and contains links to 'Centre', 'ERN', and 'Map'. The 'Centre' and 'ERN' links are circled in red. The 'Training Videos' section is in the middle and contains a list of videos. The 'CPMS user manual and documentation' section is on the right and contains a list of documents. The 'Webinars' section is at the bottom and contains a list of webinars.

European Reference Networks | ERN

Centre **ERN** Map ?

Apps

- Centre
- ERN
- Map

Training Videos

- CPMS Overview (27 min.)
- Enrol and Remove a Patient (120 s.)
- Starting a Panel and upload files (120 s.)
- Set up a Video Meeting (120 s.)

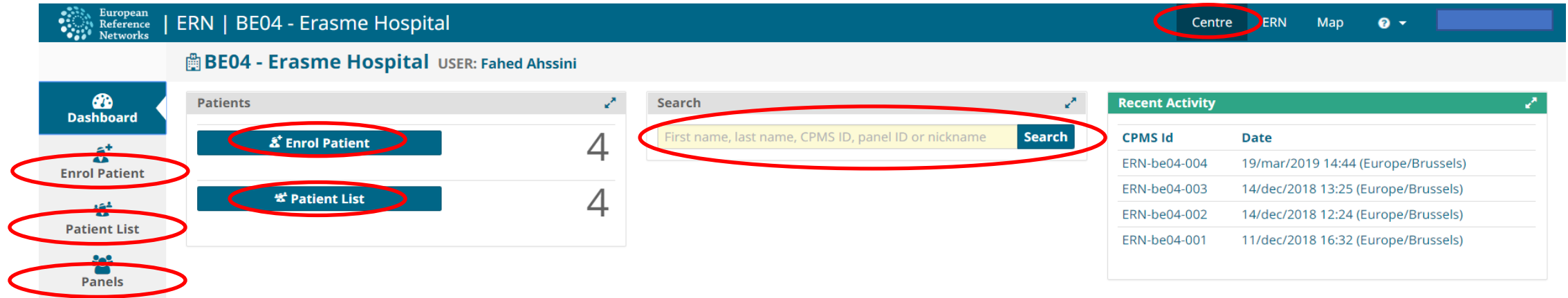
CPMS user manual and documentation

- User Manual
- Multi level role-based access
- Coding systems & Data standards
- De-Identification in CPMS
- Image Viewer
- Data Hosting
- Patient Consent Sample
- Outcome Document Template
- Good Practices of the Informed Consent
- Toolkit and Case Study for Health professionals
- CPMS Business Process

Webinars

- CPMS Webinar- General introduction
- CPMS Webinar- How to use the Consultation Form
- CPMS Webinar- How to form an Expert Panel
- CPMS Webinar- How to schedule video meetings
- CPMS Webinar - how to use the Medical Viewer
- CPMS Webinar- Users Access rights
- CPMS Webinar- Non-ERN Health Professionals
- CPMS Webinar - ERN Coordinators
- CPMS Webinar - CPMS New Features June 2018
- CPMS Webinar - CPMS Query Builder
- CPMS Webinar - Roles in CPMS

Centre Dashboard



European Reference Networks | ERN | BE04 - Erasme Hospital

Centre ERN Map

BE04 - Erasme Hospital USER: Fahed Ahssini

Patients

- Enrol Patient 4
- Patient List 4

Search


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

Recent Activity

CPMS Id	Date
ERN-be04-004	19/mar/2019 14:44 (Europe/Brussels)
ERN-be04-003	14/dec/2018 13:25 (Europe/Brussels)
ERN-be04-002	14/dec/2018 12:24 (Europe/Brussels)
ERN-be04-001	11/dec/2018 16:32 (Europe/Brussels)

- All panels of your institution are visible when you click on « Panels »
- New patient can be enrolled by clicking on « Enrol Patient »
- Current patients of your centre are visible by clicking on « Patient List »
- A « Search » button is available to search for a patient
- All authorized users from your centre can see all patients enrolled in your centre

Panel page

 European Reference Networks | ERN | BE04 - Erasme Hospital

Centre

ERNMap?


BE04 - Erasme Hospital USER:


Dashboard

Enrol Patient


Patient List

Panels

 Patient Panels

Panel ID	Nickname	Started	Lead	State	ERN	Thematic Area
# 247	énigme	17/Aug/2018	Dr. cecile BRACHET	Archived	Endo-ERN - End...	Sex Development & Maturation
 # 400	ovotesticular DSD	14/Dec/2018	Dr. cecile BRACHET	Archived	Endo-ERN - End...	Sex Development & Maturation
# 608	CDA type 2 BG	19/Mar/2019	Béatrice GULBIS	Data Co...	EuroBloodNet - ...	Congenital dyserythropoietic anemia, Blackfan-D...
# 378	Jaundice 21	29/Nov/2018	Béatrice GULBIS	Data Co...	EuroBloodNet - ...	Hereditary erythroenzymopathies and RBC mem...

Patient list page

 European Reference Networks

ERN | IT10 - "Riuniti" hospitals Vil...

Centre ERN Map ⓘ bloodnetcoordinator ▾

IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo USER: bloodnetcoordinator

 Dashboard

 Enrol Patient

 **Patient List**

 Panels

Patient List 



Enrol Patient

Enrol Patient

Patient List

Panels

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

ENROL PATIENT

* Patient Id: ERN-it10-013

* Date enrolled:

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

[Download Model Consent Forms](#)

Consents

Consent Requested	Consent Given	Date
Consent for care	<input type="radio"/> Yes <input type="radio"/> No	
Consent for ERN databases/Registries	<input type="radio"/> Yes <input type="radio"/> No	
Consent contact for research	<input type="radio"/> Yes <input type="radio"/> No	

Identifying data

* First name

* Last name

* Gender:

* Date of birth:

* Record Label

[Cancel](#) [Enrol Patient](#)

All fields should be completed and the patient has to give consent for sharing his/her data.

Patient consent forms available in several languages



**European
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for rare or low prevalence
complex diseases

Network
Hematological
Diseases (ERN EuroBloodNet)

The screenshot displays the ERN IT10 portal interface. At the top, the header shows the ERN logo and the text 'ERN | IT10 - "Riuniti" hospitals Vil...'. Below this, the main navigation bar includes 'Centre', 'ERN', 'Map', and a user profile 'bloodnetcoordinator'. The main content area is titled 'IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo' with the user 'bloodnetcoordinator'. A sidebar on the left contains links to 'Dashboard', 'Enrol Patient', 'Patient List', and 'Panels'. The 'Enrol Patient' section is active, showing a note: 'All authorised users from this centre can see all patients enrolled within this centre regardless of enrolling user.' Below this, the 'ENROL PATIENT' section is visible, with a sub-section 'Consents' containing a list of 'Consent Requested' forms. A modal window titled 'Download Consent Forms' is open, displaying a list of available forms in two columns. The forms are listed with their country codes and dates. To the right of the modal, there is a 'Reference' section with links to 'Guidelines Toolkit Case Study' and 'Good Practices Informed Consent Data Management'. At the bottom right, there is a button labeled 'Download Model Consent Forms'. The background of the portal shows a form for 'Identifying data' with fields for 'First name', 'Last name', 'Gender', and 'Date of birth'.

European Reference Networks | ERN | IT10 - "Riuniti" hospitals Vil...

