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A study aiming to reduce diagnostic delays of motor neurone disease within primary care in the UK using an automated electronic red flag alert tool

Submission date
18/11/2025

Recruitment status
No longer recruiting

Registration date
02/03/2026

Overall study status
Completed

Last Edited
02/03/2026

Condition category
Nervous System Diseases

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims
Motor neurone disease (MND) is a rare, incurable condition affecting about 5,000 UK people. It causes muscle weakness over time, making it harder for people to move, speak, and swallow, and eventually leads to difficulty breathing. Because MND is rare, general practitioners (GPs) may not always recognise it right away, leading to delays in diagnosis. On average, it can take 9 to 27 months from first symptoms to a confirmed diagnosis.
To help GPs identify MND earlier, the MND Association and the Royal College of General Practitioners (RCGP) developed the MND Red Flag Tool in 2014. This tool lists common signs and symptoms that may indicate MND, helping GPs decide when to refer patients to specialists more quickly. The MND Alert system builds on this tool as an automated aid that can be added to patient electronic health records in GP practices. It scans patient records for Red Flag Tool signs linked to MND and sends notifications to GPs when these signs are detected, helping them identify possible cases earlier and make faster referrals. Currently, the MND Alert system can detect symptoms recorded as codes in patient records, but some important information may be written in free-text notes, such as in consultation letters. To ensure nothing is missed, some patient records may need additional manual review.
This study has two stages: (1) implementing the MND Alert system in GP practices for 6 months and (2) evaluating how well it works and if GPs find it helpful. In stage 1, the MND Alert system will be used in routine GP patient consultations. In stage 2, we will interview GPs from the participating practices to understand their experiences with the tool and assess how effective and practical it is for everyday clinical use.

Who can participate?
GPs at participating sites in South Yorkshire

What does the study involve?
The tool will alert the GP during consultations to service users who may have MND-related symptoms. GPs will be invited to participate in a 60-minute semi-structured interview to explore the acceptability and usability of the MND Alert toolkit.

What are the possible benefits and risks of participating?
GPs may find it beneficial to participate in a study that aims to develop a toolkit to speed up the diagnosis of MND. There are no risks of participating.

When is the study run from?
Sheffield Institute for Translational Neuroscience (SITraN) (UK)

When is the study starting and how long is it expected to run for?
August 2025 to March 2026

Who is funding the study
1. Lifearc (UK)
2. MND Association (UK)

Who is the main contact?
Cara Gates, c.gates@sheffield.ac.uk

Contact information

Type(s)
Scientific

Contact name
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S10 2HQ
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Type(s)
Principal investigator

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Type(s)
Scientific, Public

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Additional identifiers

Integrated Research Application System (IRAS)
351043

Central Portfolio Management System (CPMS)
66185

Study information

Scientific Title
Motor Neuron Disease (MND) Alert: a mixed-method feasibility and acceptability pilot study

Acronym
MND Alert

Study objectives
There are two stages in this study, each with its own research question:

Stage 1: MND Alert implementation
Can the MND Alert toolkit help GPs identify early signs of MND in patients' health records?

Stage 2: MND Alert evaluation
Is the MND alert toolkit useful and acceptable for GPs in their everyday practice?

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 29/05/2025, Health and Care Research Wales (Floor four, North, Welsh Government Offices, Crown Building, King Edward VII Avenue, Cardiff, CF10 3NQ, United Kingdom; +44 (0) 2920230457; HCRW.approvals@wales.nhs.uk), ref: 24/NE/0231

Primary study design
Interventional

Study design
Non-randomized study

Study type(s)
Treatment

Health condition(s) or problem(s) studied
Motor neurone disease

Interventions
We will conduct a mixed-methods study to test the MND Alert toolkit in up to 30 GP practices. The aim is to see if this automated alert system can help identify potential cases of MND in patient records over a 6-month period. We want to find out if using the alert system and assessment tools can help reduce delays in diagnosing MND.

Once the toolkit is in place, it will trigger an alert when it detects signs or symptoms related to MND in a patient's record. The toolkit will generate reports that include both pseudonymised and identifiable data; however, the identifiable data will only be used within the GP practices for verification. After this verification, GP practices will share only the pseudonymised data with the central research team through secure emails. This data will include unique row numbers that correspond to individual patients, which researchers will use to access patient records during case note reviews.

Intervention Type
Other

Primary outcome(s)
1. Acceptability of the MND Alert measured using thematic analysis of qualitative interviews at after at least 6 weeks of using the toolkit

Key secondary outcome(s)
There are no secondary outcome measures

Completion date
31/03/2026

Eligibility

Key inclusion criteria

Stage 1: MND Alert implementation
GP practices:
1. Located in South Yorkshire
2. Willing to integrate the MND Alert toolkit into their electronic health records
3. Using either the SystmOne or EMIS Web clinical information systems
4. Consenting to share pseudo-anonymised patient data generated through the implementation of the MND Alert toolkit
5. Willing to provide researchers access to complete patient records for conducting case note reviews of patients who triggered an alert
6. Willing and able to regularly provide feedback and share monthly pseudo-anonymised data generated through the MND Alert toolkit with the central research team

Stage 2: MND Alert evaluation
1. English-speaking individuals who can provide informed consent
2. GPs from participating practices
3. GPs willing to participate in semi-structured interviews to share their experiences with the MND Alert toolkit
4. Individuals with access to a telephone or video-calling service (if semi-structured interviews are conducted remotely)

