

# TONiC Newsletter

## Autumn 2024

Dear TONiC participant,

You are receiving this newsletter because you joined the TONiC quality of life study for people with MS.

We hope this email finds you well and that you are enjoying everything Autumn has to offer! We thank you all for your completion of the questionnaire packs, your views have been included in the largest clinician-verified MS quality of life study in the world!



### **TONiC MS recruitment:**

MS patients recruited to Phase 4 = 4058

MS carers recruited to Phase 4 = 1129

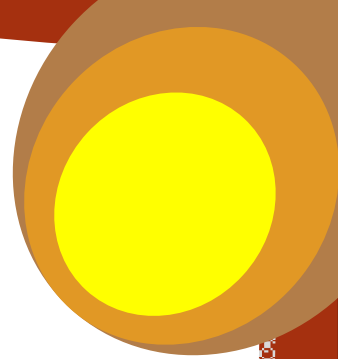
MS patients recruited to Phase 5 = 1524

MS patients recruited to Phase 6 = 446

MS patients recruited to Phase 7 = 710



**TONiC**  
Trajectories of Outcome in Neurological Conditions  
www.tonicstudy.org



## How did you sleep last night?

Researchers at Liverpool John Moores University want to know more about sleep, health and wellbeing in adults (18yrs+) with MS.

### They want to know:

- 1) What helps you sleep well?
- 2) What disturbs your sleep?
- 3) What effect sleep has on your health and wellbeing?

### What does it involve?

You would be asked to complete an online survey, which will take around one hour to complete.

### Are there any benefits to taking part?

The results of the study will be used to help us find ways to improve sleep in people with MS. We will use what we learn from the survey to design a programme that people can do at home to improve their sleep.

The first 500 participants to complete the survey can apply for a £5 Amazon voucher.

### Want to know more?

If you would like to know more about the study, please email [wcft.tonic-sleep@nhs.net](mailto:wcft.tonic-sleep@nhs.net). Please quote your full name, date of birth, address, and NHS number in the email. We will reply with your TONiC number (M number) and link to the participant information sheet and survey. If you do not have access to your NHS number, please call the TONiC team on: 0151 556 3693 and quote your full name and date of birth and this will be provided alongside your TONiC number.



\*The survey has been piloted by a representative panel of adults with MS enrolled in the TONiC Study.



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**LIVERPOOL  
JOHN MOORES  
UNIVERSITY**

# PLEASE WOULD YOU CONSIDER CONTRIBUTING FURTHER TO IMPORTANT MS RESEARCH

It is very important to study how MS changes over time in as many people as possible.

Therefore, if you have not completed a TONiC questionnaire pack at home during the last 12 months, it would be valuable if you would complete another.

Doing additional packs after the first one enables follow-up, and study of change over time. It is phase 4 of TONiC.

Your opinions of how your condition changes could have a significant impact on how you and other people with MS will be treated in the future.

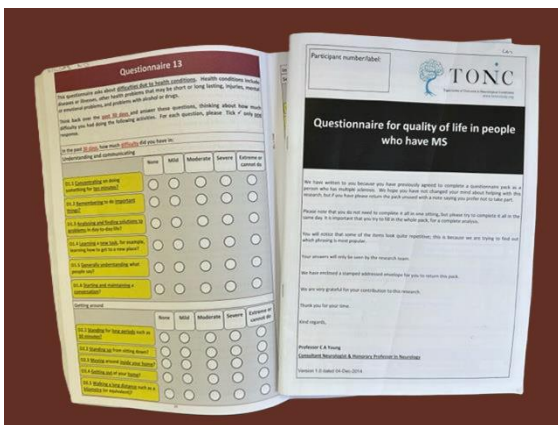
If you have taken part in phase 3 at your local hospital you can contact them to take part in phase 4. If you cannot reach them, please contact us directly using the details at the bottom of this page.

If you have already contacted the TONiC team directly and self-referred, then please contact us again.

To help understanding of the changing effect of MS over time, we need you to do at least one more questionnaire pack.