Centre ERN Map bloodnetcoordinator

IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo USER: bloodnetcoordinator

Dashboard

Enrol Patient

Patient List

Panels

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

ENROL PATIENT

Have you sought

Consents

Consent Requested

Consent for care

Consent for ERN database

Consent contact for research

Identifying data

* First name

* Last name

* Gender:

* Date of birth: dd/Mmm/yyyy

Download Consent Forms

Download Consent Forms (pdf format)

- BG (20/11/2017)
- CS (04/05/2018)
- DA (20/11/2017)
- DE (26/10/2018)
- 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 (26/10/2018)
- 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 (26/10/2018)

Reference

Guidelines Toolkit Case Study

Good Practices Informed Consent Data Management

Download Model Consent Forms

Consent Requested

Consents			
Consent Requested	Consent Given	Date	
1 Consent for care	<input checked="" type="radio"/> Yes <input type="radio"/> No <input checked="" type="button" value="X"/>	18/Apr/2019 	
2 Consent for ERN databases/Registries	<input checked="" type="radio"/> Yes <input type="radio"/> No <input checked="" type="button" value="X"/>	18/Apr/2019 	OK 4
3 Consent contact for research	<input checked="" type="radio"/> Yes <input type="radio"/> No <input checked="" type="button" value="X"/>	18/Apr/2019 	OK 5

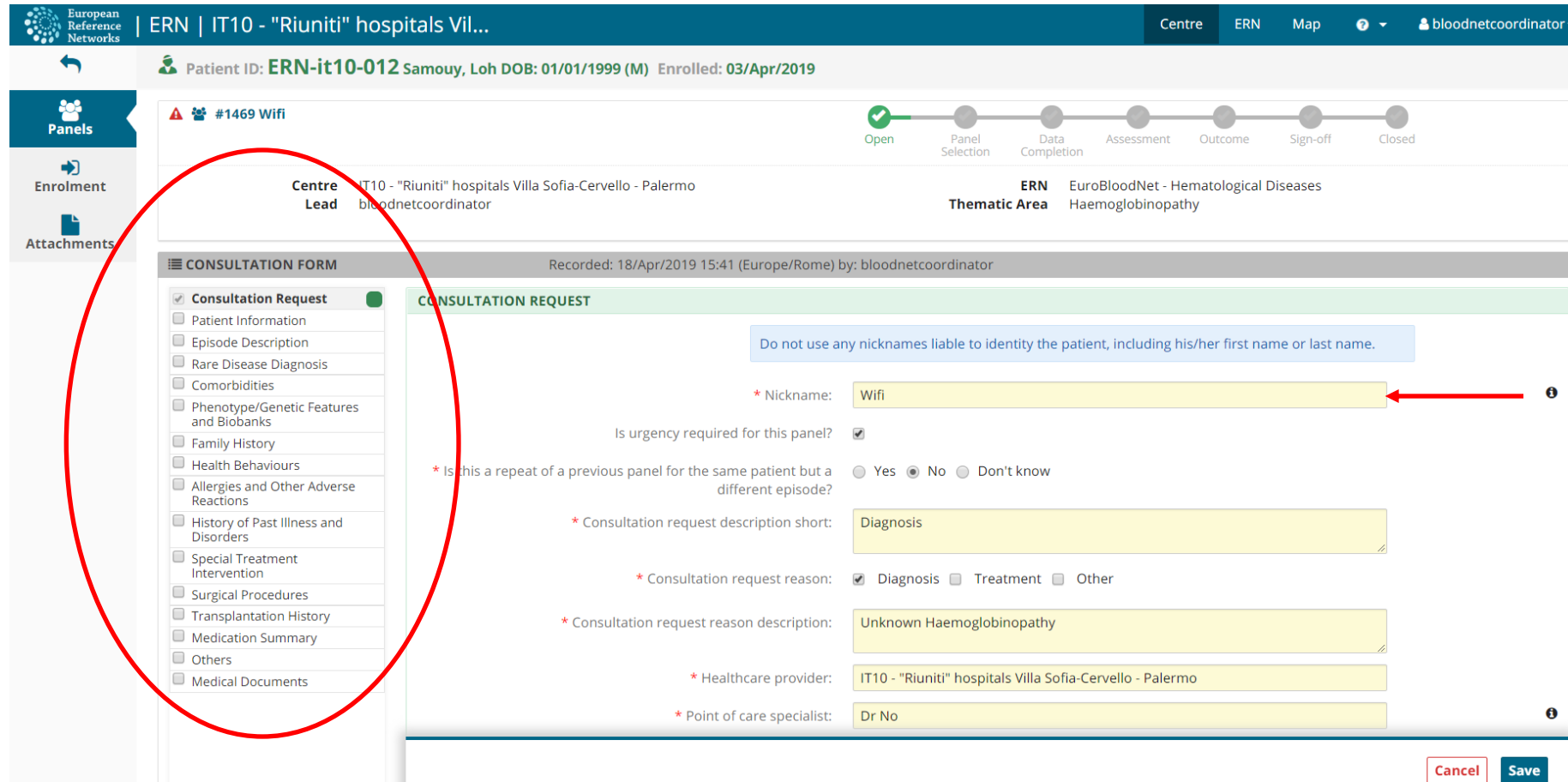
1. This consent is mandatory
2. This consent is not mandatory. Answer can be 'No' if answer is 'Yes' the Panel lead will be able to make the data available for ERN researchers after panels have been closed and an outcome has been sign-off. The Name and Date of birth won't be visible for them.
3. This consent is not mandatory, thus the answer can be 'No'. If 'Yes' it states that patients are interested to be contacted by outside ERN reasearch projects (e.g. clinical trials).
4. Field appearing if answer is 'Yes', you may specify the name of the register or just write 'Ok'
5. Field appearing if answer is 'Yes ', you may just write 'Ok'

Consultation form

- The consultation form is to be used to report the case.
- Several widgets are visible to report the data you need to report
- It can always be edited
- Several coding systems are available (e.g. ICD, ICC3-3/10, HPO, ORDO, LOINC etc.)
- The consultation form is still to be customised

Consultation form (2)

Data can be entered in those different sections



The nickname of the patient is visible for panel members outside of your center

Save the consultation form every time you fill new section

Consultation form (patient information)

- Mandatory information reported about the patient

☒ 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

Secondary thematic areas:

☐ Amyloidosis
☐ Congenital dyserythropoietic anemia, Blackfan-Diamond anemia, Acquired BMF and Inherited BMF
☒ Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis
☐ Haemophilia A, B, The rarer congenital deficiencies of other coagulation factors, Von Willebrand disease, inherited platelet defects
☐ Hereditary erythroenzymopathies and RBC membrane defects
☐ Myelodysplastic syndrome (MOS)
☐ Myeloproliferative neoplasm (MPN)
☐ Rare lymphomas

PATIENT INFORMATION

+ Add birth complication

* Gender:

☒ Female
 ☐ Male
 ☐ Undifferentiated
 ☐ Unknown

Δ Pregnancy:

☐ Yes
 ☒ No

* Country of Residence (ISO 3166-1):

Belgium

Country of birth (ISO 3166-1):

Belgium

Education Level (ISCED 2011):

ISCED 3: Upper secondary education

Occupation:

