

User Guide for Patients using the MiNDAUS Registry-Part Two

Your privacy

The MiNDAUS Registry is designed and built on a modern, dependable and highly secure platform and has been subjected to rigorous testing. A variety of security measures are incorporated, including sophisticated user permissions, protection of identifying information and end to end encryption.

User permissions ensure that anyone who registers themselves as a patient will only be able to see their own information. Health Professionals at participating Specialist Clinics must be given access following training, and they can only see patients who are enrolled at their clinic.

The information completed in the Registry, whether by patients/carers or by healthcare professionals is stored in a separate place to identifying information such as names and addresses.

As you add information to the Registry it is encrypted (changed into code) so that it is useless for anyone maliciously attempting to access it on the way to the Registry over the internet. As the information is accessed by a registered user, the same strategy is employed- the information is encrypted to protect it.

The MiNDAUS Privacy Policy can be found [here](#)

Table of Contents

Your privacy	1
Support for using the Registry	1
Moving through the Registry	2
Completing the Patient sections	2
Patient sections	3
Recording your symptoms	4
Recording or completing 'calculators'	5
Viewing your clinical data	6
The About Me and MND form	7
Creating the About Me and MND form	7
Inviting your Principal Caregiver to the Registry	8
Using the External Specialist Visit section (optional)	8

Support for using the Registry

If you need help accessing and using the Registry, please read User Guides Part One and Part Two (this one). If you need further support, your State MND organisation may be able to help as they will receive training for this purpose.

You are also welcome to contact the Operations Manager, MiNDAUS Registries for assistance and with feedback at: Catherine.hansen@deakin.edu.au.

User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 1 of 9
<i>File name: UserGuideMindausPatientApril2022PartTwoV01</i>	Hansen/Wyborn	PLEx review: KM/PR	
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Moving through the Registry

You can progress down the page using the scroll on your mouse, grabbing the sidebar on the right-hand side and pulling it down, use your trackpad or use the Tab button on the keyboard to progress through the questions. You can choose to complete the information over a few sessions- it will be safely stored, and you can also update it as changes occur.

Selecting an answer from a multiple-choice field can be done with a mouse click, or by Tab+Spacebar

Important tip: Press the green Save button regularly- at least after each section

Completing the Patient sections

Once you've completed your consents, you can continue through the rest of the Patient sections. Completing them means that your information will be shared with your MND Clinic team if you have selected a clinic. Clicking on the blue name of the section on the left-hand side of the screen will open that form, and you can also go backwards or forwards by using the blue arrows on the left and right side of the screen.

You can update the information in these sections as often as you like or need to as your needs change. You can also share the information by clicking the 'About Me pdf' which fills in a pdf with the details you've entered on the Registry and then email it or print it. The benefit of doing this and how to do it is discussed [below](#).

The Patient Sections can be completed whenever is appropriate for you and can be completed over any number of sessions

The screenshot shows the 'Australian Registry' interface for a patient named Catherine Hansen. The sidebar on the left lists various patient sections, with a red bracket and text indicating that these are some of the patient sections. The main content area displays several sections for completion, including 'Patients Personal Details', 'Language Info', 'Contact Details', 'Patient Preferred Contact Method', 'Patient Address', 'Next of Kin', and 'Medicare, Health Insurance and Support details'. The page includes 'Delete', 'Save', and 'Cancel' buttons.

Patient sections:

My Legal Documents

- An opportunity to identify if you have created legal documents, like an Advanced Care Directive, and to upload them if you wish to.

My recent symptoms (discussed below)

My journey

- My Medical History- a brief medical history.
- My Medications and Allergies- the medicine you take, when you take it, and any allergies.
- My Life History- this is to help introduce you to a new healthcare provider or similar.

My needs

- My Communication- a brief overview of how you need to communicate.
- My Positioning-a brief overview of how you feel most comfortable.
- My Breathing-to explain if you have any difficulty with your breathing and how you manage it.
- My Eating and Drinking Needs- an easy way to share your dietary needs and preferences.
- My Physical Ability-a brief overview of what you can do and what assistance you might need.
- My Personal Care-to quickly identify if you need assistance for different aspects of personal care.
- Mouth Care and Saliva-an overview of how you manage this symptom.
- My Emotions / Behaviour-a chance to explain if you have some extreme or inappropriate emotions so that you can be better understood.

