

## ALS/MND Register Privacy Notice

The purpose of this privacy notice is to give you a clear explanation about how and why the ALS/MND Register collects and processes your personal information. It is our aim to be as transparent as possible about the information we hold on you and how we use it. To this end the ALS/MND register complies with the with the Data Protection Acts 1988-2018

The Irish Amyotrophic Lateral Sclerosis (ALS)/Motor Neurone Disease (MND) register was established in 1994 and includes all known patients diagnosed with ALS/MND in Ireland each year.

The Register is administered between Beaumont Hospital and Trinity College Dublin. For the purposes of data protection, Trinity College Dublin is the Data Controller. The purpose of the Register is to track the incidence, prevalence and clinical features of ALS/ MND in the Irish population. To enable effective research in ALS/MND, we require detailed information about the frequency of the disease in Ireland (the incidence- number of new patients diagnosed each year, and the prevalence -the number of people living with the condition) and how the condition presents and progresses (clinical features) within the Irish population. The Irish ALS/MND Register is closely linked with other Registers in the UK, Netherlands, Italy, France, Sweden, Germany and Italy, through our European Research Consortium (European Network for the Cure of ALS – ENCALS). Together we can map the disease across Europe and search for genetic and environmental causes.

The General Data Protection Regulation (GDPR) and Health Research Regulations (HRR) represent the most recent changes to data protection legislation. They are designed to ensure individuals have more control over their personal data. The healthcare sector is significantly impacted by the new Data Protection Legislation because of the volume of sensitive personal data which is used for the purposes of patient care, related institutional management and scientific research.

This privacy policy provides details about:

1. What data is collected by the Irish ALS/MND register
2. The legal basis for collecting and processing your data
3. Consent
4. How we collect your data
5. Who can access your data
6. Where we process your data
7. Who we share your data with
8. How long we keep your data
9. Your right of access
10. Right to erasure
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## **1. What data are collected?**

The ALS/MND Register is a central research tool and database used to store de-identified patient data and research data. It is a web enabled database, located in Trinity College, and accessed via a secure web application. The Irish MND register collects and processes the following categories of information about its participants

- Demographic information
- Contact information
- Medical health information (including relevant test results pertaining to ALS/MND)
- Genetic information (retained on a separate database)

Often this may include collecting information about your health history, family history, your ancestral background or your current lifestyle. The purpose of this is to track the incidence, prevalence and clinical features of MND in the Irish population.

## **2. Legal basis for collecting and processing data**

The processing of personal data in general practice is necessary in order to protect the vital interests of the patient and for the provision of health care and public health. The Legal basis is covered in article 6. 1. (a) and Article 9. 2. (j) of the GDPR.

6.1.(a) Processing shall be lawful only if and to the extent that at least one of the following applies: (a) the data subject has given consent to the processing of his or her personal data for one or more specific purposes;

9.2.(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

## **3. Consent**

Persons enrolled in the Irish (ALS/MND) register have given explicit consent for that enrolment either to their treating consultant or the MND register manager employed at the Academic Unit of Neurology, Trinity College Dublin. Written evidence of this consent is kept at the Register offices in the Academic Unit of Neurology and where relevant in their medical chart in Beaumont Hospital, Dublin. GDPR gives individuals the right to withdraw their

consent for the processing of their data at any time. The Irish ALS/MND Register relies on your consent as its legal basis for processing your data and as such you have the right to withdraw this consent. This will not affect the processing that has taken place up to that point.

#### **4. How we collect your data**

Once you consent to inclusion on the ALS/MND Register the Register Manager who is a staff member of the treating consultant will review your hospital chart and collect all relevant information for inclusion on the Register database. The Register Manager will generally follow up with a phone call to ensure that you understand the process, and to clarify some of the information obtained from your chart, unless you have requested at the time of consent not to receive such a call. With your consent, the information about your condition is updated from the medical chart following each subsequent visit to the ALS/MND clinic in Beaumont Hospital, and also based on future possible follow up calls if you agree for us to contact you. You can withdraw consent for all follow-up calls at any time.

If you are linked in with the voluntary sector organisation but not attending the multi-disciplinary ALS/MND clinic in Beaumont Hospital they will ask you if you are willing to receive a call from the Register Manager for the purposes of consent and inclusion on the ALS/MND Register. If you consent to receive a phone call the Register Manager will contact you to explain the Register, its uses and what participating means for you and your clinical information. If you consent to being included a time for a phone interview to obtain the relevant information will be scheduled. We may contact you subsequently to update the information we have on you and make sure it is still correct.

You can withdraw that consent at any time and ask to have your data removed or you can request that your data remain on the Register but that we do not contact you again

#### **5. Who can access your data?**

The Irish ALS/MND Register will add your data in codified form to a database with similar data from thousands of other study participants. The key for this code is kept separately from the Register, on a dedicated computer in a locked room accessible only to the Register and Research Managers based in the Academic Unit of Neurology.

- Only authorised individuals can have access to/or view patient identifiable data
- Only authorised individuals can have access to/or view patient de-identified data
- Unauthorised individuals are not be given access to any patient identifiable or de-identified data or to the Irish MND Register.

