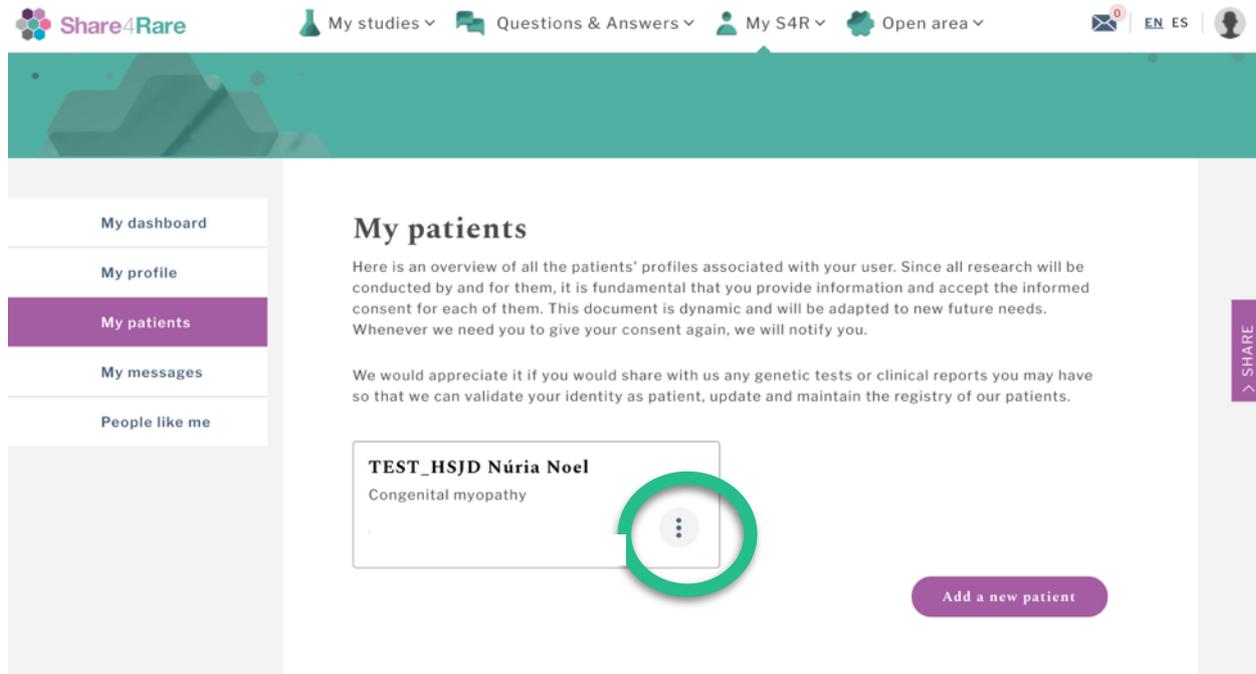


INSTRUCTIONS:

- Go to MY PATIENTS and click on the button of the “3 dots” underneath your registered patient and press EDIT.



- Once you are in, you will see all the data already submitted by you when you first registered the patient to the platform. But now you have to scroll down and get to the 2 final sections named:
  - GENETIC TEST OR CLINICAL REPORT
  - INFORMED CONSENT

a)

**Genetic test or clinical report**

This will be use as a proof of the disease this patient has and will be collected in a patient's registry. If you have a genetic test outcome, please upload it. If you do not have any, upload a medical report where the diagnosis of the patient in question is legible and clear.

[Add a new file](#)

[Upload requirements](#)

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b)

**Informed consent**

Please, [download informed consent form](#) document and read it carefully. Once you have done so, sign it (including your ID document), scan it and upload it so we can include this patient in our studies. We thank you very much for taking these steps.

[Upload requirements](#)

No s'ha triat cap fitxer

In the section a) **GENETIC TEST OR CLINICAL REPORT** you can upload as many documents as you want with Clinical report, relevant test that you think are important to share, etc. This section allow you to upload multiple files but CINICAL REPORT SI MANDATORY.

**Section b) INFORMED CONSENT** is the most important part because in this section you will have to download the blank informed consent and fill in with all the required information to give your OK to use the medical information of the patient and to participate in any type of RESEARCH. Without this informed consent you cannot participate in the community either in any research.

The document you download from the website can be edited by any PDF editor or you can also fill in by hand and then scan or take a picture of it.

