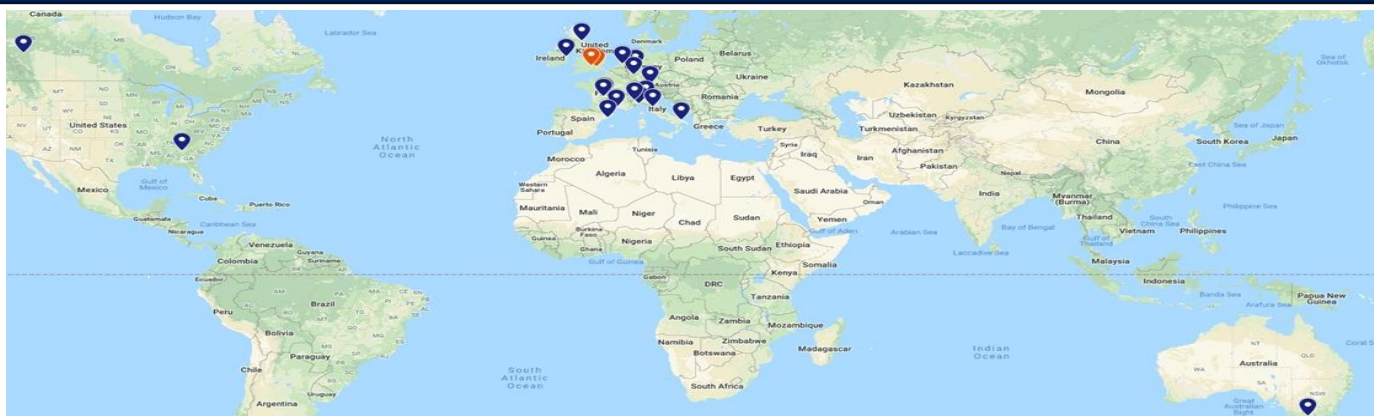


Despite the NHS providing care across England, Wales and Northern Ireland, you may be surprised to learn that there is no central place where researchers or healthcare workers can access information about every person living with MND. This means that no one knows exactly how many people at any one time are living with MND (this is known as the prevalence of a disease) nor understand how many people are diagnosed with MND each year (this is known as the incidence of a disease).



Currently, the best we can do is estimate the incidence and prevalence of MND. This is where the MND Register comes in.

By recruiting people living with MND in England, Wales and Northern Ireland into a central database (called the MND Register of England, Wales and Northern Ireland) we will be able to look at the true incidence and prevalence of MND and whether this is increasing or decreasing over time. We will also be able to ascertain whether there are any “hot spots” or clusters of people living with MND in certain areas and work towards making sure we have enough care provision in those areas. It also will help us to study whether there are environmental exposures in these “hot spots” that might be associated with the risk of developing MND.

Patient registries such as the MND Register of England, Wales and Northern Ireland are not a new concept, but the logistics of setting up a patient register across dozens of different NHS trusts, each of which may have different Research and Development (R&D) and IT policies is a big challenge.

There have been a number of bureaucratic hurdles that have had to be overcome to get the MND Register of England, Wales and Northern Ireland set up and ready to recruit people living with MND.

Despite these hurdles, the NHS provides a very strong, and quite possibly a unique environment for a population registry for people living with MND.

In this newsletter we will look at some of the other patient registers around the world that are specifically for people living with MND or Amyotrophic Lateral Sclerosis (ALS), as it is known in some parts of the world. You will note in the table found here, that some countries have several different registries that concentrate on a single region rather than spanning an entire country. These single region registries are usually based on the catchment area for a specific hospital and/or clinician researcher and create a “local” registry of people living with MND/ALS. Registries that span a whole country (or as in the case of the MND Register of England, Wales and Northern Ireland, more than one country) are population based registries that will capture information from people living with MND from lots of different regions and areas.

