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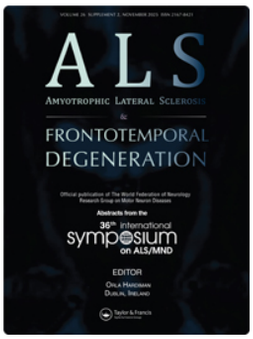

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RESEARCH ARTICLE

Limited data capture on reproductive medicine use in amyotrophic lateral sclerosis: implications for monitoring access

SHANICE ALLEN[1], JADE HOWARD[1], CHRISTOPHER J. MCDERMOTT[1,2], FELICITY BOARDMAN[3] & ALISDAIR MCNEILL[1,4]

[1]*Division of Neuroscience & Neuroscience Institute, The University of Sheffield, Sheffield, UK,* [2]*Academic Directorate of Neuroscience, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK,* [3]*Applied Health Directorate, Warwick Medical School, University of Warwick, Coventry, UK, and* [4]*Sheffield Clinical Genetics Department, Sheffield Children's Hospital NHS Foundation Trust, Sheffield, UK*

Abstract

There is very limited evidence around the use of reproductive genetic testing in individuals with amyotrophic lateral sclerosis (ALS)-linked gene variants. This study aimed to identify the use of reproductive genetic testing in these individuals to understand patterns of (under)utilization and to identify barriers to equitable access. Freedom of information requests were sent in January 2025 to the 22 regional clinical genetics centers across the UK around reproductive services for individuals with, or at risk for, ALS and Huntington's disease. Limited data were available with only six trusts answering in full. The data that our study yielded raises significant concerns and inconsistencies regarding clinical recording and reporting of reproductive genetic counseling and testing. The absence of standardized retrievable data limits the ability to assess utilization and may point toward a systemic issue in data capture of reproductive genetic services for individuals at risk of ALS, and by extension, those affected by other genetic conditions.

Keywords: *MND, ALS, Huntington's disease, reproductive genetic testing, reproductive genetic counseling*

Introduction

Up to 20% of individuals with amyotrophic lateral sclerosis (ALS) (also known as motor neuron disease (MND)) have an identifiable genetic cause (1), with a 50% chance of transmission to offspring (2). Reproductive genetic testing (preimplantation genetic testing and prenatal testing) allows individuals with or at risk of a genetic disease to have a child unaffected by the condition (3).

There is no published research around the use of reproductive genetic services in individuals with ALS-linked gene variants. Awareness of these options is crucial for informed reproductive decision-making which has been found to be highly complex and multi-faceted in other adult-onset monogenic disorders, e.g. Huntington disease or hereditary cancers (4,5).

Our study aimed to determine the use of reproductive services (reproductive genetic counseling and/or reproductive genetic testing) by individuals with ALS-linked gene variants (affected and at risk) to understand patterns of (under)utilization and identify barriers to equitable access. We also sought data on Huntington's disease as a comparison due to its similar prevalence and inheritance pattern.

Materials and methods

Ethical approval was granted by the University of Sheffield (065452). Freedom of information (FOI) requests were sent in January 2025 to the 22 UK clinical genetics centers. FOI requests are formal requests that give everyone the right to access recorded information from UK public authorities under the Freedom of Information Act 2000. The

Correspondence: Shanice Allen, Division of Neuroscience, 385a Glossop Road, Sheffield S10 2HQ, UK. E-mail: sallen9@sheffield.ac.uk

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Table 1. Questions trusts were asked.

1	How many individuals with or at risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have been seen for reproductive genetic counseling (i.e. to discuss recurrence risk and options such as PGT or PNT) in the last 12 months?
2	How many individuals with or at risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have proceeded with preimplantation genetic testing (PGT) in the last 12 months?
3	How many individuals with or at risk of a causal variant in an MND gene (presymptomatic or clinically affected with MND) have proceeded with prenatal testing (PNT) in the last 12 months?
4	How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington disease) have been seen for reproductive genetic counseling (i.e. to discuss recurrence risk and options such as PGT or PNT) in the last 12 months?
5	How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington disease) have proceeded with PGT in the last 12 months?
6	How many individuals with or at risk of a CAG repeat in the huntingtin gene (HTT) (presymptomatic or clinically affected with Huntington disease) have proceeded with PNT in the last 12 months?
7	On behalf of which organization and department are you answering this request?
8	Optional free text

requests were sent to the FOI team at each trust for forwarding to the respective clinical genetics center.

The request sought information on referrals to reproductive genetic counseling and the utilization of reproductive genetic testing for individuals with ALS or Huntingdon disease-linked gene variants (January 2024–January 2025). Table 1 outlines the questions posed.

A horizon scan was also undertaken to explore how other countries record and report the use of preimplantation genetic testing. The USA, Europe, Australia, and New Zealand were chosen for their comparable healthcare, ethical and regulatory frameworks and have established reproductive genetic services.

Results

A total of 20/22 responses were received (91%), yet only six trusts answered in full.

The primary reason for partial responses or refusals was that the requested data were not centrally recorded, collated, or easily accessible. Therefore, locating and extracting the information would take longer than the statutory 18-hour cost limit under section 12 of the FOI Act. Nine trusts stated this as their reasoning for refusal or partial response. Accounting for five trusts' refusal or partial responses was that the data are not routinely collected, recorded, or held. Supplementary material 1 details trust responses and reasoning.

The horizon scan of international practice revealed that while most countries collect overall data on the number of preimplantation genetic testing cycles and permitted indications, only the Netherlands systematically recorded cycles by specific indication with France only recording them for the most common indications. Supplementary material 2 contains full horizon scan information.

Discussion

This study aimed to identify the use of reproductive genetic services in individuals with ALS-linked gene variants and HD-linked gene variants as a comparison. However, FOI responses demonstrated that data on reproductive genetic counseling and testing utilization are inconsistently recorded and therefore often inaccessible across UK centers for both ALS and Huntingdon disease.

This lack of standardized data capture across the UK highlights that services are failing to systematically monitor the uptake of reproductive genetic services, and as a result, it is difficult to understand who is accessing these services, identify patterns of use, or evaluate equity of provision. These findings point to a wider systemic issue in data capture across genetic services—an issue that is likely affecting other rare and genetic conditions.

Complementing this, the horizon scan of international practice revealed that the UK is not alone in facing challenges and barriers to recording this data, but also that disease-specific data capture is feasible. This underscores both the UK's inability to monitor access and equity in reproductive genetic services for ALS and Huntingdon disease, and the opportunity to draw on international examples to inform national data collection improvements.

Conclusions

This study's findings highlight the need for standardized, improved data capture in reproductive genetic services. Enhancing data consistency and granularity in UK services is essential for monitoring access and equity, an ethical imperative. The feasibility of systematic, disease-specific data capture is shown in The Netherlands. Adopting a similar approach—through better coordination between UK national bodies like the Human Fertilisation & Embryology Authority and the National Health Service and increasing standards

for recording reproductive genetic service activity, including indication-specific data on ALS and other genetic conditions, will enhance monitoring, inform research on reproductive choices, and fulfill this ethical duty.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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ORCID

Shanice Allen http://orcid.org/0009-0000-1619-2930

Christopher J. McDermott http://orcid.org/0000-0002-1269-9053

Data availability statement

Data supporting this study are included within the article and/or supporting materials.

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