My Calculators (discussed below)

My Care Team

- This section allows you to add details of any healthcare provider involved in your care.

Appointment schedule

Adding appointments here can help you keep track.

Any of the sections above can be changed or updated as often as you need to.

User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 3 of 9
File name: UserGuideMindausPatientApril2022PartTwoV01	Hansen/Wyborn	PLEx review: KM/PR	
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Recording your symptoms

You can select 'My recent symptoms' which will open a list of commonly experienced symptoms. The question is how much each of those symptoms has troubled you in the **last two weeks**.

Each time you wish to record your symptoms, click '+Add'. This will open a new form which will also allow you to compare the score of each of those symptoms with previous scores and the date they were recorded. This might be useful if you have recently commenced a new treatment for cramps, for example, to see how well that symptom is being managed.

The screenshot shows the Australian Registry patient portal for Catherine TEST. The page displays a list of symptoms with visual scales from 'None' to 'Severe' and recorded scores. The symptoms and their scores are:

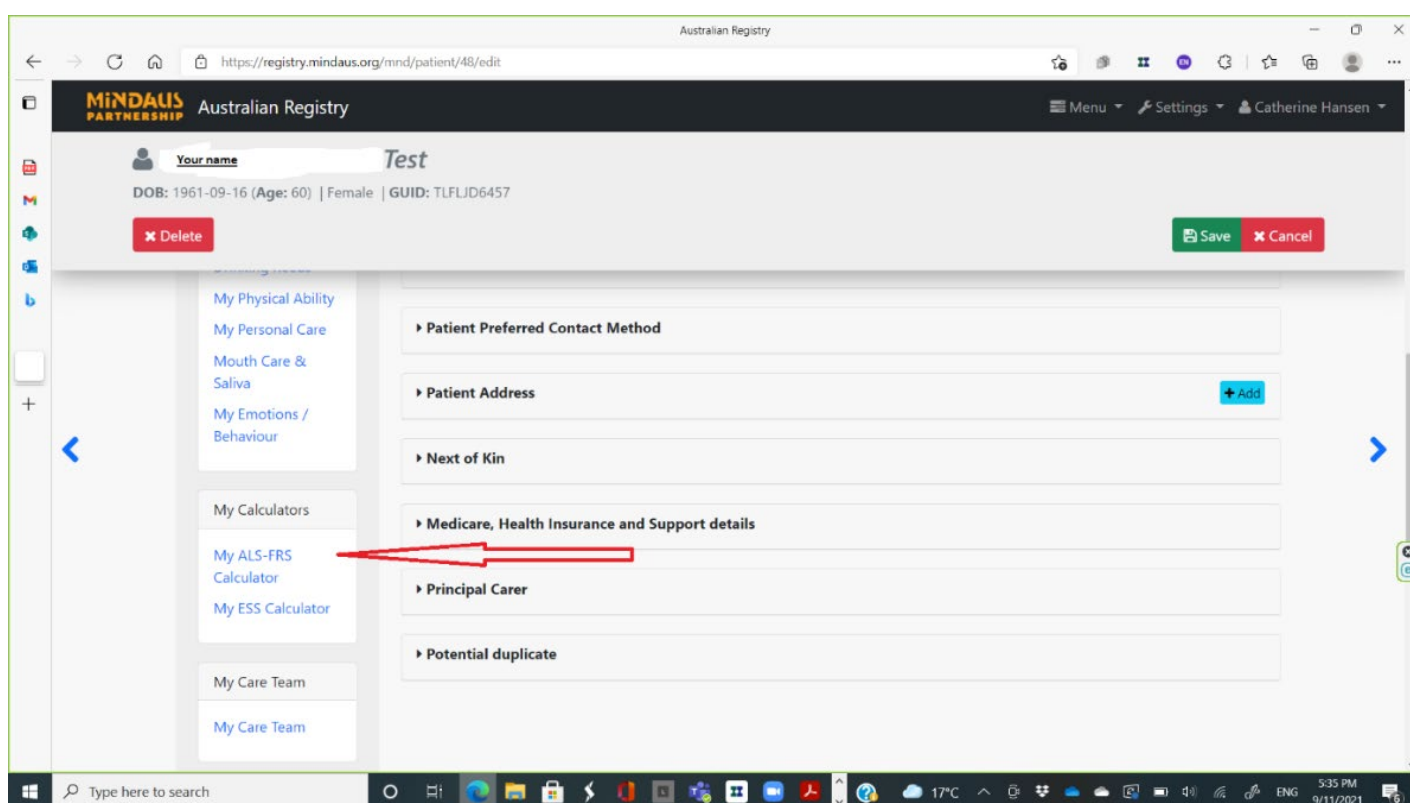
Symptom	Score
Fatigue	5
Pain	2
Muscle Cramps/twitching	5
Excessive saliva	3
Constipation	6
Disturbed Sleep	1
Shortness of breath	3
Stiffness/spasticity	3
Choking sensation	2
Depression	3

