How to Join the UK MS Register Website

- * Go to ukmsregister.org, make sure that you press 'Accept Cookies' if the black box appears at the bottom of the screen, otherwise the website will not work.
- * Enter your email address and choose a password, press 'join'.
- * Next you will find a simple registration form and then a series of questionnaires waiting to be completed.
- * It generally takes just over 30 minutes, but you can save your answers and come back within 24 hours if you need a break.
- * Each finished questionnaire will appear as 'completed' and show the date when you should return again (don't worry we will send you an email reminder).

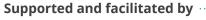
Register online at ukmsregister.org

*Help Make Sense of MS

Your contribution will lead to a better understanding of living with MS and the knowledge we gain from this study will fuel campaigns for fair, relevant policy and improved healthcare for people living with MS in the UK.

To see the kind of results and research that the MS Register generates please visit our website. For any questions or help, please get in touch!

- **** 01792 606354
- contact@ukmsregister.org
- UK MS Register Data Science Building, Swansea University Medical School, Swansea, SA2 8PP
- f facebook.com/UKMSRegister
- twitter.com/UKMSRegister









*Help Make Sense of MS

The MS Register is a ground breaking study designed to increase our understanding of living with MS in the UK.

Join today by logging onto the website and answering questionnaires about you and your MS.

By joining the community and contributing to the MS Register, you will be adding to three years worth of research which will work towards influencing policy and improving the care of Multiple Sclerosis in the UK.

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What is the UK MS Register?

If you are aged over 18, have a confirmed diagnosis of MS and live in the UK, you can join the Register! The MS Register gathers data from two main areas - the website and hospital records.

Both areas are equally important and help generate crucial research, but being involved in both parts creates the richest, highest quality data that researchers can then study to find out more about MS.

*Having these linked sources gives the best data ukmsregister.org Data provided by you from the website hospital records Data from your clinician and your consented record

*Join the 14,000 people who have signed up so far

You can always keep up to date with what the Register team are working on, or what has been published already by visiting our website.



Register online at ukmsregister.org

Website

Whether you have your own computer, tablet or smartphone, or you have a friend or relative who is willing to help, then you can join the online part of the Register. All you need is an email address to log on with and to return regularly to the website to answer your questionnaires. This gives us a 'snap-shot' of you and your MS over time.

Don't worry, you will receive an email reminder when it is time to return. Use the instructions overleaf to log on and start answering questionnaires now! You will receive a quarterly newsletter which will let you know about what we are finding out from all this data.



Clinical Sites

In addition to the online part of the UK MS Register, we are working with a number of NHS clinical sites across the UK. If you attend a clinic at one of these sites then you can also give your consent for your medical information to be securely transmitted to the Register and your clinical details can be 'linked' to your questionnaire results.

Data linkage is the merging of two or more separate data sets (e.g. outpatient information and Portal responses about the same person) for research purposes.

This linked data creates an extremely rich source of information that can be used by researchers to help make sense of MS. For a list of current partner sites, go to ukmsregister.org or ask your clinician for more information.

Confidentiality, Security & Your Data

The UK MS Register collects a large amount of data from as many relevant sources as possible. The security and confidentiality of this data is of the highest importance to us and therefore we ensure that we use the highest levels of encryption and security throughout its collection, storage and use. All data that researchers have access to is anonymised and nothing identifiable is ever released.