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## Merry Christmas from the TONiC Team!

### Christmas is here! 🎅

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Dear

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 includes:

- [Patient Partner Group meetings - get involved!](#)
- [MSIS-29: What to expect in your TONiC pack](#)
- [Phase 5 consent: Linking your data](#)
- [Take part in our TONiC Targets survey!](#)
- [Sleep study with LJMU](#)

- [TONiC Questionnaire Packs](#)
  - [DNA Collection: At-Home Genetic Testing](#)
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## Get Involved in Patient Partner Group (PPG) discussions!

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### 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.

We now conduct PPG sessions of an evening and daytime once a month. Please do not attend both sessions, as the content is exactly the same.

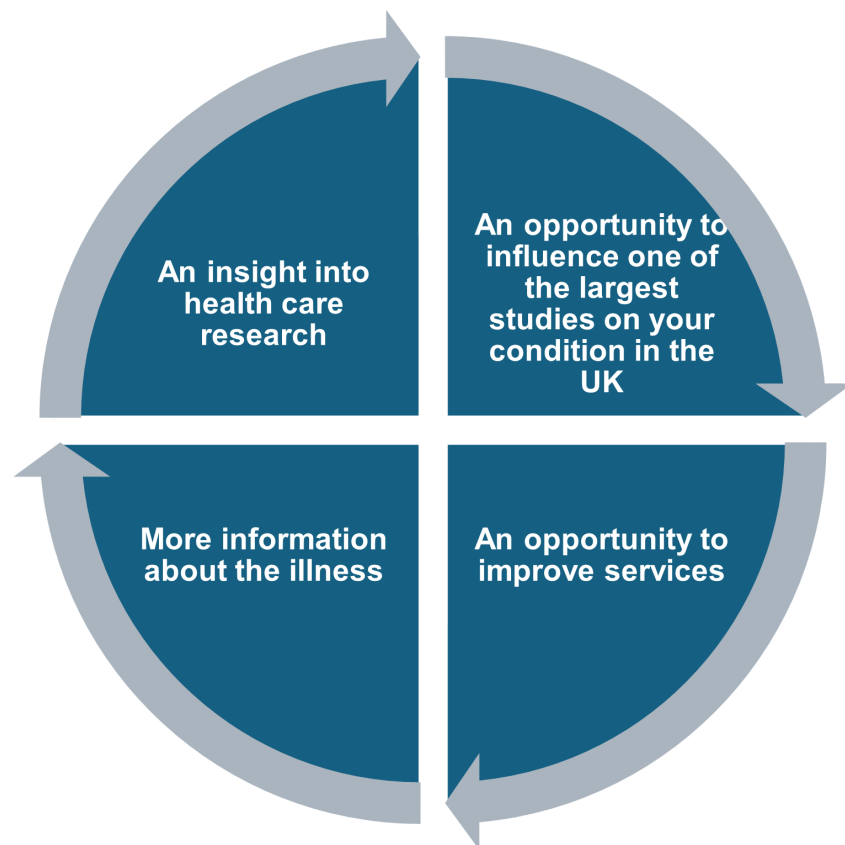
*Please note that the discussion is not for clinical purposes.*

### 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 also be 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.

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## MSIS-29: Why your pack may look a little different this time

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When you receive your next TONiC pack, you may notice an extra one-page questionnaire (29 items) in your pack.

This is for an important project comparing the two versions of the Multiple Sclerosis Impact Scale (MSIS-29), a widely used measure in MS research and clinical trials.

Both versions have been in use for over a decade, but researchers currently can't reliably convert results from Version 1 to Version 2.

An analogy would be that the original conversion between stones and kilograms required using both scales simultaneously to find the correct ratio. That is exactly what we need to do here.

To create a conversion chart, we need **500 people** to complete **both versions on the same day**. To avoid doing them back-to-back, we've placed the extra page either at the front or back of your pack—half of you will complete Version 1 then Version 2, and half the reverse. The extra questionnaire is just one sheet of A4.

By spending just a few extra minutes completing the additional page, you'll help make future MS research more accurate and comparable worldwide. Once we have enough responses, we'll publish a conversion table for everyone who uses the MSIS-29.

If you receive a pack that does not contain the additional page, please do not worry, and complete your pack as you normally would. As this research is only for 500 people, not all of you will receive the extra page.

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## Phase 5 - Help us to link your data!

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### What is it?

Phase 5 is about linking TONiC with other health studies, hospital records and scans (like MRI). This will give us powerful insights into what influences disease severity and quality of life – from genetics to treatments.

Phase 5 allows us to:

- Contact you in the future about relevant research opportunities.
- Link data from the TONiC study to future research.