Employee working full-time

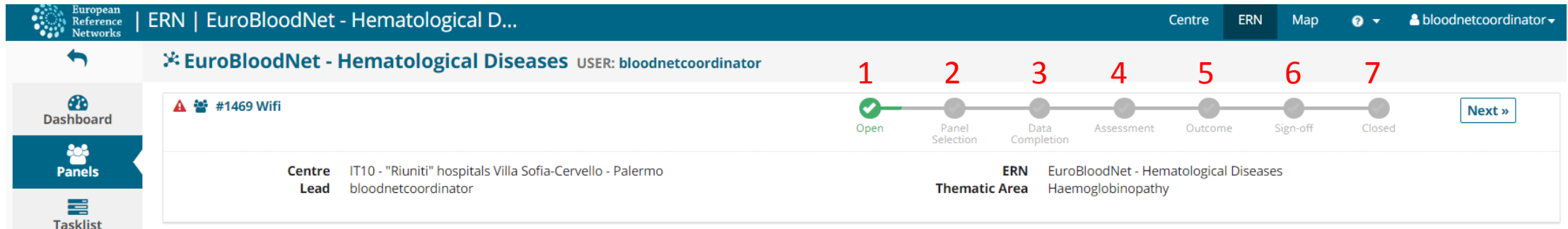
+ Add functional status and/or disability

Cancel

Save

Once all mandatory 'Patient information' is reported click 'Save'


Panel workflow




- **1:** Open panel: First step to discuss a diagnosis or a treatment for a rare case.
- **2:** Panel selection: The panel lead invites the experts whom their advice is expected from.
- **3:** Data completion: Filling data to give the maximum information about the case (you may schedule and have a meeting about the case). If you save your data you may come back at any time to refill in data if you wish.
- **4:** Assessment: Record the contributions of the panel members (you may schedule and have a meeting about the case).
- **5*:** Outcome: Conclusion.
- **6*:** Sign-off: Ending of the panel conclusion and assessment.
- **7*:** Closed: Panel is closed.
- After closing the panel it will be archived

*Those steps of the workflow will be revised by DG santé to facilitate and decrease the number of steps.



Panel selection (how to invite an expert to your panel)


ERN | EuroBloodNet - Hematological D...

Centre
ERN
Map
bloodnetcoordinator


EuroBloodNet - Hematological Diseases
USER: bloodnetcoordinator

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Panels
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Panel Management
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CO-ORDINATOR
Performance Indicators
ERN meetings



#1469 Wifi

Open
Panel Selection
Data Completion
Assessment
Outcome
Sign-off
Closed

Next »

Centre Lead
IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
bloodnetcoordinator

ERN Thematic Area
EuroBloodNet - Hematological Diseases
Haemoglobinopathy

[Invite Members](#)
[Schedule Meeting](#)
[Request Additional Data](#)

CONSULTATION FORM
Recorded: 18/Apr/2019 15:41 (Europe/Rome) by: bloodnetcoordinator
PDF

CONSULTATION REQUEST

* Nickname: Wifi

Is urgency required for this panel? Yes

* Is this a repeat of a previous panel for the same patient but a different episode? No

* Consultation request description short: Diagnosis

* Consultation request reason: Diagnosis

* Consultation request reason description: Unknown Haemoglobinopathy

Healthcare provider: IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo

Point of care specialist: Dr No

* ERN: EuroBloodNet

* Panel lead: bloodnetcoordinator

* Primary thematic area: Haemoglobinopathy

Secondary thematic areas: Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

TIMELINE

18/Apr/2019: A new Panel was started by bloodnetcoordinator.

Patient Documents

Created	Last Update
Panel #1469	18/Apr/2019

23/Apr/2019: The Panel is now in state "Panel Selection"

Panel Members

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 23/Apr/2019

There are no outstanding invitations

Add a comment

At the panel selection level you invite the expert on your case by clicking on the 'Invite Members' button


Panel selection (how to invite an expert to your panel) (2)

Panel Selection

Choose the expert you
want to invite

AvailableInvitedInvite Guest MembersForward Panel

Thematic Area: Haemoglobinopathy

Available Healthcare Professionals	HCPs	Specialisation	 Invite All
TESTUSER, bloodnethpuser2	BG07 - Varna Expert Center of coagulopathies and rare anemias	Surgeon	<div>Invite</div>
TESTUSER, bloodnethpuser4	CZ08 - University Hospital Brno	biologist	<div>Invite</div>
TESTUSER, bloodnethpuser5	FR08 - Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Surgeon	<div>Invite</div>

Close


Expert invited (accept or refuse invitation)




European
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complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

 ERN | EuroBloodNet - Hematological D...CentreERNMapbloodnethpuser2 testuser

 **EuroBloodNet - Hematological Diseases** USER: bloodnethpuser2 testuser

Dashboard



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  #1469 Wifi

Centre

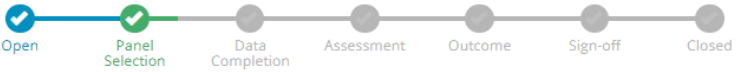
Lead

IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
bloodnetcoordinator

ERN

Thematic Area

EuroBloodNet - Hematological Diseases
Haemoglobinopathy



Open

Panel Selection


Data Completion

Assessment

Outcome

Sign-off

Closed


 You have been invited to join this panel. Please Accept/Refuse.

Accept / Refuse Invitation

Request Additional Data

CONSULTATION FORM

Recorded: 18/Apr/2019 16:41 (Europe/Sofia) by: bloodnetcoordinator



CONSULTATION REQUEST

* Nickname:

Wifi

Is urgency required for this panel?

Yes

* Is this a repeat of a previous panel for the same patient but a different episode?

No

* Consultation request description short:

Diagnosis

* Consultation request reason:

Diagnosis

* Consultation request reason description:

Unknown Haemoglobinopathy

Healthcare provider:

IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo

Point of care specialist:

Dr No

* ERN:

EuroBloodNet

* Panel lead:

bloodnetcoordinator

* Primary thematic area:

Haemoglobinopathy

Secondary thematic areas:

Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

TIMELINE

18/Apr/2019: A new Panel was started by bloodnetcoordinator.

Patient Documents

Created	Last Update
Panel #1469	18/Apr/2019

23/Apr/2019: The Panel is now in state "Panel Selection"

Panel Members

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 23/Apr/2019
bloodnethpuser2 testuser	Invited	Invited: 23/Apr/2019
bloodnethpuser4 testuser	Invited	Invited: 23/Apr/2019
bloodnethpuser5 testuser	Invited	Invited: 23/Apr/2019

3 invitations are outstanding

Expert invited (accept or refuse invitation) (2)

Panel Members

The invited expert
may click 'Accept'
and then 'Close'

Accept / Refuse

Invited

You have been invited to participate in this Panel.
Please indicate below whether you are interested in participating in this Panel.

Refuse

✓ Accept

Close

Panel lead

- As a panel lead you are able to accept or refuse the invitation for the others on behalf of yourself, you are also able to give the 'Lead' to a panel member

Panel Selection

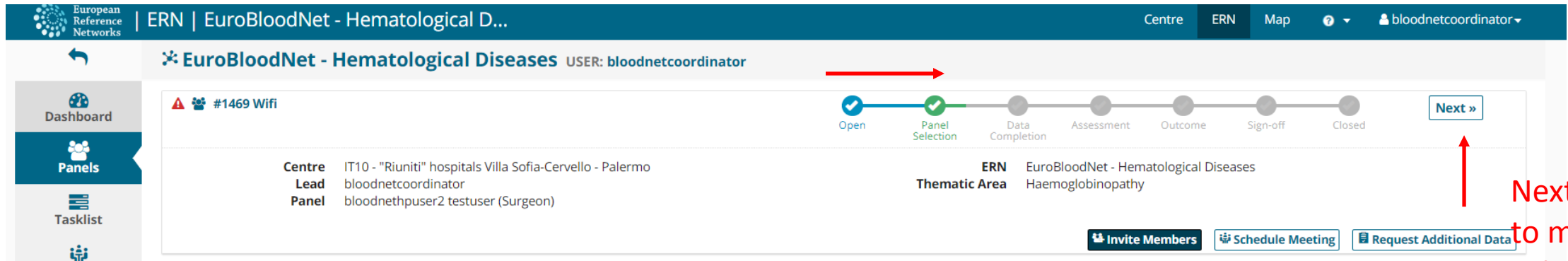
Available Invited Invite Guest Members Forward Panel