The final section of this document includes a section to add the ID of the patient. If you find that adding the picture of the ID (or any document that includes the name and photo of the patient) to the current pdf is difficult, just save this ID document in another file and you will be able to upload it to the section a) GENTEIC TEST OR CLINICAL REPORT.

Once completed you have to upload this document back the platform. Please note that this section only allows one document to be uploaded. For that reason we recommend you to upload the PDF of the informed consent WITH MULTIPLE PAGES here and (in case you have trouble adding the ID to the pdf or you have the infomed consent in different pdfs), upload the extra documents onto the section a) GENTEIC TEST OR CLINICAL REPORT.

Once you have uploaded all the documents you will see the sections like the example below and you can now press SAVE.

#### Genetic test or clinical report

This will be use as a proof of the disease this patient has and will be collected in a patient's registry. If you have a genetic test outcome, please upload it. If you do not have any, upload a medical report where the diagnosis of the patient in question is legible and clear.

ID\_document.pdf

310.37 KB

Remove

#### Add a new file

Trieu els fitxers No s'ha triat cap fitxer

[Upload requirements](#)

#### Informed consent

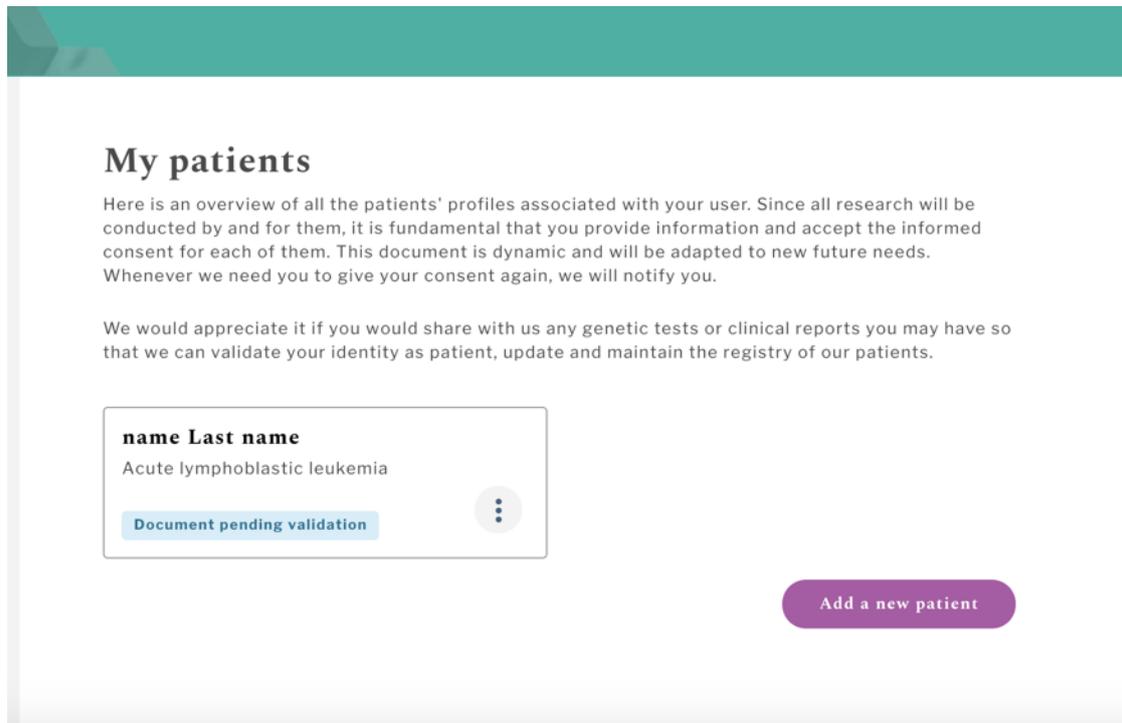
We thank you very much for having signed and uploaded the informed consent document, together with the personal ID document. No further action is required from your part at this moment. We will validate them as soon as possible.

s4r\_informed\_consent\_en.pdf

418.79 KB

Save

You will see, then, that your patient is categorized as DOCUMENT PENDING VALIDATION.



## My patients

Here is an overview of all the patients' profiles associated with your user. Since all research will be conducted by and for them, it is fundamental that you provide information and accept the informed consent for each of them. This document is dynamic and will be adapted to new future needs. Whenever we need you to give your consent again, we will notify you.

