



Participant Information Leaflet

Study Title	The impact of working with Amyotrophic Lateral Sclerosis/Motor Neurone Disease on Healthcare Professionals – A Cross-Sectional Survey.
Principal Investigator and Co-Investigators	<p>Megan Walls: Lead Researcher & PhD Scholar, Academic Unit of Neurology, School of Medicine, Trinity College Dublin.</p> <p>e: wallsme@tcd.ie</p> <p>Dr Miriam Galvin – Principal Investigator & Co Supervisor, Academic Unit of Neurology, School of Medicine, Trinity College Dublin.</p> <p>e: galvinmi@tcd.ie</p> <p>Dr Austin Claffey - Co Supervisor, Institute of Health & Social Care, London South Bank University, 103 Borough Road, London, United Kingdom, SE1 0AA</p> <p>e: claffeya@lsbu.ac.uk</p>
Study Funder	Irish Health Research Board
Joint Data Controllers	Trinity College Dublin and London South Bank University.
Data Protection Officer	Data Protection Officer Secretary's Office Trinity College Dublin Dublin 2 e: dataprotection@tcd.ie

You are invited to participate in a study being carried out by Megan Walls, as part of her PhD Research with the Academic Unit of Neurology, Trinity College Dublin, Ireland. Before you decide whether you wish to take part, please take time to read this information leaflet carefully. If there is anything that is not clear, or if you would like more information, please email a member of the research team.

There are **four** parts to this information leaflet:

Part 1 - The Study

Part 2 - Data Protection

Part 3 – Future Research

Part 4 - Approval, Organising and Funding

Part 1 - The Study

Why have I been invited to take part?

You are a **healthcare professional** who is **currently working** or has **recently worked** (within the **last two years**) in a **service for people living with ALS/MND** in **Europe**.

Why is this study being done?

This survey is being completed to understand the impact of working with people living with ALS/MND on the well-being and quality-of-life of healthcare professionals involved in their care. We hope that this survey will identify how we can best support and sustain healthcare professionals to continue working in this rewarding but often challenging area of clinical practice.

What does taking part involve?

If you decide to take part, you will be asked to complete this online survey at a time and location that is most convenient for you. If you currently work in an ALS/MND service, the survey will take approximately 20 minutes. If you aren't currently working in an ALS/MND service, it will take approximately 10 minutes. You are asked to identify a time to complete the survey when you are least likely to be distracted by other demands. If you need to take a break, you can leave the survey and return within one week. Your responses will be saved during this time.

There are **four main parts** to this survey, and you are asked to **complete each part**;

1. Part one will ask **demographic and work-related questions** about your professional background and level of experience working with ALS/MND.
2. Part two will ask questions about your understanding and experience of a phenomenon known as **moral distress**.
3. Part three is **The Professional Quality of Life Scale** – this will ask about your personal experience of working with ALS/MND and how this may impact on your personal and professional well-being.

4. The final part is **The Brief Resilient Coping Scale** - this will ask about how you typically respond to difficult circumstances or stressors.

Do I have to take part?

Participation in this research is entirely voluntary. You will be asked to indicate your consent to participate before answering the survey questions however, once you start the survey, you can discontinue at any time by exiting the survey.

What are the possible benefits of taking part?

Taking part in this study may not directly benefit you. However, your responses will help us to better understand how working with people and families living with ALS/MND may impact on the personal and professional well-being of the healthcare professionals involved in their care. We hope that the findings of this survey, will help us to identify and prioritise the aspects of caring for people living with ALS/MND that healthcare professionals may benefit from additional support with. We also hope to identify ways in which we can sustain healthcare professionals, with high levels of clinical knowledge and expertise, to continue working in this important area of clinical practice, while maintaining positive personal and professional health and well-being.

Are there any possible disadvantages or risks from taking part?

There is limited risk of a data breach. This is an anonymous survey, Qualtrics will not collect your IP address or any other information that could personally identify you.

If you experience feelings of discomfort or upset, while answering any of the questions asked in this survey, we ask you to stop answering and to speak with a trusted colleague or medical professional about how you are feeling.

What will happen to the results of the study?

The results of the study will be reported in scientific and medical journals and presented at international conferences. The findings will also be reported in the lead researcher's thesis for fulfilment of a PhD qualification.

Part 2 - Data Protection

What information about me (personal data) will be used for this study

We will not collect any information that will personally identify you. You will be asked to provide information about your gender, the country you are working in, your professional background and level of experience working with people living with ALS/MND. We will be unable to identify you from this information.

Who will access my data?

Only the research team (named above) will have access to this anonymous data. There is a legal joint control agreement in place between Trinity College Dublin and London Southbank University for the security of data collected for this study.

How is the information kept confidential and secure?

This survey will use the online survey platform, Qualtrics. The Qualtrics platform preferred provider is Amazon Web Services (AWS), which have data centres located in Ireland. When the anonymous data is exported from Qualtrics, it will be stored securely on the Trinity College Dublin network. A data protection risk assessment was carried out for this study and the risk identified was low. Each member of the research team has completed up to date data protection and management training and have a professional code of ethics to ensure the data you provide is managed to the highest standard.

What are my rights under Data Protection law?

This is an anonymous survey which means that you will be unable to access your data, receive a copy of it, restrict processing, delete or receive your data in a portable format because we will be unable to identify which responses are yours. You have the right to discontinue the survey at any time by closing the Qualtrics tab of your internet browser.

Part 3 - Future Research

Will my personal data be used in future studies?

With your consent, we would like to keep the data collected from you for this study for future research on professional well-being and ALS/MND care. We hope this will help researchers continue to examine and further understand professional well-being in the years to come.

Part 4 - Approval, Organising and Funding

Has this study been approved by a research ethics committee?

This study was approved by the School of Medicine, Research Ethics Committee (REC) in Trinity College Dublin, on the 22.10.24. (REF: 3500)

Who is organising and funding this study?

This study is being undertaken by Megan Walls as part of her PhD research within the Academic Unit of Neurology, School of Medicine, Trinity College Dublin, Ireland. This research is funded by the Irish Health Research Board.

Will I be paid for taking part?

There is no financial reward for participation in this research.

Who should I contact for information or concerns?

If you have any concerns or questions, you can contact:

The lead researcher Megan Walls – wallsme@tcd.ie

If you have any questions in relation to your rights under data protection law, you can contact the Data Protection Officer, Trinity College Dublin: Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. Email: dataprotection@tcd.ie. Website: www.dataprotection.ie

Under GDPR, if you are not satisfied with how your data is being processed, you have the right to raise a concern with the Office of the Data Protection Commission, 21 Fitzwilliam Square South, Dublin 2, Ireland. Website: www.dataprotection.ie