*If you would like to read more about the study, please click the link below:*

<https://www.finders-study.org/tonic>



This is a TONiC questionnaire pack. Thousands of people with MS have completed at least one of these since 2014 and we are re-contacting as many of our previous completers as possible to ask them if they would be willing to complete another pack, at home, if we post it to them with an SAE. This may apply to you. We can use this information to see how MS changes over time.

We will use your new information to see how MS has changed over time. If you are in TONiC and have changed address or email, please notify us at: **Tel: 0151 556 3693** or **Email: [wcf.tonic@nhs.net](mailto:wcf.tonic@nhs.net)**

# PAPERS PRODUCED ON BEHALF OF THE TONiC STUDY GROUP IN 2024

## ***Prevalence, Treatment and Correlates of Depression in Multiple Sclerosis***

*Young CA, Langdon D, Rog D, Chhetri SK, Tanasescu R, Kalra S, Webster G, Nicholas R, Ford HL, Woolmore J, Paling D, Tennant A, Mills R; TONiC study group.*

*Summary: Depression is common in the MS population. Patient reported outcome measures (PROMs) that examine depressive symptoms are often used to determine the prevalence of depression in people with MS. Participants were enrolled from the TONiC-MS project and provided demographic data, PROMs, co-morbidities, and medication information. A multi-attribute estimate of depression in MS is essential because using only screening questionnaires, diagnoses, or antidepressant medication all underestimate the true prevalence. We found that baseline data in 5633 participants showed the prevalence of depression to be 25.3 %, and almost half of those with depression were either untreated or still had symptoms indicating probable depression despite treatment. Services for depression in MS must be pro-active and flexible, recognising the diversity of outcomes and reaching out to those with ongoing symptoms.*

Link: [Prevalence, treatment and correlates of depression in multiple sclerosis - Multiple Sclerosis and Related Disorders \(msard-journal.com\)](https://www.msard-journal.com/articles/10.1007/s00485-024-01000-0)

*If you would like to read more of our research papers, please click the link below:*

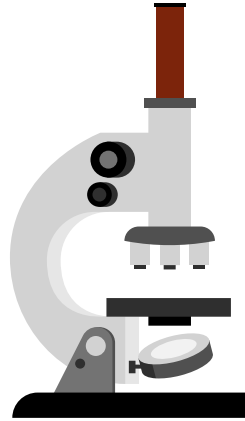
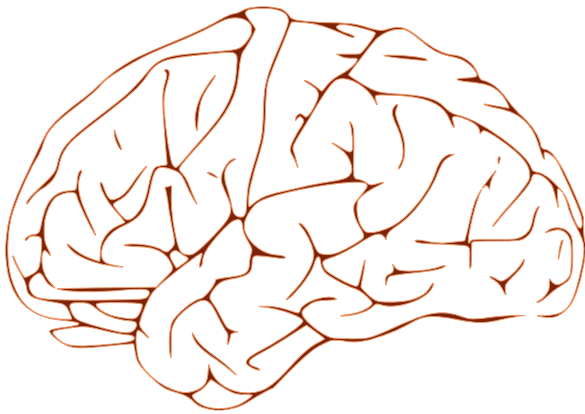
<https://www.finders-study.org/research-papers>



Having done MS clinics since 1988, I know that many people with MS share my aim of improving MS care. The TONiC study is already improving care, but we need more follow-up because this is a long-term condition. Please consider ticking through another pack at home, we will compare against your previous answers to study the impact of MS over time.



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*The Walton Centre NHS Foundation Trust*  
**TONiC Team**  
*Sid Watkins Building*  
*Lower Lane, Fazakerley, Liverpool*  
**L9 7BB**

Where can I get more information about TONiC?

**Tel: 0151 556 3693**  
**Website: [www.finders-study.org](http://www.finders-study.org)**

Thank you all so much for your input so far - the results will help to improve future care for people with MS!

We are grateful for support from several organisations, including:



**NHS**  
**National Institute for  
Health Research**

**NHS**  
**The Walton Centre**  
NHS Foundation Trust