

TONiC Summer updates July 2025!

Summer is here!

Dear participant,

You are receiving this newsletter as you are a member of the TONiC study for people with MS.

We hope this newsletter finds you well!

We have some exciting news and updates for you!

This newsletter is going to include:

- [Sleep study](#)
- [Co-production event May 2025](#)
- [Website updates](#)
- [An opportunity for your friends and family to get involved with research at The Walton Centre](#)

Sleep study: How did you sleep last night?

TONiC and researchers at Liverpool John Moores University (LJMU) are studying sleep in MS

We want to know more about sleep in preparation for developing an app or some other non-drug way of helping people with MS sleep better. This is an important aim because MS symptoms are easier to manage on days when people with MS wake up refreshed - so we want to improve sleep.

What does it involve?

You would be asked to complete an online survey, which will take around one hour to complete. You can do it at home on a computer, laptop, tablet or phone.

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

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 take part in the survey or wish to know more about the study, please email **wcft.tonic-sleep@nhs.net**. Please quote your full name, date of birth, address, or your NHS number in the email. We need these details so we can cross-match to your TONiC number, which we will provide to you because you need to enter it on the online survey. If you have trouble finding these details, please call the TONiC team on:

0151 556 3693 and quote your full name and date of birth and we will be happy to help you.

In collaboration with...



Join the sleep study here!

Important information

Please make sure you know your TONiC number before you complete the sleep study survey.

Your TONiC number will begin with an M followed by 4 numbers and then a hyphen and finish with two letters in the format M****-**.

If you already know your TONiC participant number, please click 'Join the sleep study here' at the bottom of the page or scan the QR code.

If you do not know your TONiC number, please email wcft.tonic-sleep@nhs.net, and quote your full name, date of birth and NHS number.

[Join the sleep study here»](#)



Sleep study: What are we doing with your input?

On Saturday 24th May 2025, TONiC and LJMU hosted a **Co-production event @ The Walton Centre** to hear your views on sleep and wellbeing! Thank you so much to those who attended, your feedback is important to us.

What is co-production?

Co-production is an approach to service design, delivery, and evaluation in which service users, or those affected by a particular issue, and the professionals who assist them, work together as equal partners. In this case, we wanted people living with MS to help design advice on sleep and wellbeing that can be used to help people living with MS.

Why did we offer a co-production event?

Co-production actively engages people with lived experience in creating solutions that address their needs and wants, whilst also giving professionals a better insight into patient views.

What happened on the day?

We had a lecture on sleep from Dr Tara Kidd, a Health Psychologist from Liverpool John Moores University.

Professor Young talked on co-production and TONiC.

Finally, we looked at what is already available (as we do not wish to re-invent the wheel) and whether it met the needs of people with MS.

Don't worry if you didn't attend the co-production day, the answers from your sleep study survey will still help to shape the future tools used for wellbeing and sleep in MS!

Take a look at some of the pictures below from the event!





Website Updates!

We've made improvements to [our website to make it easier for you to learn how your data is helping advance science and healthcare.](#)

We have created [this document](#) to assist you in navigating the TONiC papers on our website. Hopefully after reading this, you will:

- Be able to access our catalogue of over 50-peer review research articles
- Know how to find TONiC research papers that are interesting and relevant to you
- Be more familiar with the terms that are commonly used in our research papers

CONTROL RESEARCH PARTICIPANTS NEEDED!

Help establish the UK normal ranges for neurofilaments (nFL) by donating a blood

sample!

We are looking for control participants to form the baseline level of neurofilaments in the UK. Please reach out to friends, spouses, relatives and neighbours to come down to **The Walton Centre** and donate anytime between **8:45am and 2:30pm Tuesday - Friday!**

*You can also donate at St Bart's hospital in London, if this is closer to you, but these days and times may vary.

St Barts London: 020 7882 2327

What is a neurofilament?

Neurofilaments are a type of protein that holds up the structure of a neuron. When neurons are damaged through disease or injury, these neurofilaments are released into the blood. High levels of neurofilaments in blood can mean neuronal damage and are often used as a biomarker for various neurological disorders. Measuring neurofilament levels can help diagnose and monitor disease progression. But we need to know what normal levels look like so we can compare.

 We are looking for people who:

Are aged between **20 years & 70 years old**
Have **no neurological disorder** (e.g. Epilepsy, MS, MND)
Are willing to **donate 2 teaspoons of blood**

What will participants be asked to do?

- Visit the Neuroscience Research Centre in the Outpatients Department of the Walton Centre **once** (for about 10 mins), at a time and date that suits them.
- Sign a consent form
- Provide 10 mls of blood – 2 teaspoons.
- Complete a short, one side A4 questionnaire about things like age and height.

[Find out more about the study](#)



What will we do with your samples?

The samples you give will be used to set the normal range for neurofilaments in the UK!

The UK currently relies on normal ranges from neurofilament levels of volunteers from countries like US and Switzerland; however, it is known that each country should establish their own normal ranges.

Neurofilaments are being explored as biomarkers for disease activity in people with MS. We must have 'normal' ranges to compare any blood tests from patients.

It's vital that people like you take part, so that when patients have this test in future, we can properly assess its meaning.

Commonly asked questions...

What classes as a neurological disorder?

Neurological disorders are conditions that disrupt the normal functioning of the brain, spinal cord, and nerves.

Common examples include Epilepsy, Multiple Sclerosis, MND, Alzheimer's and Parkinson's disease.

I had a stroke a few years ago, can I still take part?

YES. If you had a stroke more than 2 years ago, you can take part.

Can I still take part if I am neurodiverse?

YES. People with neurodiversity such as ADHD, autism, dyslexia and dyspraxia can still take part in the study!

I have a psychiatric disorder, can I still take part?

YES. Conditions such as stress, anxiety, depression and bipolar come under the umbrella term of neuropsychiatric disorder, rather than neurological.

If you are still unsure if your condition classes as a neurological disorder, please contact the TONiC team on 0151 556 3693.

[More examples of neurological disorders](#)

In collaboration with...



Contact us

If you have any questions regarding the information provided, please contact us here:

[Contact us](#)

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