Invited Panel Members

Name	Specialisation	Status	When
bloodnetcoordinator		Lead	Invited: 23/Apr/2019
bloodnethpuser2 testuser	Surgeon	Accepted ▾	Invited: 23/Apr/2019 Accepted: 23/Apr/2019
bloodnethpuser4 testuser	biologist	Invited ▾	Invited: 23/Apr/2019
bloodnethpuser5 testuser	Surgeon	Accept Refuse Set As Lead	Invited: 23/Apr/2019

Close

Panel selection done -> Moving to data completion



The screenshot shows the user interface for the EuroBloodNet - Hematological Diseases platform. The top navigation bar includes the ERN logo, the text "ERN | EuroBloodNet - Hematological D...", and a user profile "bloodnetcoordinator". The main content area features a progress bar with stages: Open, Panel Selection (highlighted with a green checkmark), Data Completion, Assessment, Outcome, Sign-off, and Closed. A red arrow points from the "Panel Selection" stage to the "Data Completion" stage. Below the progress bar, there is a table with details for the current panel:

Centre	Lead	Panel
IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo	bloodnetcoordinator	bloodnethpuser2 testuser (Surgeon)

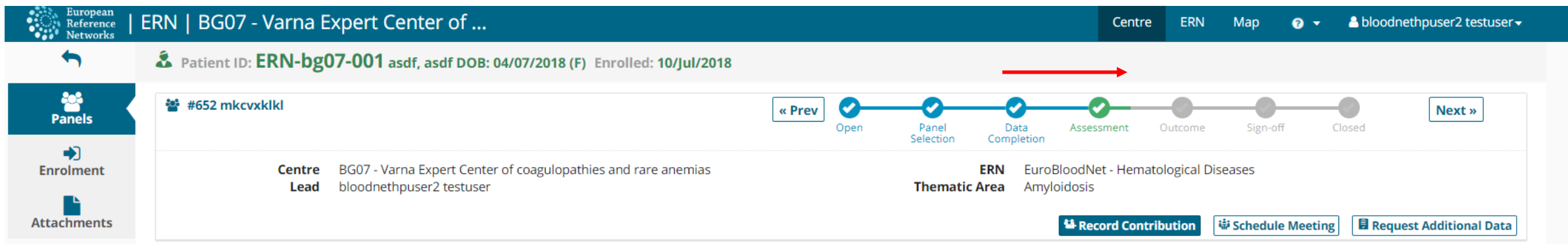
Below the table, there are three buttons: "Invite Members", "Schedule Meeting", and "Request Additional Data". A red arrow points from the "Request Additional Data" button to the "Next »" button in the top right corner of the progress bar.

Next button
to move to
subsequent
station

Another panel member
can 'Request Additional
Data', which you can
complete during the
'Data Completion'
station

Data completion and assessment

- Once you move to the Data completion station you should report all major data in the consultation form.
- After having reported important information to enable invited experts to give their assessment they can record their contribution at the Assessment level.



The screenshot displays the ERN patient record interface for a patient with ID ERN-bg07-001. The interface includes a top navigation bar with the ERN logo and patient information, a left sidebar with navigation options (Panels, Enrolment, Attachments), and a main content area. The main content area shows a progress bar with stages: Open, Panel Selection, Data Completion, Assessment, Outcome, Sign-off, and Closed. The 'Assessment' stage is currently active, indicated by a green checkmark and a red arrow pointing to it. Below the progress bar, there is a table with patient details, including Centre Lead, ERN Thematic Area, and a list of actions: Record Contribution, Schedule Meeting, and Request Additional Data.

Centre Lead	ERN Thematic Area
BG07 - Varna Expert Center of coagulopathies and rare anemias bloodnethpuser2 testuser	EuroBloodNet - Hematological Diseases Amyloidosis

[Record Contribution](#) [Schedule Meeting](#) [Request Additional Data](#)

Here by clicking on 'Record Contribution' the invited expert can give an advice

Assessment

Panel Contributions

uroBloodNet)

bloodnetcoordinator

bloodnethpuser2 testuser

Haemoglobinopathy : Sickle Cell disease further examination needed. Kidney assessment?



Here the expert can
write the advice or
the opinion

Or attach file:

Choose file...

How much time did you spend on this Assessment?

0

HRS

0

MINS

Cancel

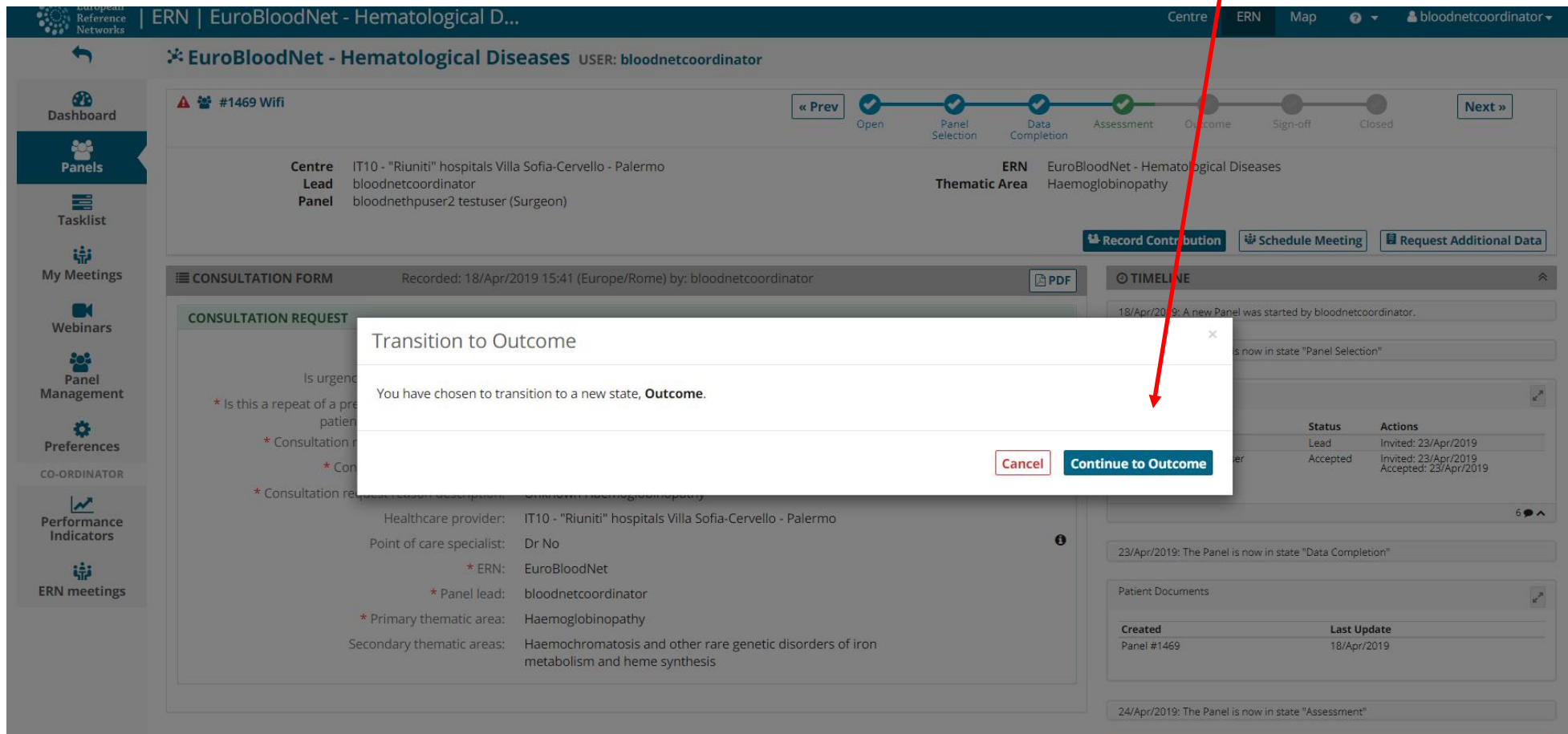
Record My Contribution



Click to record
your contribution

Transition to Outcome

When the Panel lead has received contribution from invited experts the Panel lead can choose to make the transition to the Outcome station