Summary of key data from the 20 MND/ALS Registries:

Name of Registry	Country	Date ended	Number of people included
National ALS Registry	USA	2010 - Ongoing	15,927
Australian MND Registry	Australia	2004 - Ongoing	1,834 (as of 2015)
Canadian Neuromuscular Disease Registry	Canada	2010 - Ongoing	1,085
South-East England register for ALS (SEALS)	England	1990 - Ongoing	575 (incident cases)
MND Register of England, Wales and Northern Ireland	England, Wales and Northern Ireland	2016 - Ongoing	1,906
French Register of Amyotrophic Lateral Sclerosis in the Limousin region (FRALim)	France	2000 - 2011	279 (incident cases)
Languedoc Roussillon ALS Registry in Montpellier	France	2003 - 2011	93
Neurology Department at the Limoges Hospital	France	1977 - 1985	69
ALS registry Nordrhein-Westfalen	Germany	2009 - 2015	200
ALS registry Rhineland-Palatinate	Germany	2009 - 2012	200
ALS registry swabia	Germany	2008 - 2010	520
Irish registry of amyotrophic lateral sclerosis and motor neurone disease	Republic of Ireland	1994 - Ongoing	2300 (of which 1,250 have provided DNA samples)
Lombardy ALS Register	Italy	1998 - 2002	517
Puglia ALS Register	Italy	1998 - 1999	130
The Liguria Amyotrophic Lateral Sclerosis Registry (LIGALS)	Italy	2009 - 2014	298
The Piemonte and Valle d'Aosta Register (PARALS)	Italy	1995 - 2014	2,702
Tuscany Registry for ALS	Italy	2005 - 2009	282
ALS database	Netherlands	2006 - Ongoing	3,300
Scottish MND Register	Scotland	1989 - Ongoing	1,226 (diagnosed between 1989 and 1998 as reported in 2004)
Neuromuscular Disease - Espana (NMD - ES): Amyotrophic Lateral Sclerosis Registry	Spain	2004 - Ongoing	491 (of which 41 were new cases within the Catalonia region)

Preliminary data from the first 655 people who joined the MND Register of England, Wales and Northern Ireland show that the most common site of onset (where the first symptom appears in the body) is spinal (weakness in limbs), the average age of diagnosis is 63 years of age and more males than females are diagnosed with MND

To date, over 1,800 people have signed up to the MND Register of England, Wales and Northern Ireland, making it one of the biggest MND Registers in Europe. How does it compare to the other MND/ALS Registries out there?

From the 20 MND/ALS registries (containing information about over 32,000 people living with MND/ALS) that we know about across the world, only seven are national registries that are continuous and ongoing in their recruitment of people living with MND/ALS.

The first registry was founded at Limoges Hospital, France in 1977 and ran until 1985. This was a regional registry (recruiting people living with ALS from the hospitals 'catchment' area) and collected a total of 69 people living with ALS.

The largest is the [National ALS Registry](#) in the United States of America which started in 2010 and since then has collected information on 15,927 people living with MND (with a peak age of onset for ALS of between the ages of 60-69 years of age).

The longest running register is the South-East England register for ALS ([SEALS](#)) which has been



running for 29 years and collected people who have been newly diagnosed with MND (incident cases). The average age of onset was 61.5 years of age with limb onset being the most common site of onset and more males than females being diagnosed with MND.

Despite different population characteristics and methods that have been used by the MND and ALS Registries across the world, the results are quite consistent with the average age of diagnosis being above 60 years of age, spinal or limb onset (weakness in the arms or legs) as the most common site of onset and more males than females being diagnosed with MND/ALS.

There are also MND/ALS registries in Belgrade, Belgium and the Russian Federation

that have recently started their journey, which will all add vital information to our understanding of MND/ALS around the world.

Disease registries are critical tools in understanding how the incidence and prevalence of MND/ALS is changing over time and location. They give us an insight into the age when most people are diagnosed and where in the body the disease may be starting (site of onset). Collecting information about who has MND/ALS and where they are located will help us ensure that care resources are being put into the right areas and study whether there might be environmental factors at play.

Thank you to everyone who has joined the MND Register to date and to everyone who will join the MND Register in the future. The MND Register of England, Wales and Northern Ireland has already become the fourth largest population register for MND/ALS in Europe and as the project continues to move forward apace, is set to become one of the biggest MND/ALS Registers in the world.

We anticipate that the MND Register of England, Wales and Northern Ireland will make a fundamental contribution to our understanding of how MND may be changing across the three countries as well as improvements in treatments over the coming years.



The MND Register is run by King's College London and the University of Oxford and supported by the above funders and a family trust that wishes to remain anonymous