User Guide for Patient Registry

The MiNDAUS Patient Registry, found at https://www.mindaus.org aims to give you the ability to enter as much information about yourself as you wish to add, store it in a secure place and allow you to share it when you want. To use the Patient Registry, you only need to consent to two simple statements, and this is done on the site.

Once you are registered yourself, you can invite your Carer to the Registry and they'll be able to update, edit and view your details.

This guide provides a step-by-step process of the steps involved in self-registration and getting started with using the Registry.

The second part of this guide shows you through all the different sections that can be completed by yourself or your carer (if applicable).

Clinical Registry

During registration for the Patient Registry, you'll be able to download and read the full Participant Information and Consent Form about taking part in the Clinical Registry, or you can also access it on the website here.

You will be able to consent electronically to each of the consent sections which are the same as the ones on the pdf

A thorough explanation of the background to the development of the Patient and Clinical Registry and its purpose can be found in the following comprehensive document: MiNDAUS Framework.

Registration

After opening the website click "Patient Self Registration" under the "Access the Registry" tab to begin.
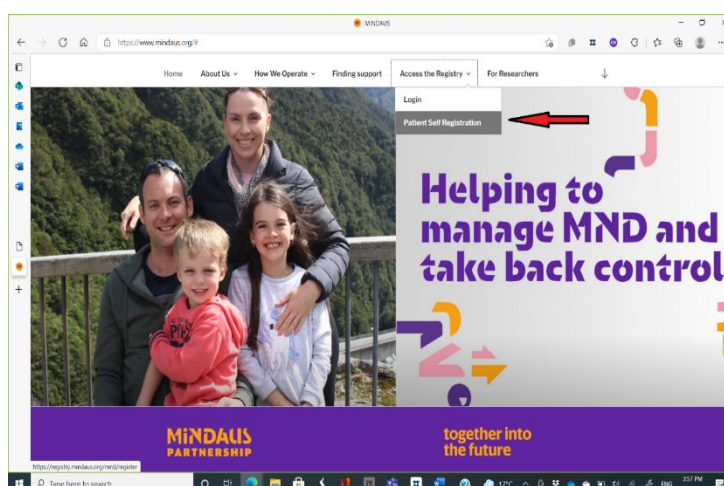
This is the page that you will see next. Complete each field to register.

Your username will be your email address.

Following registration, you'll be sent an email with an activation link. Clicking on that link will take you to the login page.
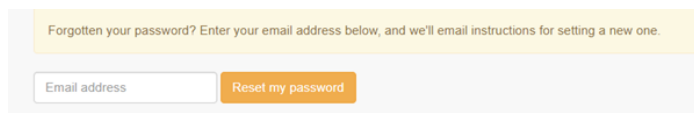
This is the 'login page'. If the email address you used to register is not automatically completed, please fill it in and enter the password you chose (unless your browser has filled it in for you). Use the 'trouble logging in' link if there's a problem with your password.

Forgotten password

This is the screen you will see if you click on the 'Trouble logging in' link.

Enter your email address in this screen and click 'Reset my password' and you will be sent an email. The banner looks like this. If you can't see it, please check your junk or spam folder if you can't see it in your Inbox..

The email will be like this.

Once you click on the link in the email, you'll be asked to create a new password.
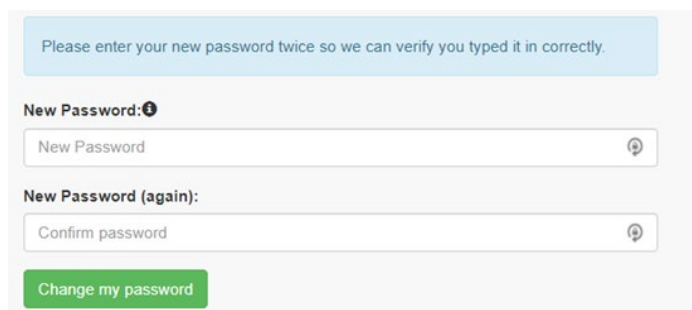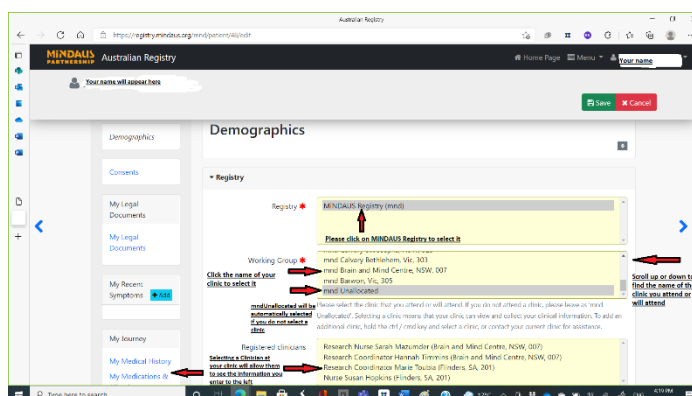
Enter your new password and then click on the 'Change my password' field.