The screenshot displays the EuroBloodNet - Hematological Diseases interface. A modal dialog box titled "Transition to Outcome" is centered on the screen, containing the text: "You have chosen to transition to a new state, **Outcome**." Below the text are two buttons: "Cancel" and "Continue to Outcome". A red arrow points from the "Continue to Outcome" button in the dialog box to the "Outcome" station in the top navigation bar. The background interface shows a progress bar with stations: Open, Panel Selection, Data Completion, Assessment, Outcome, Sign-off, and Closed. The "Outcome" station is currently selected. Below the progress bar, the "CONSULTATION FORM" is visible, showing details for a consultation request recorded on 18/Apr/2019. The form includes fields for Centre Lead, Panel, ERN Thematic Area, and various consultation details.

Record Outcome




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Outcome can be recorded
by clicking on the 'Record
Outcome' button

 ERN | EuroBloodNet - Hematological D...

CentreERNMap ⓘ bloodnetcoordinator ▾

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Performance

  #1469 Wifi

« Prev

Open

Panel Selection

Data Completion

Assessment

Outcome

Sign-off

Closed

Next »

CentreIT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo

Leadbloodnetcoordinator

Panelbloodnethpuser2 testuser (Surgeon)

ERNEuroBloodNet - Hematological Diseases

Thematic AreaHaemoglobinopathy

Record Outcome

Schedule Meeting

Request Additional Data

CONSULTATION FORM

Recorded: 18/Apr/2019 15:41 (Europe/Rome) by: bloodnetcoordinator

PDF

CONSULTATION REQUEST

* Nickname:Wifi ⓘ

Is urgency required for this panel?Yes

* Is this a repeat of a previous panel for the same patient but a different episode?No

* Consultation request description short:Diagnosis

* Consultation request reason:Diagnosis

* Consultation request reason description:Unknown Haemoglobinopathy

Healthcare provider:IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo

TIMELINE

18/Apr/2019: A new Panel was started by bloodnetcoordinator.

23/Apr/2019: The Panel is now in state "Panel Selection"

Panel Members

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 23/Apr/2019
bloodnethpuser2 testuser	Accepted	Invited: 23/Apr/2019 Accepted: 23/Apr/2019

Record Outcome (2)

Panel Outcome (draft)

Write the Panel Outcome:

Sickle cell disease



Outcome can be
written in this field

3 questions have to be
answered: 1) Your
panel role? 2) Score for
the utility of the Panel
3) Score for satisfaction
of the Outcome

Are you the point of care specialist, the panel lead or a panel participant?

Did you find this virtual panel useful? (Please rate the usefulness of the panel on a scale from 1 to 10 where 1 is "not useful" and 10 is "extremely useful")

How satisfied are you with the outcome of this panel? (Please rate your satisfaction on a scale from 1 to 10 where 1 is "completely unsatisfied" and 10 is "completely satisfied".)

Point of care specialist

Panel Lead

Panel Participant

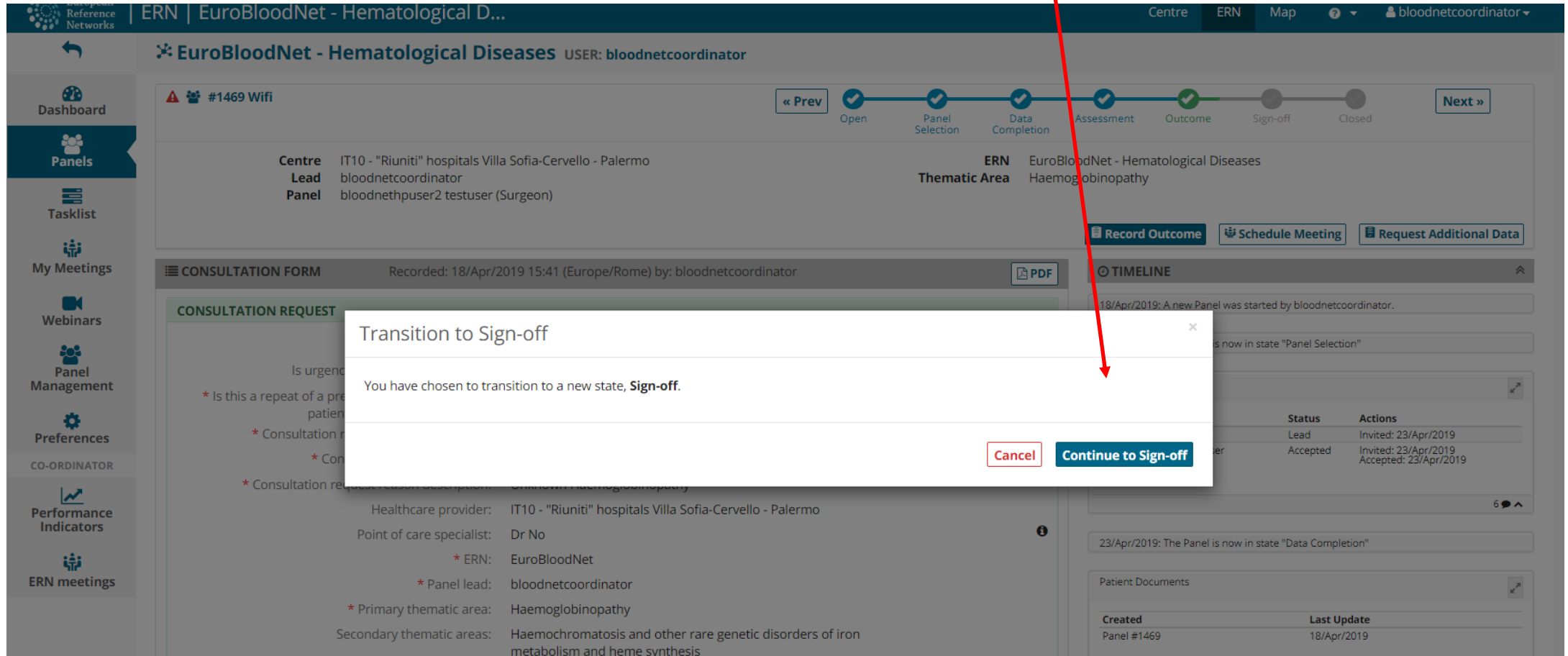


Cancel

Save Panel Outcome (draft)

Transition to sign-off

The Panel lead makes the transition to the Sign-off station and signs it off when the outcome has been confirmed.



