

The year 2020 has not been as anyone of us either expected or planned. When the bells rang in the New Year, none of us had heard of COVID-19 let alone contemplated that in less than 3 months' time, we would be in the grips of a highly contagious viral pandemic and be in lockdown.



*"We moved the majority of our clinic appointments from face to face to either telephone or video conference appointments. This included the patients we would normally see out in our satellite clinics across the Network.*

*"However, we felt that it was very important to continue to see people who were being diagnosed with MND in a face to face appointment and not in a virtual appointment setting.*

*"We kept in regular contact with all of the people living with MND, and the work that the MND Association volunteers did to help us keep in contact with everyone was extremely helpful, they contacted people they knew as well as offering support to people who they hadn't previously been in contact with."*

The MND Register has two methods of recruitment. The first and (up until COVID-19) most often used is face to face recruitment. As part of a clinical appointment, potential participants are asked if they would like to take part in the MND Register and then key questions are asked such as when did the first symptoms occur and what they were.

The second way to join the MND Register is via the self-registration website. This is where a person living with MND can register themselves and provide the information that is securely sent into the MND Register database.

COVID-19 has meant that the MND Register has had to adapt to the changing times and this has impacted on the recruiting sites in a number of different ways.

Some recruitment sites (Care Centres and clinics) have been able to continue to get patient consent through newly established virtual clinics but the majority instead are encouraging people with MND to join the MND Register via the self-registration website.- <https://mndregister.ac.uk/>.

We caught up with the Norfolk MND Care and Research Team (who appeared in our Winter 2020 edition of Thumbprint) to see how COVID-19 has impacted them.

*"At the start of COVID-19, there were several staff, particularly within our community trusts who had to undergo re-training and moved into frontline roles.*

*"We moved the majority of our clinic appointments from face to face to either telephone or videoconference appointments. This included the patients we would normally see face to face out in our satellite clinics across the Network.*

Unfortunately, COVID-19 has not just impacted the 32 Care Centres and Clinics that were recruiting participants into the MND Register, but has also impacted those that are trying to get approvals in place to start recruiting.

As you might expect research associated with Covid-19 is being prioritised for ethical approval within the NHS. We therefore expect to see significant delays in sites getting approval to start recruitment. At this stage, we don't know what the impact will be of these delays but will update you as soon as we know more.

The final word goes to Professor Ammar Al-Chalabi, the co-lead for the MND Register *"While COVID-19 has meant that we have had to change the way that people are able to sign up to the MND Register, we have not stopped recruitment completely during the lockdown period. Lockdown will have slowed recruitment a little, but we aim to have all of our sites return to face-to-face recruitment into the MND Register as soon as safe and practical to do so"*.

