

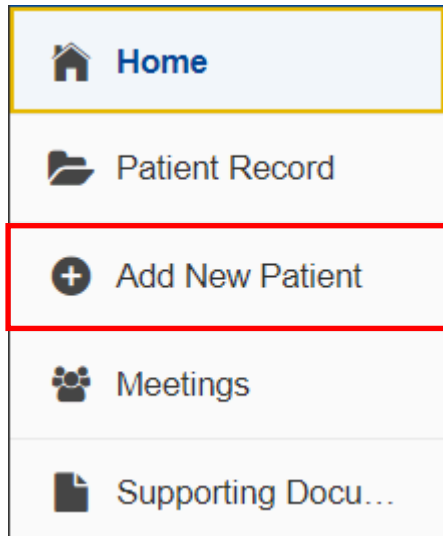
Creating a patient record in CPMS 2.0

!!!Please note, without informed consent a patient cannot be discussed in the system!!!

Please note, the following step-by-step guide uses only mock patient data that is not related to any real case to illustrate CPMS 2.0 functionality.

To create a patient record inside CPMS 2.0 follow these steps:

- Go to <https://cpms2.ern-net.eu/> and log in using your EU login credentials.
- Click on “Add New Patient” in the menu on the left:



- **A patient can only be added to the system if they have provided specific consent to discuss their case in the CPMS.** To indicate the patient has given their consent, tick yes under “Consent given” (red box in the screenshot below) The optional consents are not applicable for ERN GENTURIS and can be skipped.

Consent for care

Before you can add a patient to the system you must gain their consent.
Your hospital has a specific form or procedure to obtain consent from a patient for this system.
If you are unaware of this internal procedure, please contact your hospital Data Protection Officer (DPO) and/or ERN specific representative.

Consent given *

Yes No

OPTIONAL - Consent for education purposes

Yes No

OPTIONAL - Consent for inclusion in registries

Yes No

Disclaimer

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- Once the patient's consent has been confirmed, please provide the patient details. Please note, the data you input here will only be visible to clinicians with an active CPMS account from your hospital.

Identifying data

First Name *

Last Name *

Sex *

Date of birth *

Nationality *

- Click the "Next" button at the bottom of the page to proceed to the next step.
- In the next step, set up a nickname and details of the patient, including HCP and thematic area.
 - o In the Nickname field, please enter **ERN-[Name of your institute]-GENTURIS-[Patient number]**.
Please note that the system will generate a nickname that looks like a real patient name automatically. Since this could cause confusion regarding patient privacy, we use our own naming convention to nickname ERN GENTURIS patient records. Specifically, [Name of your institute] should be the exact name of your institute that is indicated in the Healthcare provider field dropdown list (see box 1 in the screenshot below) and [Patient number] should be a consecutive number representing the total number of patients that have been submitted to the CPMS from your institute since 2017.
EXAMPLE: ERN-Radboud University Medical Centre Nijmegen-GENTURIS-0071 (this represents the 71st patient submitted to the CPMS from Radboudumc)
 - o Please make sure all fields marked with * (mandatory) are filled with the relevant information.
 - o Please indicate the thematic area (mandatory) and the subthematic area (optional, but highly recommended to fill in if possible) of the patient record as shown in box 2 in the screenshot below.

The nickname must be unique

Wright Niels 991

This nickname is valid

Healthcare provider details

ERN *

Healthcare provider * 1

Lead *

Thematic Area * 2

Subthematic Area

- The resulting filled page should look like this:

Nickname

The nickname must be unique

Healthcare provider details

ERN *

Healthcare provider *

Treatment country *

Lead *

Thematic Area *

Subthematic Area *

- Click the “Next” button at the bottom of the page to proceed to the next step.
- On the next page, an overview of all the patient information you have just entered is shown:

Overview

1	Consent given *	Yes
	Date of consent for Care *	01/01/2025
	OPTIONAL - Consent for education purposes	No
	Date of consent for Education	-
	OPTIONAL - Consent for inclusion in registries	No
	Date of consent for Inclusion	-
	First Name *	Bladie
	Last Name *	Bla
	Date of birth *	01/01/2024
	Sex *	Undifferentiated
	Nationality *	Dutch
2	Nickname	ERN-Radboud University Medical Centre Nijmegen-GENTURIS-0071
3	ERN *	GENTURIS
	Healthcare provider *	Radboud University Medical Centre Nijmegen
	Treatment country *	Netherlands
	Lead *	Jurriaan Holzenspies
	Thematic Area *	TG4: Other rare – predominantly malignant - genturis
	Subthematic Area	4.3 Birt-Hogg-Dubé Syndrome (BHD Syndrome)

[Edit details](#)
[Add patient >](#)