Demographics page

This is the page you will first see once you login. Demographics refers to your basic details, such as which clinic you will attend, your name, address, contact details etc. A screenshot of this appears here.

It is important to select your clinic (if you attend one).

Once those fields have been selected, you can now complete the sections and questions you choose to start creating your own personal record
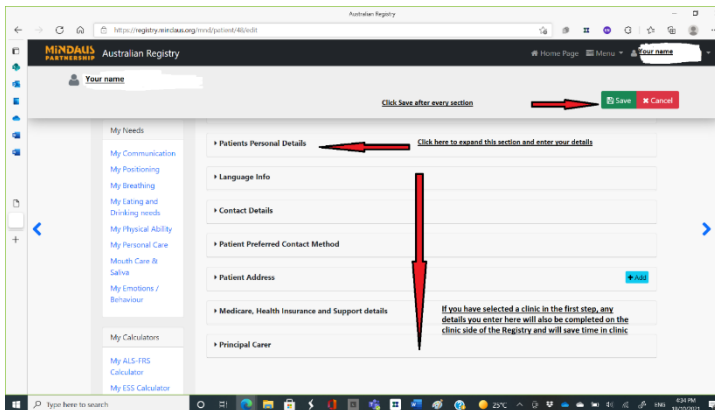
Tips and shortcuts

You can progress down the page using the scroll on your mouse, grabbing the sidebar on the right had 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

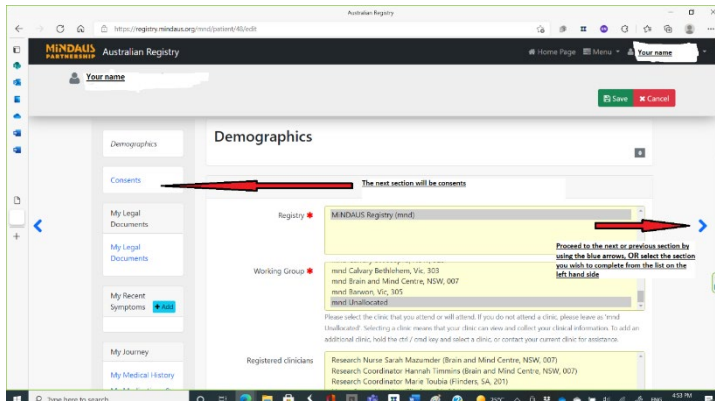**Important tip**: Press the green Save button regularly- at least after each section

There are only a few questions you must answer- these questions are marked with a Red Asterisk like this

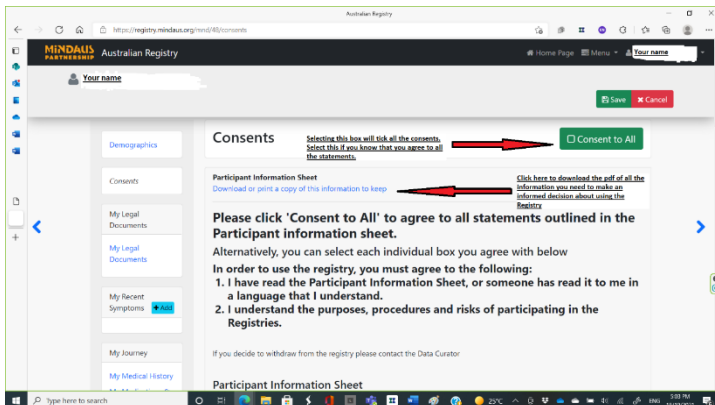Once you've completed this Demographics page, progress to the next section which will be Consents.

Consent section

Access the Consent section either by clicking on the word 'consent' which appears in blue on the left hand side of the screen or by using the blue pointer on the right hand side of the screen.

Please download and read the Participant Information Sheet and then select which consent statements you agree to. This must be done if you want to participate in the Clinical Registry.

Even if you only want to use the Registry for your own purposes (and not take part in the Clinical Registry), you must agree to these two statements:

Once you have consented to all the statements you agree to, either one by one or by selecting 'Consent to all', press Save and then you can proceed to the next sections- covered in Part Two of this guide.