### What's involved?

- ✓ We will stay in touch to contact you about related future research
- ✓ No active participation
- ✓ No extra hospital visits

- ✓ No new tests
- ✓ Just permission to link information already collected about you!

### Why take part?

- Help researchers answer important questions about neurological conditions
- Contribute to improving future care and services
- Stay at the heart of one of the UK's leading neurological research projects
- Your choice, your control.

Whatever you decide, your hospital care will not be affected.

## Sign up here!

### How to sign a Phase 5 consent form

You can read the Participant Information Sheet and sign the Consent Form electronically by clicking the button below:

Phase 5 consent

Signing this consent form does **not** mean you are obligated to take part in future research.

**If you find it difficult to access the link, please contact the TONiC team with your name and date of birth or NHS number and we will help you.**

Summary of Phase 5

## TONiC Targets Survey: We need your views!

The TONiC team is planning future research and would really value your opinions.

As you would have noticed as someone who is living with MS, MS isn't a 'one-size-fits-all'.

We aim to understand why people with MS experience such different outcomes and how we might better predict the course of MS early on.

To support this important work, we have launched a sister study, FINDeRS, which looks at factors that influence MS prognosis. Improving prognosis could help guide treatment decisions, offer reassurance, and provide better support—but we also want to understand any concerns people may have.

We would especially like your thoughts on two key questions:

**1) Should researchers look for methods to predict who is likely to do well and who may be at risk of a more severe MS course?**

**2) Is it OK to ask people with MS if they are willing to have a research lumbar puncture, even if you are the doctor that looks after them?**

Your feedback will directly shape how we design future studies.

**Please take a moment to complete our short survey below:**

[Complete the survey here!](#)

## **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?**

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...



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## Join the sleep study here!

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To join the sleep study, please click the button below, or scan the QR code.

**📌 Important:**

**You'll need your TONiC number to take part. Please see your TONiC number below:**

Please enter it correctly so we can register your responses properly.

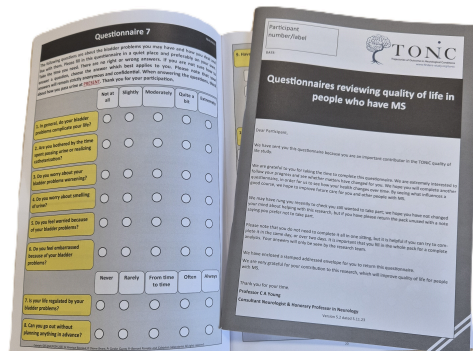
If you are unsure whether you have already completed the sleep study, or want further information, please email wcft.tonic-sleep@nhs.net, and quote your TONiC number, or your full name, date of birth and NHS number.

Join the sleep study here»

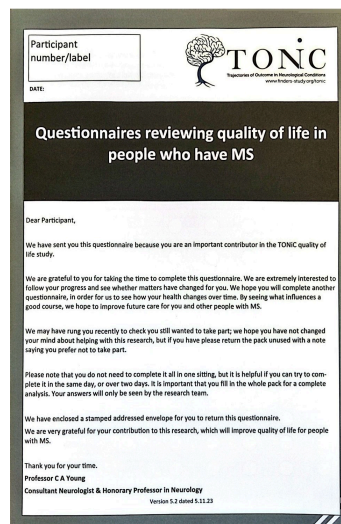


## TONiC Questionnaire packs

This is a TONiC questionnaire pack. 6851 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.



If you are in TONiC and have changed address, please notify us at: **Tel: 0151 556 3693** or **Email: wcft.tonic@nhs.net**



The last time you completed a questionnaire pack was . If you have not completed a questionnaire pack in the last 12 months, please contact us using the information below, and we will post one out to you.

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## DNA Collection: At-Home Genetic Testing

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We are working with Regeneron, a US-based biotech company, to secure funding for genetic testing in 5,000 TONiC participants. Regeneron has already supported testing in over 3 million people worldwide and is currently collaborating with the UK Biobank (though not specifically on MS research).

### What would the study involve?

Participants would provide a saliva sample at home, returned with their usual questionnaire pack. No hospital visits would be required, and all materials and instructions would be provided.

### Where are we now?

We are progressing through the legal and contracting process with Regeneron. The study can only begin once contracts are signed and Walton management has approved data-storage safeguards.

### What do you need to do?

Nothing for now. If the study is approved, we will contact you to ask if you'd like to take part. Please ensure you have signed a **Phase 5 consent form** if you wish to be informed about genetic research opportunities, otherwise we will be unable to invite you.



## Contact us

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

Contact us

Find out more about us at our website:

Visit Our Website

Lower Lane. Liverpool, L9 7LJ

Please note that unsubscribing does not equate to withdrawal from the study.

To update your details or change your subscription preferences, please click [here](#)

Lower Lane, Liverpool, L9 7LJ