We would appreciate it if you would share with us any genetic tests or clinical reports you may have so that we can validate your identity as patient, update and maintain the registry of our patients.

**name Last name**

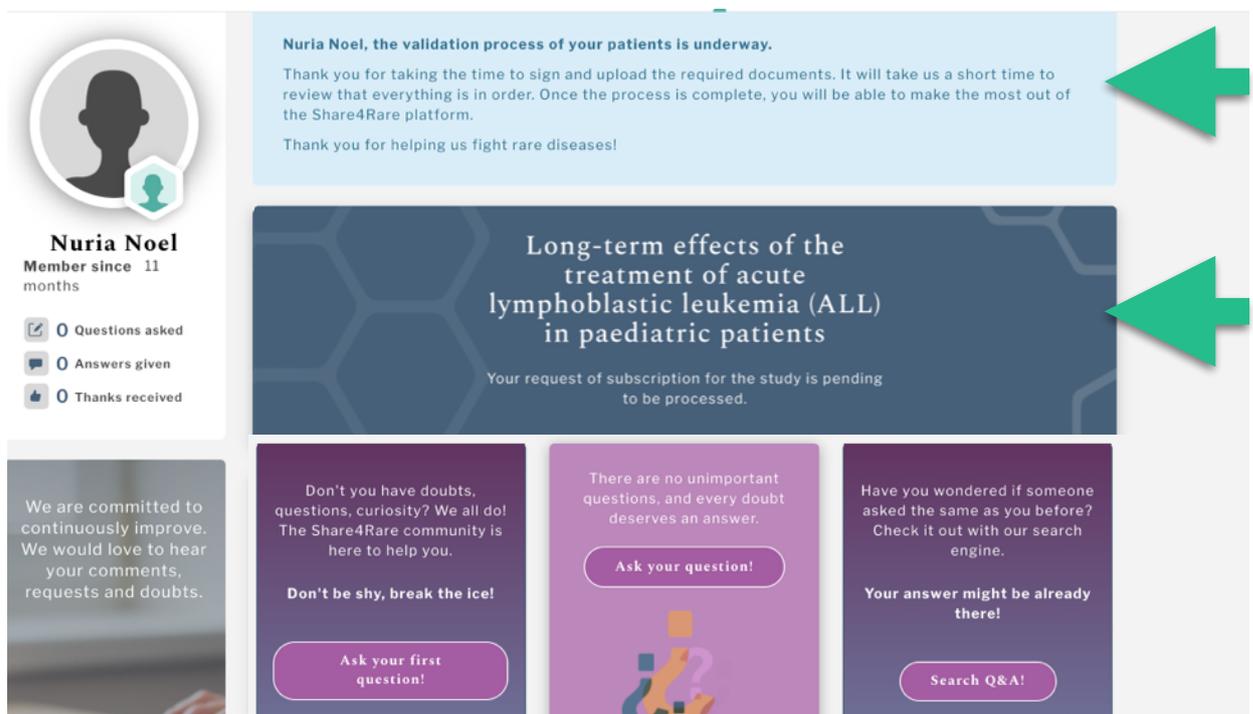
Acute lymphoblastic leukemia

Document pending validation

⋮

Add a new patient

And in your DASHBOARD you will see this message, and if there is any available study research for the disease of the patient, you will find a second message.





**Nuria Noel**  
Member since 11 months

- 📄 0 Questions asked
- 💬 0 Answers given
- 👍 0 Thanks received

**Nuria Noel, the validation process of your patients is underway.**

Thank you for taking the time to sign and upload the required documents. It will take us a short time to review that everything is in order. Once the process is complete, you will be able to make the most out of the Share4Rare platform.

Thank you for helping us fight rare diseases!

**Long-term effects of the treatment of acute lymphoblastic leukemia (ALL) in paediatric patients**

Your request of subscription for the study is pending to be processed.

We are committed to continuously improve. We would love to hear your comments, requests and doubts.

Don't you have doubts, questions, curiosity? We all do! The Share4Rare community is here to help you.

**Don't be shy, break the ice!**

Ask your first question!

There are no unimportant questions, and every doubt deserves an answer.

Ask your question!

Have you wondered if someone asked the same as you before? Check it out with our search engine.

**Your answer might be already there!**

Search Q&A!

Once The Share4Rare Team Validate Your Documents You Will Be Able To Participate In Community And In The Study!