The leader of the Irish ALS/MND research group controls all access to the Irish ALS/MND database where your data is stored. Only a limited number of members of the Irish ALS/MND research group can access the codified Register database and only after after signing a mandatory Register user agreement outlining the terms and conditions of use. After this is signed and set-up is complete a member of the ALS/MND Research Group can access the Register only when the following conditions are met:

- They use a machine that is allowed through the firewall (must be on the Trinity College Network)
- They use a web browser with a HPRC client certificate installed
- They have a username and password

Time-stamped, user-specific logs are recorded for all activity on the web application including login, viewing of records and CSV export of data by Trinity College High Performance Computing (TCHPC) who host the Register for the Irish ALS/MND Research Group based in the Academic Unit of Neurology.

## **6. Where we process your data**

The Irish ALS/MND Register securely processes participant information initially at Beaumont Hospital, Beaumont, Dublin 9; and later at Trinity College Dublin, where information is securely stored and processed. When we store your personal data on our systems the data will be stored either on the University premises or on secure IT platforms within the EEA which are also subject to European data protection requirements.

## **7. Who we share your data with**

Where applicable, Register data will be shared within the Irish ALS/MND research group as required to inform other distinct studies to which participants will be individually informed about and consented to. The Irish ALS/MND Register may share anonymised data from the Register for the purposes of scientific research with trusted third-party healthcare research collaborators working in ALS/MND and neurodegenerative disease research.

## **8. How long do we keep your data**

Data will be codified at the time of collection. Identifiable information will not be held or shared with the rest of the data but rather stored in separate encrypted files kept in a secure facility in the Academic Unit of Neurology, Trinity College Dublin for long term storage, in keeping with best research practices. Data will be destroyed locally after such time as it is no longer deemed necessary to retain or is no longer fit for purpose, however, given the purpose of the ALS/MND Register as a population register for a rare condition the intention is to store the information indefinitely.

## **What are your rights?**

### **9. Your Right of Access to Your Health Information**

You have the right of access to all the personal information held about you by this practice. To exercise these rights please send a written request to:

Data Protection  
Academic Unit of Neurology  
Trinity Biomedical Science Institute,  
Pearse Street,  
Dublin 2.

This request must be signed and accompanied by proof of identification, the Irish ALS/MND register cannot progress such requests until the identity of the requestor is confirmed. The Irish ALS/MND register will process your data access request within 30 days.

## **10. Right to erasure**

Under GDPR, individuals have a right to erasure or ‘right to be forgotten’. This means that individuals have a right to have their personal data removed if they no longer wish for it to be processed.

Additionally individuals have a right to request the restriction or suppression of their personal data. These are not absolute rights however.

The Irish (ALS/MND) register applies the general principle in line with GDPR that personal data should be kept for no longer than is necessary for the purpose(s) for which it was collected. The Irish (ALS/MND) register has a number of legal obligations in terms of the data and records it retains which supersede the right to be forgotten.

## **11. Right to rectification**

You have the right to have inaccuracies in personal data that we hold about you rectified. This is known as the ‘right to rectification’. If your data is incomplete, you can ask for the organisation to complete it by adding more details.

## **12. Right to object and restriction of processing**

Individuals have a right to object to the processing of their data and to restrict processing of their data in certain circumstances, where:

- The accuracy of the data is being contested and you request it to be restricted while we verify its accuracy
- The processing of your data is unlawful
- The Irish ALS/MND register no longer needs the data for processing but you require it to be kept for the establishment, exercise or defence of a legal claim
- You are objecting to the legal basis for the processing of your data, in which case the processing may be restricted until the legal basis is verified.
- Individuals also have an absolute right to object to processing of their data for marketing purposes.

### **13. Right to data Portability**

Data portability allows the individual to obtain their personal data held by the data controller in a structured, accessible format and to reuse their data for their own purposes across different services. This means that you can request and receive personal data that you have previously provided to a controller in a commonly used and machine-readable format. The right also means that you can request one controller to transfer your personal data to another controller.

### **14. Right to object to automated decision making and profiling**

The GDPR gives individuals the right to object to automated individual decision making (i.e. making a decision solely by automated means without any human involvement) and profiling (i.e. automated processing of personal data to evaluate certain things about an individual). The Irish ALS/MND Register does not make any decisions about participants using wholly automated means.

### **15. Changes to our privacy policy**

Any changes we may make to our Privacy Policy in the future will be reflected by updating this document. Please check back frequently to see any updates or changes to our Privacy Policy.

### **16. Contact Us**

If you have any questions regarding this privacy policy, you may contact us via

**Postal Address:** ALS/MND Register, Academic Unit of Neurology, Fifth Floor, Trinity Biomedical Sciences Institute, Trinity College Dublin, 152 - 160 Pearse St, Dublin 2

**Telephone:** 01 8964497 or 01 8964376

**Email:** [ResearchMND@tcd.ie](mailto:ResearchMND@tcd.ie)

If you wish to make a complaint or escalate an issue relating to your rights, you can contact the Data Protection Officer at [dataprotection@tcd.ie](mailto:dataprotection@tcd.ie).

Finally if you are not satisfied with the information we have provided to you in relation to the processing of your data or you can also make a complaint to the Data Protection Commissioner via the link in their website [Making a Complaint to the DPC](#).