The screenshot displays the EuroBloodNet - Hematological Diseases interface. A red arrow points from the text above to the 'Sign-off' step in the process flow. A modal dialog titled 'Transition to Sign-off' is open, showing the message: 'You have chosen to transition to a new state, **Sign-off**.' The dialog has 'Cancel' and 'Continue to Sign-off' buttons. The background interface shows a sidebar with navigation options, a top navigation bar, and a main content area with a consultation form and a timeline.

Process Flow: Open → Panel Selection → Data Completion → Assessment → Outcome → Sign-off → Closed

Centre Lead Panel: IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
bloodnetcoordinator
bloodnethpuser2 testuser (Surgeon)

ERN Thematic Area: EuroBloodNet - Hematological Diseases
Haemoglobinopathy

CONSULTATION FORM Recorded: 18/Apr/2019 15:41 (Europe/Rome) by: bloodnetcoordinator

CONSULTATION REQUEST

- Is urgent
- * Is this a repeat of a previous consultation?
- * Consultation request description: Unknown Haemoglobinopathy
- * Consultation request reason description: Unknown Haemoglobinopathy

Healthcare provider: IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
Point of care specialist: Dr No
*** ERN:** EuroBloodNet
*** Panel lead:** bloodnetcoordinator
*** Primary thematic area:** Haemoglobinopathy
Secondary thematic areas: Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

TIMELINE

- 18/Apr/2019: A new Panel was started by bloodnetcoordinator.
- Panel is now in state "Panel Selection"
- 23/Apr/2019: The Panel is now in state "Data Completion"

Status Actions

Status	Actions
Lead	Invited: 23/Apr/2019
Accepted	Invited: 23/Apr/2019 Accepted: 23/Apr/2019

Patient Documents

Created	Last Update
Panel #1469	18/Apr/2019

Sign-off Panel Outcome

Panel Outcome

Write the Panel Outcome:

Sickle cell disease

The Panel Lead signs off the Panel Outcome to confirm it.

* Are you the point of care specialist, the panel lead or a panel participant?

Panel Lead ▼

* Did you find this virtual panel useful? (Please rate the usefulness of the panel on a scale from 1 to 10 where 1 is "not useful" and 10 is "extremely useful")

8 ▼

* How satisfied are you with the outcome of this panel? (Please rate your satisfaction on a scale from 1 to 10 where 1 is "completely unsatisfied" and 10 is "completely satisfied".)

8 ▼

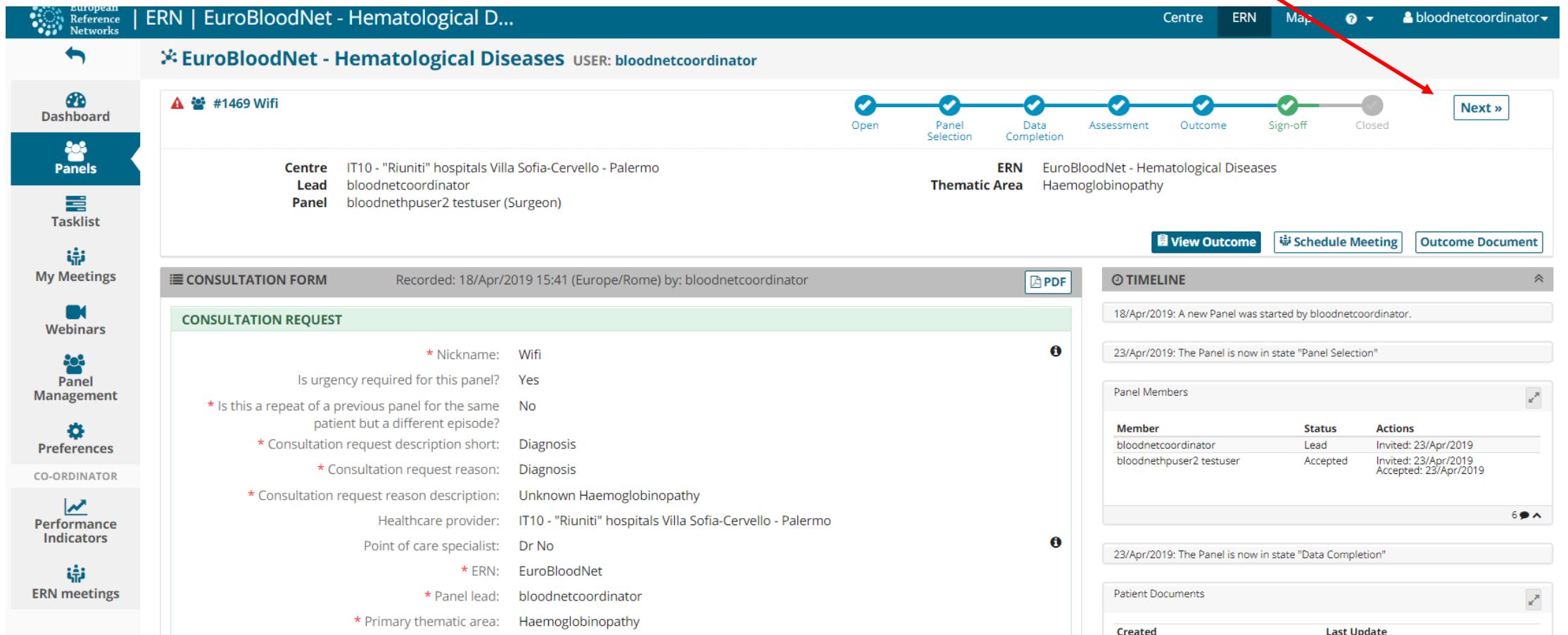
Cancel

Save Panel Outcome

Sign-off Panel Outcome

Transition to Closed

If the Panel Lead clicks 'Next' she/he will be in position to close the Panel.



The screenshot displays the EuroBloodNet - Hematological Diseases interface. The top navigation bar includes the ERN logo, the title "ERN | EuroBloodNet - Hematological D...", and user information "Centre ERN Map" and "bloodnetcoordinator". The left sidebar contains navigation options: Dashboard, Panels (selected), Tasklist, My Meetings, Webinars, Panel Management, Preferences, CO-ORDINATOR, Performance Indicators, and ERN meetings.

The main content area shows the "EuroBloodNet - Hematological Diseases" panel for user "bloodnetcoordinator". A progress bar at the top indicates the current state: Open, Panel Selection, Data Completion, Assessment, Outcome, Sign-off, and Closed. The "Next »" button is highlighted with a red arrow.

Below the progress bar, the panel details are displayed:

- Centre Lead Panel:** IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo; bloodnetcoordinator; bloodnethpuser2 testuser (Surgeon)
- ERN Thematic Area:** EuroBloodNet - Hematological Diseases; Haemoglobinopathy

Buttons for "View Outcome", "Schedule Meeting", and "Outcome Document" are visible.