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
0

Key exclusion criteria
Stage 1: MND Alert implementation
GP practices:
1. Located outside of the NHS South Yorkshire ICB region
2. Unwilling or unable to integrate the MND Alert toolkit into their electronic health records
3. Not using either the SystmOne or EMIS Web clinical information systems
4. Not consenting to share pseudo-anonymised patient data generated through the implementation of the MND Alert toolkit
5. Unwilling or unable to provide researchers access to complete patient records for conducting case note reviews of patients who triggered an alert
6. Unwilling or unable to regularly provide feedback and share monthly data generated through the MND Alert toolkit with the central research team

Stage 2: MND Alert evaluation
1. GPs unwilling to participate in semi-structured interviews to share their experiences with the MND Alert toolkit

Date of first enrolment
20/08/2025

Date of final enrolment
30/03/2026

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Broom Lane Medical Centre
70 Broom Lane
Broom
Rotherham
England
S60 3EW

Study participating centre
Buchanan Road Surgery
72 Buchanan Road
Sheffield
England
S5 8AL

Study participating centre
Clifton Medical Centre
Doncaster Gate
Rotherham
England
S65 1DA

Study participating centre
Clover City Practice
1 Mulberry Street
Sheffield
England
S1 2PJ

Study participating centre
Clover Group Practice
Darnall Primary Care Centre
290 Main Road
Sheffield
England
S9 4QH

Study participating centre
Highgate Surgery
Highgate
Sheffield
England
S9 1WN

Study participating centre
Conisbrough Group Practice
The Stone Castle Centre
Gardens Lane
Conisbrough
Doncaster
England
DN12 3JW

Study participating centre
Devonshire Green Medical Centre
126 Devonshire Street
Sheffield
England
S3 7SF

Study participating centre
Dono Valley Healthcare - Sprotbrough Site
Newton Lane
Doncaster
England
DN5 8DA

Study participating centre

The Dove Valley Pms Practice
Worsbrough Healthcare Centre
Powell Street
Worsbrough
Barnsley
England
S70 5NZ

Study participating centre
Dykes Hall Medical Centre
156 Dykes Hall Road
Sheffield
England
S6 4GQ

Study participating centre
Far Lane Medical Centre
1 Far Lane
Sheffield
England
S6 4FA

Study participating centre
Forge Health Group
Pitsmoor Surgery
151 Burngreave Road
Sheffield
England
S3 9DL

Study participating centre
Gleadless Medical Centre
636 Gleadless Road
Sheffield
England
S14 1PQ

Study participating centre
Greasbrough Medical Centre
Munsbrough Rise
Greasbrough

Rotherham
England
S61 4RB

Study participating centre
Greystones Medical Centre
33 Greystones Road
Sheffield
England
S11 7BJ

Study participating centre
Harold Street Medical Centre
2 Harold Street
Sheffield
England
S6 3QW

Study participating centre
Heeley Green Surgery
302 Gleadless Road
Sheffield
England
S2 3AJ

Study participating centre
Clover North Darnall Health Centre
2 York Road, Darnall
Sheffield
England
S9 5DH

Study participating centre
Oughtibridge Surgery
Church Street
Oughtibridge
Sheffield
England
S35 0FW

Study participating centre
Sothall & Beighton Health Centres
24 Eckington Road
Beighton
Sheffield
England
S20 1HQ

Study participating centre
Swallownest Health Centre
Worksop Road
Swallownest
Sheffield
England
S26 4WD

Study participating centre
The Crookes Practice
203-205 School Road
Sheffield
England
S10 1GN

Study participating centre
The Lakeside Practice
The White Wings Centre
Spa Pool Road
Askern
Doncaster
England
DN6 0HZ

Study participating centre
The Thorpe Practice
Moorthorpe Bank
Owlthorpe
Sheffield
England
S20 6PD

Study participating centre
Woodhouse Health Centre (pcn Sheffield) - COVID Local Vaccination Service
Woodhouse Health Centre
5-9 Skelton Lane
Woodhouse
Sheffield
England
S13 7LY

Study participating centre
Woodseats Medical Centre
The Roddick Building
900 Chesterfield Road
Sheffield
England
S8 0SH

Study participating centre
Woodstock Bower Group Practice
1 Kimberworth Road
Rotherham
England
S61 1AH

Sponsor information

Organisation
University of Sheffield

ROR
https://ror.org/05krs5044

Funder(s)

Funder type
Charity

Funder Name
Motor Neurone Disease Association

Alternative Name(s)
MND Association, Motor neurone disease (MND), Mndassos, MNDA

Funding Body Type
Private sector organisation

Funding Body Subtype
Associations and societies (private and public)

Location
United Kingdom

Funder Name
LifeArc

Alternative Name(s)

Funding Body Type
Private sector organisation

Funding Body Subtype
Other non-profit organizations

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study will be available upon request from Dr Liam Knox (L.knox@sheffield.ac.uk).
Type of data: anonymised interview data or analysis of interviews, practice-level based on Alert Tool usage, suggest qualitative patient-level data from case notes is neither appropriate nor useful to be made available.
When the data will be available and for how long: Anonymised data will be kept for at least five years and will be available after the completion of the study.
For what types of analyses: secondary analysis of interviews.
Interview participant consent will be taken for data sharing (when anonymised).
Consent not obtained from patients to access records and view consultation details (this was approved via CAG), therefore it is not appropriate to share this data.

IPD sharing plan summary
Available on request