Recording or completing 'calculators'

You can complete surveys such as the ALSFRS-R at your discretion and the registry will keep a record of your previous scores. The ALSFRS-R is often used during Specialist appointments as a measure of disease progression.

The Epworth Sleepiness Scale (ESS) is also included and is used to distinguish fatigue from sleepiness. Higher scores indicate excessive daytime sleepiness. Find out about the ESS [here](#). Increased levels of daytime sleepiness can indicate disturbed sleep, and this may need investigation.

Please discuss all survey results with your Clinician.



User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 5 of 9
File name: UserGuideMindausPatientApril2022PartTwoV01	Hansen/Wyborn	PLEx review: KM/PR	
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Viewing your clinical data

Looking at your clinical data may be an important step in self-management and will often contain terminology that you may not understand. Please use reputable sources of information if you need help to understand the terms, measurements and surveys that were completed during your visit. Reputable sources can be your treating Clinician (Neurologist), The Clinic Nurse Coordinator, your MND Association Advisor, your GP or other Health Professional. A reliable website is [MND Connect](#) and there is also an Info Line available from Monday to Friday on 1800 777 175.

The screenshot shows the 'Australian Registry' patient portal interface. The page title is 'Australian Registry' and the URL is 'https://registry.mindaus.org/mnd/forms/32/48/201'. The user is logged in as 'Your name'. The main content area is divided into sections: 'My Appointments' with a link to 'Appointment Schedule'; 'Clinical Visits' with links for 'First Visit' and 'Completion Form'; 'Subsequent Visits' with an '+ Add' button; and 'About Me PDF'. Two red arrows point to the 'Clinical Visits' and 'About Me PDF' sections. A text box explains that selecting a clinical visit form allows viewing but not changing information. Another text box explains that the 'About Me PDF' option creates a report of all entered information. The top right has 'Save', 'Cancel', and 'Print' buttons. The bottom of the page shows a Windows taskbar with the date and time '5:31 PM 18/10/2021'.

User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 6 of 9
File name: UserGuideMindausPatientApril2022PartTwoV01		Hansen/Wyborn	PLEx review: KM/PR
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The About Me and MND form

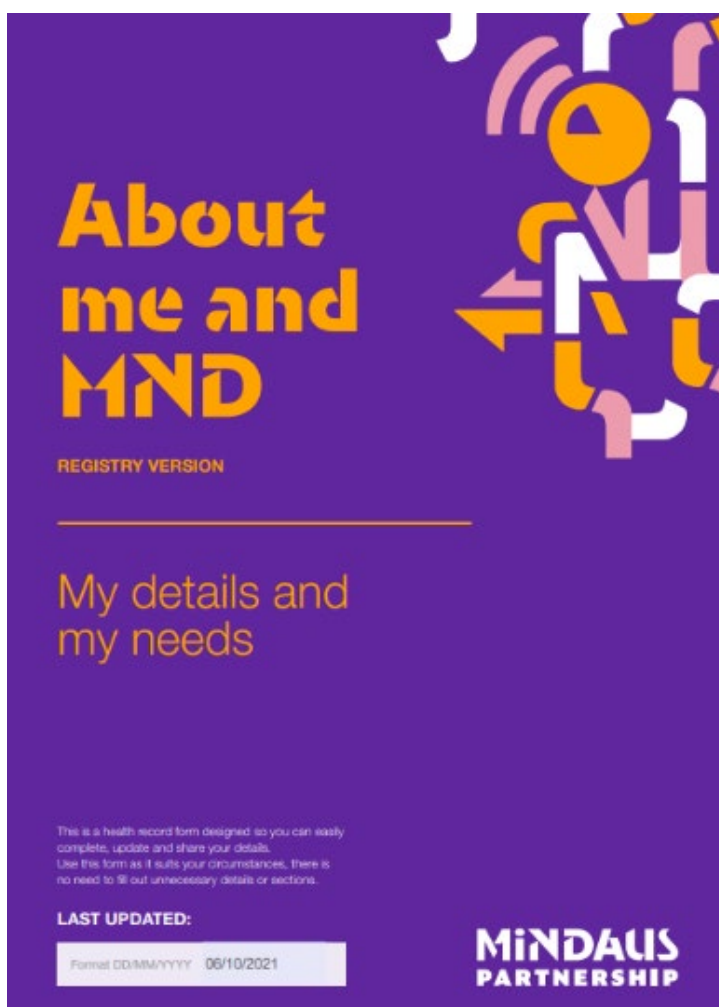
All the details and information you enter onto the Registry will automatically complete onto this form when you create it. Each time the form is created it updates with the latest information.