The "CONSULTATION FORM" section shows a "CONSULTATION REQUEST" recorded on 18/Apr/2019 at 15:41 (Europe/Rome) by bloodnetcoordinator. The form includes the following fields:

- * Nickname: Wifi
- Is urgency required for this panel? Yes
- * Is this a repeat of a previous panel for the same patient but a different episode? No
- * Consultation request description short: Diagnosis
- * Consultation request reason: Diagnosis
- * Consultation request reason description: Unknown Haemoglobinopathy
- Healthcare provider: IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
- Point of care specialist: Dr No
- * ERN: EuroBloodNet
- * Panel lead: bloodnetcoordinator
- * Primary thematic area: Haemoglobinopathy

The "TIMELINE" section shows the following events:

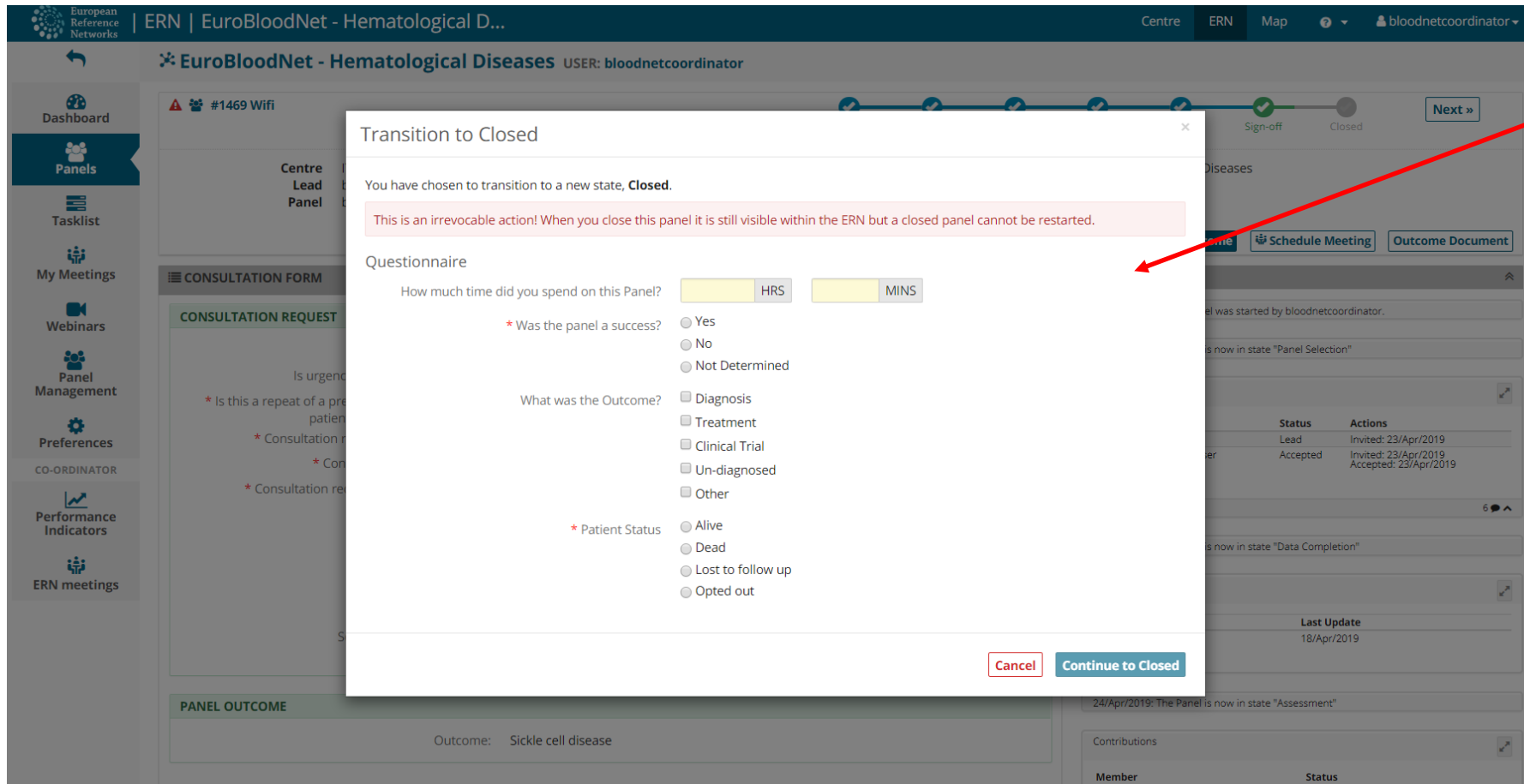
- 18/Apr/2019: A new Panel was started by bloodnetcoordinator.
- 23/Apr/2019: The Panel is now in state "Panel Selection"
- 23/Apr/2019: The Panel is now in state "Data Completion"

The "Panel Members" table lists the following members:

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 23/Apr/2019
bloodnethpuser2 testuser	Accepted	Invited: 23/Apr/2019 Accepted: 23/Apr/2019

The "Patient Documents" section shows a table with columns "Created" and "Last Update".

Closed Panel



European Reference Networks | ERN | EuroBloodNet - Hematological D... Centre ERN Map bloodnetcoordinator

EuroBloodNet - Hematological Diseases USER: bloodnetcoordinator

Dashboard Panels Tasklist My Meetings Webinars Panel Management Preferences CO-ORDINATOR Performance Indicators ERN meetings

Centre Lead Panel

CONSULTATION FORM

CONSULTATION REQUEST

Is urgency

* Is this a repeat of a pre patient

* Consultation re

* Consultation re

PANEL OUTCOME

Outcome: Sickle cell disease

Transition to Closed

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

This is an irrevocable action! When you close this panel it is still visible within the ERN but a closed panel cannot be restarted.

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

☐ Un-diagnosed

☐ Other

* Patient Status

☐ Alive

☐ Dead

☐ Lost to follow up

☐ Opted out

Cancel Continue to Closed

Sign-off Closed Next »

Schedule Meeting Outcome Document

Status Actions

Lead	Invited: 23/Apr/2019
Accepted	Invited: 23/Apr/2019
	Accepted: 23/Apr/2019

Last Update 18/Apr/2019

24/Apr/2019: The Panel is now in state "Assessment"

Contributions

Member	Status
--------	--------

When clicking 'Next' this message appears and a small questionnaire has to be filled in


Panel closed - Archive



European
Reference
Network


for rare or low prevalence
complex diseases

 **Network**
Hematological
Diseases (ERN EuroBloodNet)

 European Reference Networks

ERN | EuroBloodNet - Hematological D...

CentreERNMap ⓘ bloodnetcoordinator ▾

 **EuroBloodNet - Hematological Diseases** USER: bloodnetcoordinator

Dashboard

Panels

Tasklist

My Meetings

Webinars



Panel Management

Preferences

CO-ORDINATOR

Performance Indicators

ERN meetings

  #1469 Wifi

Open

Panel Selection

Data Completion

Assessment

Outcome

Sign-off

Closed

Archive

Centre
Lead
Panel

IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
bloodnetcoordinator
bloodnethpuser2 testuser (Surgeon)

ERN
Thematic Area

EuroBloodNet - Hematological Diseases
Haemoglobinopathy

Make Data Available for ERN Databases/Registries

Outcome Document

CONSULTATION FORM

Recorded: 18/Apr/2019 15:41 (Europe/Rome) by: bloodnetcoordinator

PDF

CONSULTATION REQUEST

* Nickname: Wifi

Is urgency required for this panel? Yes

* Is this a repeat of a previous panel for the same patient but a different episode? No

* Consultation request description short: Diagnosis

* Consultation request reason: Diagnosis

* Consultation request reason description: Unknown Haemoglobinopathy

Healthcare provider: IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo

Point of care specialist: Dr No

* ERN: EuroBloodNet

* Panel lead: bloodnetcoordinator

* Primary thematic area: Haemoglobinopathy

Secondary thematic areas: Haemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis

TIMELINE

18/Apr/2019: A new Panel was started by bloodnetcoordinator.

