TONiC Summer updates July 2025!

Dear TONiC participant,

You are receiving this newsletter because you joined the TONiC study for people with MND.

We thank you for your completion of the questionnaire packs, which have helped to improve understanding and care for people with MND.

We have updates regarding new studies and about our ongoing studies.

This newsletter includes:

- Updates to our website
- Patient Partner Group (PPG) information
- Teleheath in MND Research (TiM-R)
- 'Jumping Genes' and how to donate blood if you are a patient at the Walton Centre
- An opportunity for your friends and family to get involved with research at the Walton Centre

---

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

---

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.

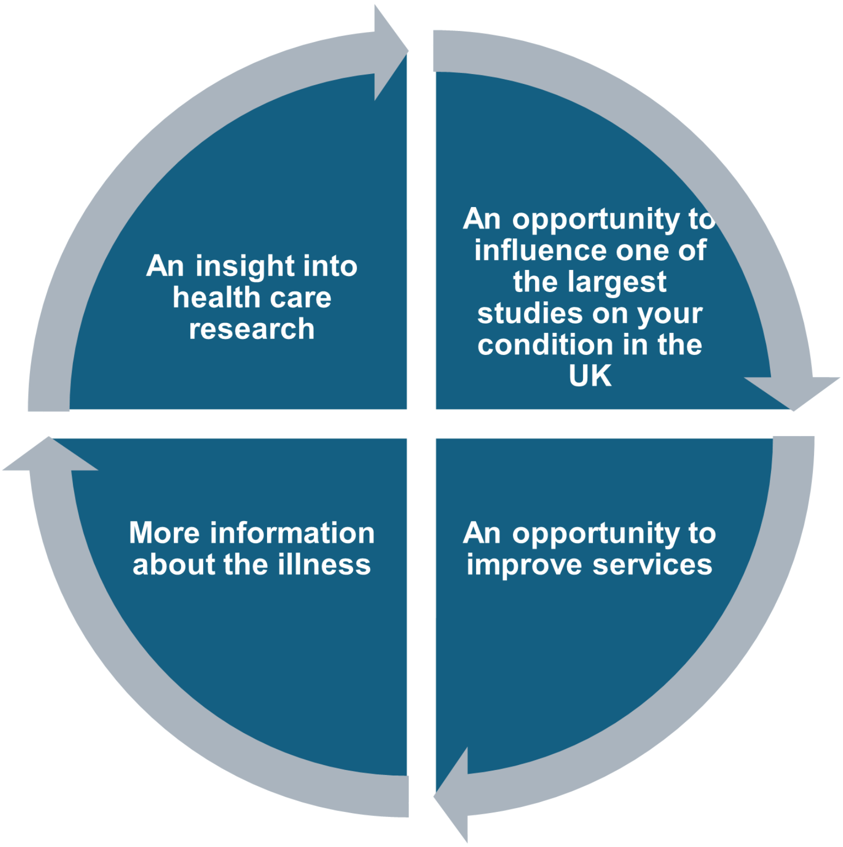
Please note that the discussion is not for clinical purposes.

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.

Telehealth in MND-Research (TiM-R)

Telehealth in MND-Research (or TiM-R for short) is an online service to enable people with MND to engage in research regardless of where they live. All you need is a phone, or any internet connected device.

TiM-R is easy to use and another way to keep up to date with research news, or possibly receive invitations to studies that you may be interested to participate in.

Some but not all of the TONiC questionnaires are available on TiM-R. If you are doing the regular questionaires on TiM-R, please let us know and we can send you a reduced paper pack, just containing the missed questionaires.

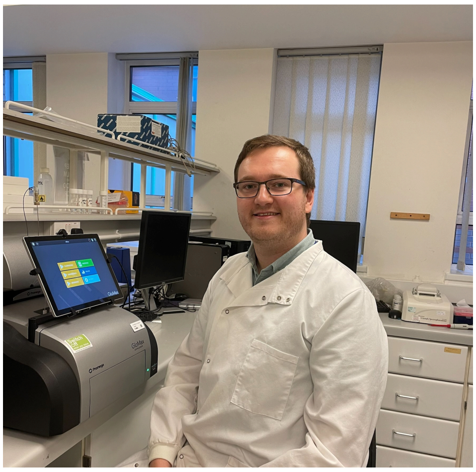
If you prefer paper completion of TONiC questionnaires, you are welcome to continue with paper. Please just email or ring us to let us know your preference.

'Jumping genes' - what are they?

We have collaborators at the University of Liverpool:

- Professor John Quinn - Chair of Neurobiology at the University of Liverpool

- Dr Ben Middlehurst - Tenure Track Fellow in the Department of Pharmacology and Therapeutics



John and Ben are identifying and characterising biological pathways and genetic variations that underpin risk for and progression of MND.

Embedded within national and international consortia, they use state-of-the-art cell models and computer analysis to identify new targets that could modify MND progression.

In particular, they focus on what are called **'jumping genes'**, which are highly variable in our DNA and have been found to tip the balance between healthy ageing and disease.

They have demonstrated in many publications that variation in these regions correlates with MND.

The challenge now is to translate those findings into the clinic, with TONiC being one route forward to help predict an individual's disease progression and the most appropriate care to allow for a better quality of life.

This work is currently funded by MNDA.

Previously, it has been supported by studentships from the Wellcome Trust, Medical Research Council (MRC), Biotechnology and Biological Sciences Research Council (BBSRC), University of Liverpool and The Pain Relief Foundation

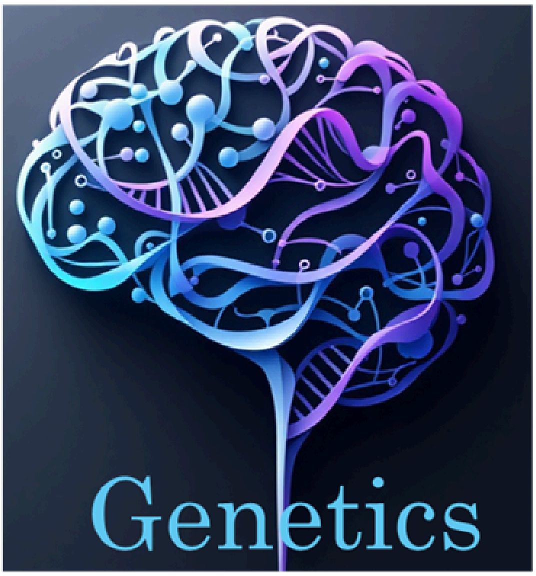
Can I get involved?

To monitor how these genes behave over time ('longitudinally'), we need to take blood samples on several occasions.

If you are a patient based at the Walton Centre:

We may contact you if you have an upcoming appointment, asking you if you wish to donate a blood sample

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



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. Neurofilaments (NfL) can be used to monitor treatment, by measuring NfL levels over time we can assess the effectiveness of potential treatments for MND.
But we need to know what normal levels look like so we can compare. So we need people without MND to give 2 tspns of blood.

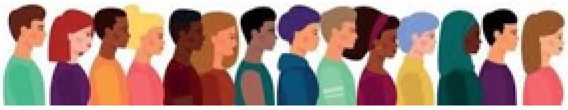
📢 We are looking for people who:

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



Contact us

If you believe you have been sent this in error, please let us know.

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

Contact us

Lower Lane. Liverpool, L9 7LJ