Creating the About Me and MND form

Once you've entered all your information, create the About Me pdf by clicking the name where it appears on the lower left-hand side of the Registry page (see the image above). The document will open in a new tab in your browser.

The About Me and MND form looks like this and will have a date on the title page which reflects the last time it was created.

This document can then be printed or emailed to share with whomever you like.

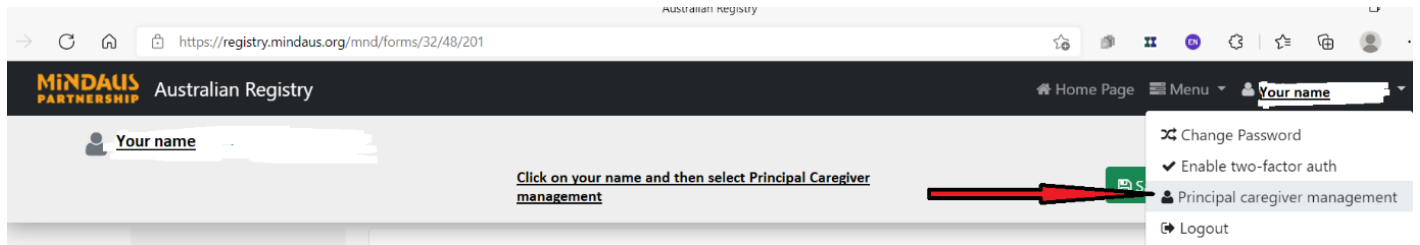


User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 7 of 9
File name: UserGuideMindausPatientApril2022PartTwoV01		Hansen/Wyborn	PLEx review: KM/PR
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Inviting your Principal Caregiver to the Registry

Carers cannot register themselves into the Registry, but you can invite yours. Inviting them will enable them to complete information on your behalf and view the clinical data collected about you. You can only invite one carer to act on your behalf in this way.

This process results in your Carer being sent an email with an activation link. If your Carer changes for any reason, you can deactivate one and invite another as you wish.