23/Apr/2019: The Panel is now in state "Panel Selection"

Panel Members

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 23/Apr/2019
bloodnethpuser2 testuser	Accepted	Invited: 23/Apr/2019 Accepted: 23/Apr/2019

23/Apr/2019: The Panel is now in state "Data Completion"

Patient Documents

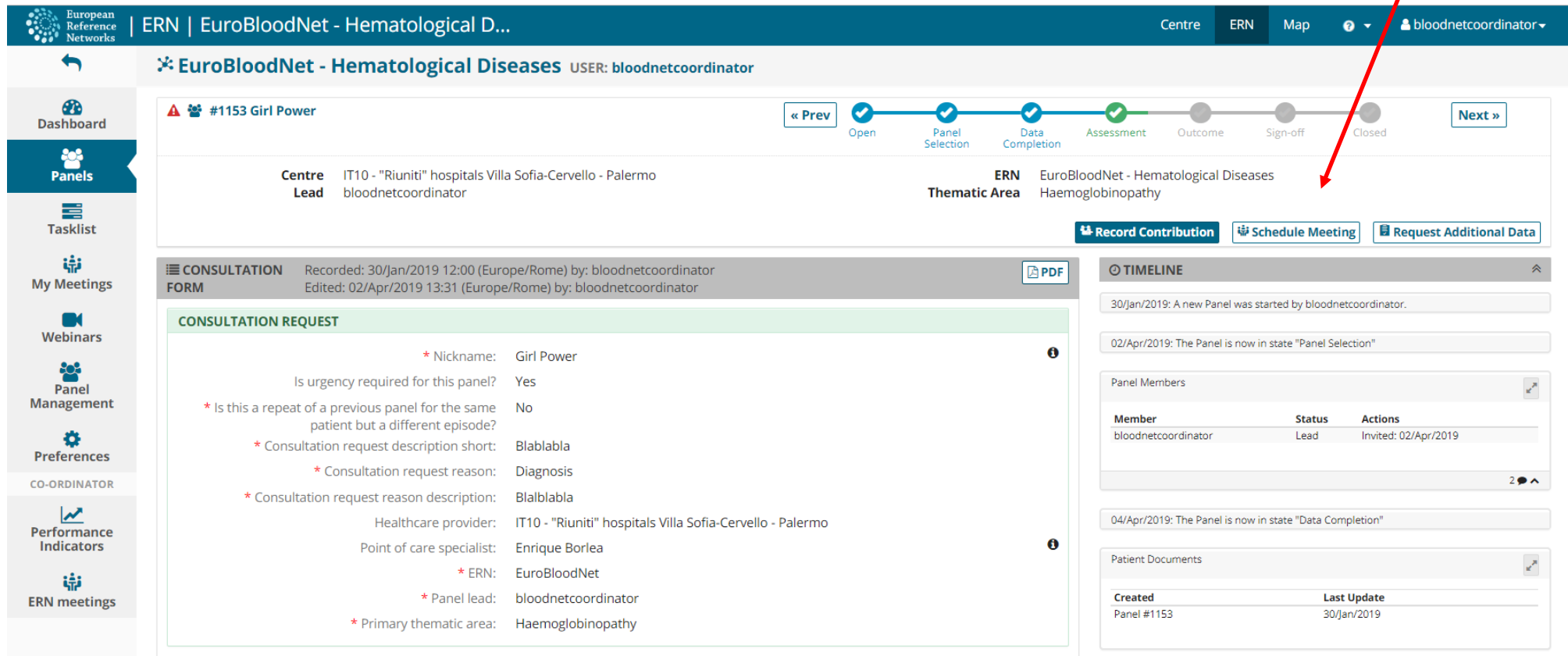
Created	Last Update
Panel #1469	18/Apr/2019

Archiving
Panel

Make Data Available
for ERN
Databases/Registries

Meeting scheduling to discuss a Panel

- The Meeting option is available during Panel discussion.
- How to schedule a Meeting



The screenshot shows the EuroBloodNet - Hematological Diseases interface. The top navigation bar includes the ERN logo, the title 'ERN | EuroBloodNet - Hematological D...', and user information 'Centre ERN Map bloodnetcoordinator'. The main header displays 'EuroBloodNet - Hematological Diseases' and the user 'bloodnetcoordinator'.

The left sidebar contains navigation options: Dashboard, Panels, Tasklist, My Meetings, Webinars, Panel Management, Preferences, CO-ORDINATOR, Performance Indicators, and ERN meetings.

The main content area shows a consultation request for '#1153 Girl Power'. A progress bar at the top indicates the current state: Open, Panel Selection, Data Completion, Assessment, Outcome, Sign-off, and Closed. The 'Schedule Meeting' button is highlighted with a red arrow.

The consultation request details are as follows:

- Centre Lead:** IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
- ERN Thematic Area:** EuroBloodNet - Hematological Diseases Haemoglobinopathy
- Record Contribution** (button)
- Schedule Meeting** (button)
- Request Additional Data** (button)

The consultation request form includes the following fields:

- CONSULTATION REQUEST**
- * Nickname:** Girl Power
- Is urgency required for this panel?** Yes
- * Is this a repeat of a previous panel for the same patient but a different episode?** No
- * Consultation request description short:** Blablabla
- * Consultation request reason:** Diagnosis
- * Consultation request reason description:** Blablabla
- Healthcare provider:** IT10 - "Riuniti" hospitals Villa Sofia-Cervello - Palermo
- Point of care specialist:** Enrique Borlea
- * ERN:** EuroBloodNet
- * Panel lead:** bloodnetcoordinator
- * Primary thematic area:** Haemoglobinopathy

The right sidebar shows the **TIMELINE** of events:

- 30/Jan/2019: A new Panel was started by bloodnetcoordinator.
- 02/Apr/2019: The Panel is now in state "Panel Selection"
- 04/Apr/2019: The Panel is now in state "Data Completion"

The **Panel Members** table shows:

Member	Status	Actions
bloodnetcoordinator	Lead	Invited: 02/Apr/2019

The **Patient Documents** table shows:

Created	Last Update
Panel #1153	30/Jan/2019

Meeting scheduling

Define the title of the meeting, a short description and the type of meeting, then click 'Schedule Meeting'

Schedule meeting ×

Title of meeting:

Description:

Type of meeting:

- ☒ Part of ERN recurring meeting
- ☐ Individual meeting
- ☐ Proposed meeting

ERN meeting:

Meeting scheduling (2)

Click 'Edit' Button to set up the meeting parameters.

Meeting: Panel discussion ×

Date & Time

ERN recurring meeting

Participants

Summary

Title of meeting:

Panel discussion

Description:

Diagnosis

Meeting Status:

Upcoming

Type of meeting:

Part of ERN recurring meeting


Duration:

minutes

Meeting Panel:

Girl Power

Test video =

 Edit

Meeting comments

Add a comment

Close

Meeting parameters

Meeting: Panel discussion ×

Date & Time	Participants	Summary
<div>Test video ▾</div> <div>Title of meeting: <input type="text" value="Panel discussion"/></div> <div>Description: <input type="text" value="Diagnosis"/></div> <div>Meeting Status: <input checked="" type="radio"/> Upcoming <input type="radio"/> Started <input type="radio"/> Finished <input type="radio"/> Cancelled</div> <div>Type of meeting: Individual meeting</div> <div>Duration: <input type="text" value=""/> minutes</div> <div>When: <input type="text" value="dd/Mmm/yyyy"/> <input type="text" value="hh:mm"/> Europe/Rome</div> <div><input type="button" value="Add a comment"/></div> <div><input type="button" value="Cancel"/> <input type="button" value="Update"/></div>		

Thank you

Contact if you need help:

Fahed.ahssini@erasme.ulb.ac.be