

TONiC Summer updates August 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:

- [Website updates!](#)
- [Sleep study](#)
- [Co-production event May 2025](#)
- [An opportunity for your friends and family to get involved with research at The Walton Centre](#)
- [TONiC Questionnaire Packs](#)
- [Patient Partner Group meetings - get involved!](#)

Website Updates!

We're continually making improvements to [our website](#) to make it easier for you to learn all about our research, how you can get involved, and how your data is helping advance science and healthcare.

We have created [this document](#) to assist you in navigating our website.

Hopefully after reading this, you will:

Find out what happens
to the data we collect
from your
questionnaire packs

Be able to access our
catalogue of over 50-
peer review research
articles

Know how to find
research papers that
are interesting and
relevant to you

Understand what a
research paper is

Be more familiar with
the terms that are
commonly used in our
research papers

Sleep study: How did you sleep last night?

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!



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 establish the normal range for neurofilaments in the UK. Please reach out to friends, partners, and relatives to come 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 Bart's 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.

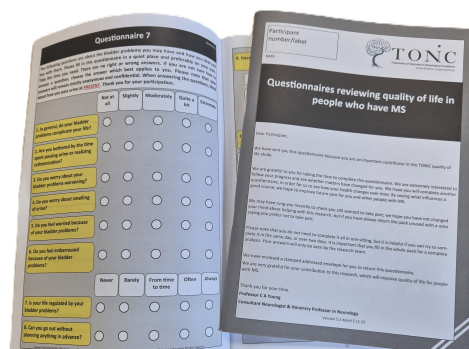
More examples of neurological disorders

In collaboration with...



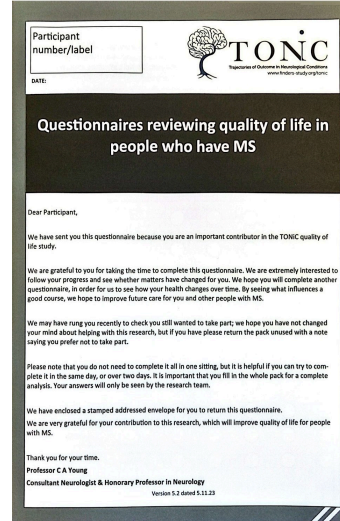
Questionnaire packs

This is a TONiC questionnaire pack. 6841 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**



Get Involved in Patient Partner Group (PPG) discussions!

What is a Patient Partner Group (PPG) discussion?

We are very keen to engage with our participants in a group discussion to talk about different aspects of our research.

These are called **Patient Partner Group (PPG) discussions**, as you are our research partners!

We believe that the quality of our study will be greatly improved by incorporating different perspectives and experiences from you and other people actually taking part in the study.

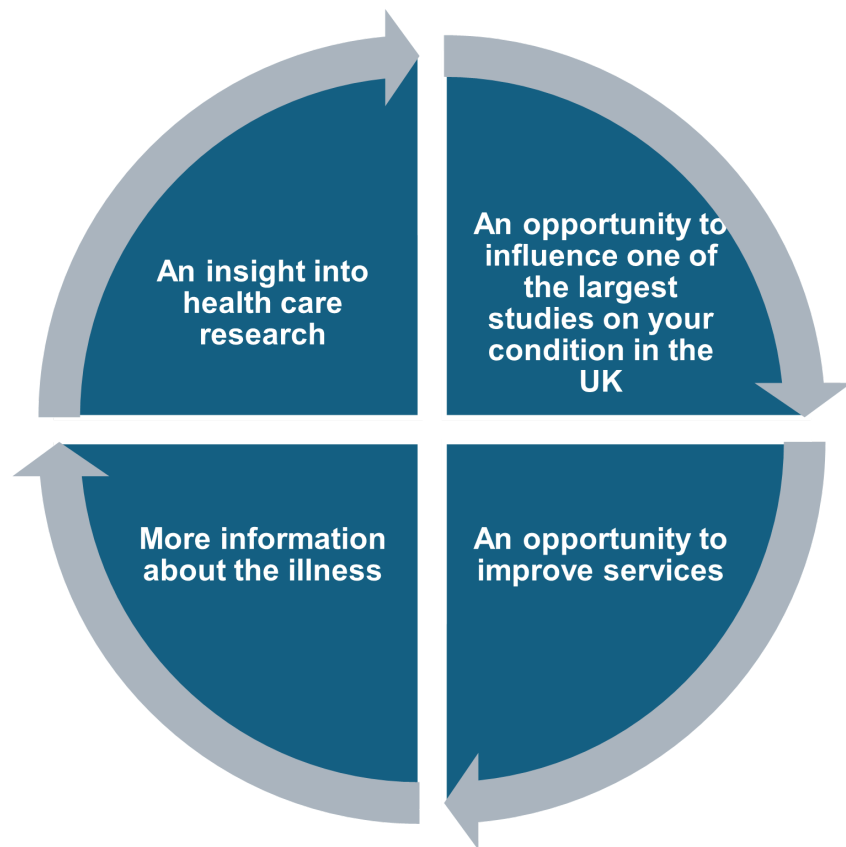
Please note that the discussion is not for clinical purposes.

What would involvement include?

PPG discussions will be held **online with Professor Carolyn Young**. If you prefer, you can attend the online meeting accompanied. Other participants with your condition and TONiC team members will be also attending the meeting.

You can have your camera turned on or off during the meeting and can use a nickname if you prefer. You are very welcome to contribute as much or as little as you wish. Joining one meeting does not oblige you to join the future meetings.

What are the benefits?



Interested in PPG discussions?

If you are interested in joining PPG discussions, please send an email to: **wcft.tonic@nhs.net** with your full name, DoB, and NHS number (if possible), so that we can find you on the TONiC database.

Contact us

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

Contact us

Lower Lane. Liverpool, L9 7LJ

Please note that unsubscribing does not equate to withdrawal. If you would like to withdraw, please contact TONiC directly using the link above

Lower Lane, Liverpool, L9 7LJ