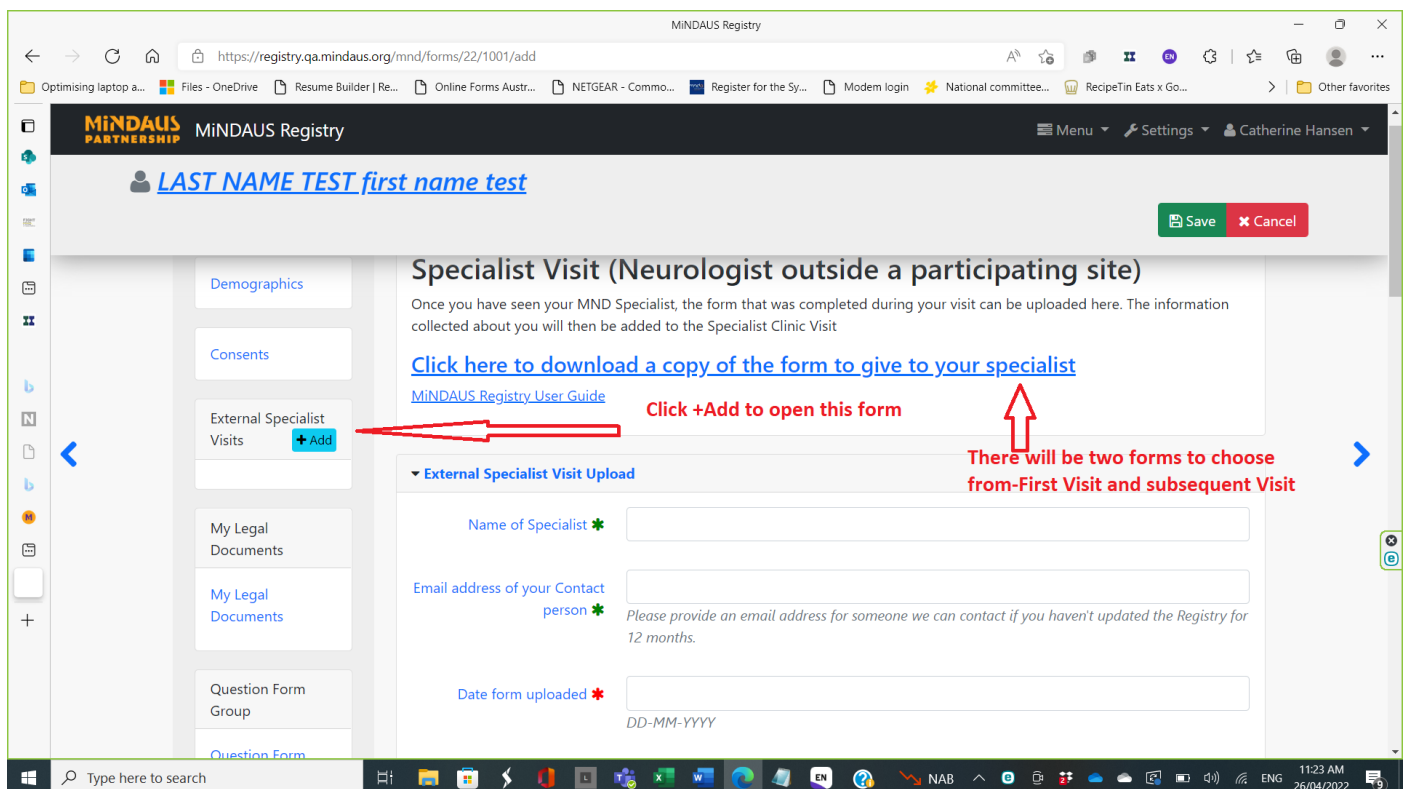


Using the External Specialist Visit section (optional)

This section has been added for patients who do not attend a MiNDAUS participating clinic and may see a Neurologist privately or attend a clinic at another hospital or health service.

It is designed to enable patients in this situation to collect, control and contribute their clinical information.

Before you see your Specialist, download, and print the appropriate form to take with you to your Specialist. If it's the first time you're asking for this to be done, use the First Visit form. If it is a follow up visit, then use the Subsequent Visit form. Please see the screenshot below.



User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 8 of 9
File name: UserGuideMindausPatientApril2022PartTwoV01	Hansen/Wyborn	PLEx review: KM/PR	
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We have designed these forms to enable completion as quickly as possible by the Specialist, with some sections appropriately completed by yourself or your Carer on your behalf.

After your appointment, please scan the paper form to pdf and upload it to this section. Naming the document with your initials and the date of the visit is a good habit or use any convention that makes sense to you.

You will be asked to record the date of this visit and the name of your Specialist. We will also ask you to record the email address of someone we can contact if 12 months elapses when your record is not updated. If this happens, we will contact this person to find out why. If they tell us that you have passed away, we will ask them the date this happened, and it will be recorded. Recording this means that we can understand how your disease progressed which can contribute to our greater understanding of MND. This will benefit other people with MND in the future.

Please discuss this with your contact person so they are prepared. They are welcome to contact the Operations Manager, MiNDAUS Registry with this information at catherine.hansen@deakin.edu.au.

Thank you for participating in the MiNDAUS Registry

User Guide Patient MiNDAUS Registry Part Two	Version: 1.0	April 2022	Page 9 of 9
<i>File name: UserGuideMindausPatientApril2022PartTwoV01</i>	Hansen/Wyborn	PLeX review: KM/PR	
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