(Please note, this screenshot was made in the test system and contains fake data)

- Please check whether the information is correct and then click “Add patient >” at the bottom of the page to add the patient to the CPMS.
- The patient record page is now shown. Next, click the “Open discussion” button (red box in the screenshot below) in the top right of the page and add a brief description of the case (4-5 sentences), including (if possible/applicable):
 - Diagnosis details, including details of the genetic variant
 - Relevant family history
 - Any clinical questions you would like to discuss

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Search for a record > Lefebvre Ferrel 170

Lefebvre Ferrel 170

P0000247 Discussed

Details | Files | Participants | History

Patient Details

Sex: Male Age: 38 Years

Record created: 11 April 2024

Thematic and Sub-thematic area: TG4: Other rare – predominantly malignant - genturis(inactive)

Healthcare provider details

ERN GENTURIS

Healthcare provider: Universitätsklinikum Carl Gustav Carus

Discussion topic

Currently there is no open discussion.

[Open discussion](#)

Currently no discussion is open. Open a new discussion to start messaging

(Please note, this screenshot was made in the test system and contains fake data)

- When the description of the patient details has been added to the discussion, please contact our CPMS helpdesk manager, Jurriaan Hölzenspies, to add the patient to one of our recurring CPMS meetings (send an email to jurriaan.holzenspies@radboudumc.nl or use the chat function in CPMS 2.0 at the top right of the page to send him a message).
- The patient record page also includes tabs for “Details”, “Files”, “Participants” and “History” (red box in the screenshot below):

Search for a record > Lefebvre Ferrel 170

Lefebvre Ferrel 170

P0000247 Discussed

Details | Files | Participants | History

Patient Details

Sex: Male Age: 38 Years

Record created: 11 April 2024

Thematic and Sub-thematic area: TG4: Other rare – predominantly malignant - genturis(inactive)

Healthcare provider details

ERN GENTURIS

Healthcare provider: Universitätsklinikum Carl Gustav Carus

Discussion topic

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[Open discussion](#)

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(Please note, this screenshot was made in the test system and contains fake data)

- o The “Details” tab shows the (non-identifiable) information you have just entered.

- The “Files” tab allows you to upload any files relevant to the patient record.
 - Files can be easily added using drag and drop or browse functions. Click the “Upload” button to open a popup window that allows you to upload files:

Upload File

Only 1 file can be uploaded at a time. Zip files must only contain DICOM files ⓘ
CPMS 2.0 system only allows certain file extensions ⓘ

Drag and drop file here

Here you can add details about this file:

File category

Investigation date

Description

By ticking this checkbox, you confirm that you have checked and manually removed all identifiable personal data from selected file(s), including comments & annotations. *

Please note, the upload can only be completed if you tick the box in the bottom left of the upload window (red rectangle) to indicate that you have checked and manually removed all identifiable personal data from selected file(s), including comments & annotations.

- A DICOM viewer is included and any DICOM files that are uploaded to the patient record will be recognised as such and can be viewed directly in the system.

- The “Participants” tab allows you to invite ERN GENTURIS experts based on their self-indicated expertise.
 - Please note that you can only invite a **maximum of 10 experts** to a patient record, so please make sure you only invite experts with relevant expertise.
 - Click the “Add participant” button to open the participants popup window.
 - Select “GENTURIS” under “ERN” and click the “Search” button to show only ERN GENTURIS experts:

Add participant

Search

Search by group

ERN

GENTURIS ▼

Name

Search by name

Thematic Area

Select / search by thema... ▼

Centre

Search by centre

Profession

Search by profession

Search



- Select the relevant thematic group under “Thematic Area” and click search to find experts with specific expertise.
- If you need help to find experts, please contact CPMS helpdesk manager Jurriaan Hölzenspies (send an email to jurriaan.holzenspies@radboudumc.nl) or use the chat function in CPMS 2.0 at the top right of the page)

- The “History” tab shows an overview of previous and ongoing discussions, where the description and conclusion of each discussion is visible in the timeline and the full discussion including all comments can be accessed by clicking the “View discussion” link:

Lefebvre Ferrel 170

P0000247 Discussed

Details Files Participants **History**

- Discussion closed** [View discussion](#) 
8th January 2025
Conclusion
- Discussion opened**
11th April 2024
Open again.
- Discussion closed** [View discussion](#) 
11th April 2024
Over.
- Discussion opened**
11th April 2024
Hello!
- Created on**
11th April 2024

(Please note, this screenshot was made in the test system and contains fake data)

If you have any questions, comments or bug reports, please contact our CPMS helpdesk manager, Jurriaan Hölzenspies, using jurriaan.holzespies@radboudumc.nl or the chat function in CPMS 2.0 at the top right of the page.