Funding Brief:

UK MS Register Data Discovery Awards

Let's stop MS **together**

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1. Introduction

The UK MS Register is the world's first register to combine information collected directly from people about their MS, with clinical and NHS data.

Over 17,000 people have joined so far since its launch in May 2011. The Register collects data from:

1. People with MS recording information about their MS directly via questionnaires every 6 months
2. A growing number of hospitals –over 40- across the UK linking consented website participants' medical records with their questionnaire responses
3. Routinely collected NHS data e.g. via the SAIL databank

Patient-reported data includes:
- Demographics
- Onset and diagnosis information dates
- Education, Employment and Care details
- 'Core' PROMs - Hospital Anxiety and Depression Score (HADS), EQ5D, MSIS29v2, FSS
- Ad Hoc PROMs - Medication, webEDSS, Comorbidity, Symptoms

Clinical site data includes:
>   Minimum data set
>   - Demographics
>   - Ethnicity
>   - Onset date
>   - Diagnosis date
>   - MS Type at diagnosis
>
>   Expanded data set
>   - Current/previous DMT
>   - MS Type at visit
>   - Smoking status
>   - EDSS
>   - Relapses
>   - Walking assessment
>   - Onset localisation/symptoms

Routinely collected Data (Wales)/ Other linkable data sources:
The SAIL Databank is a world-class system for the robust secure storage and use of anonymised person-based data for research to improve health, well-being and services. (SAIL Data Bank use requires an additional application and cost)
Current list of linkable data:
- Inpatient and Outpatients (Patient Episode Database for Wales (PEDW))
- GP Data
- ONS Information
- Indicies of deprivation
- Pathology data

The UK MS Register is a valuable piece of research infrastructure funded by the MS Society. We are now launching a new funding call to stimulate the use of register data and support the building of data science capability among the UK MS research community.

We want these awards to further our understanding of risk factors for MS. This will move us towards a more consolidated approach to assessing MS risk and ultimately towards the development of preventative strategies.

We are also aware that there are many other MS datasets in the UK and we believe that by collaborating with the UK MS Register, researchers can draw from a wider pool of data to support their work.

If the call is successful, we intend to run the call again in 2023 and 2024.

2. Award scope

These awards will be for up to £50,000 for one year. A total of £100,000 is available for this call and we hope to fund between 2-4 awards.

It is expected these awards will commence before December 2022 and will typically be finished within 12 months.

They must include use of data from the UK MS Register either alone or in combination with other existing datasets. Collaboration with other local, national or international MS datasets or other relevant data repositories is encouraged.

Lead applicants must be based at a UK research institution. International co-applicants, and collaborations with international datasets, are permitted.

Each award should directly address one of the following aims:
1. **Uncover new risk factors for developing MS**. We are particularly interested in modifiable risk factors that could be relevant for primary prevention.
2. **Further characterise known MS risk factors in a way that will take us forwards towards prevention strategies.** Applications addressing this aim should clearly explain how the new information produced will move our understanding forward in a way that will help the community tackle MS prevention.
3. **Increase our understanding of modifiable risk factors and comorbidities that influence the likelihood of MS progression**

Investigations into pharmacological interventions licenced for MS are **out of scope of this call.** Applications relating to these will not be accepted.

You must involve people affected by MS in the development of your application.

3. Application process

You MUST speak to the UK MS Register team before submitting an application for funding. This will help to confirm if the UK MS Register holds the appropriate data for the project and confirm the estimated cost of accessing the data. Please complete an application scoping form to arrange a discussion with the team. You will receive a Feedback form after the call with the UK MS Register team. This should be attached to your grant application form before submission.

If you wish to also use your own data, this can be uploaded to the Register Secure eResearch Platform (SeRP) where there are sufficient identifiers linkage can be made with the UK MS Register data. Applicants must confirm in their application they have the appropriate approval to do this and provide details of consent or institutional approval to upload that data.

A full application should be submitted via our onlineGrant Tracker system https://research.mssociety.org.uk/Login.aspx

You have the opportunity to apply for Lay summary development. This offers the chance to receive input from our Research Network **before** you submit your application to our grant round. Download a Lay Summary development form from our website to find out how to access this.

Applications will be reviewed by members of the UK MS Register Scientific Steering Committee. There will be an opportunity for you to respond to reviewer comments before consideration by the final review panel. The review panel will consider the applications and will make a funding recommendation to us.

Key activity	Date
Discussions with UK MS Register team	Feb-May 2022
Call open	Monday 14 May 2022
Lay summary development scheme closes	Friday 1 April
Deadline for applications	Wednesday 11 May
Applicant response	Mid-June 2022
Review panel meeting	July 2022
Applicants advised of outcome	August 2022
Award start date	By December 2022

If you have any questions or would like to discuss this funding opportunity further, please contact Dr Jacqui Hanley Jacqui-ann.hanley@mssociety.org.uk

4. Application review criteria

Applications will be assessed by members of the UK MS Register Scientific Steering Committee. This committee is made up of scientific members and people affected by MS.

Applications will be reviewed against the following criteria:

a) Scientific strategy

- How closely does the application meet one of the three aims?
- How much will the project take us forward towards prevention strategies?
- Please note, if there are more than two fundable applications, then applications relevant to primary prevention (addressing aims 1 or 2 in the scope) will be prioritised.

b) Plan of Investigation

- Is the data selected appropriate to answer the proposed question?
- Does the team have the correct permissions in place to access and analyse the data?
- Is the data analysis plan realistic in proposed timeframe?
- Are the planned outputs appropriate to answer the proposed question?
- How have people affected by MS been involved in the development of the project? And how will they be involved in the project delivery?
- Have all requested costs been fully justified and represent value for money?

c) Research environment and track record of success

- Does the project team have a track record of success in this area?
- Do the team have access to appropriate support/research environment for this project?
- If conducting the analysis themselves, do the team have the appropriate skills/experience to do this?

d) Added value through collaboration

- How will the project develop new, or progress current, collaborations in this area?
- What is the potential for further collaboration following successful completion of the project?
- Please note, letters of support should be provided to support collaboration statements.

e) Building capacity in MS research

- Will the project team bring new data expertise into MS, or develop data expertise among existing MS researchers?

f) Dissemination

- Are dissemination plans appropriate and ambitious?
- Have people affected by MS been involved in development on dissemination plans?
- Have the costs of dissemination been included and fully justified?

5. Guidance on completing an application form

This guidance section should be used to help you complete the application form on our web-based grant management system.

A. Finance and costs

Only direct research costs can be claimed. You can download our standard Applicant Guidance from our website for a more detailed breakdown of eligible and ineligible costs.

Please note the salary of the lead applicant can be claimed providing they are working on the project, and the project would not go ahead if their salary was not covered. If you are claiming for salary costs, the relevant salary scales must be attached in the Appendix section.

The cost of accessing the UK MS Register (up to £5,000) will be covered by the MS Society, separately to the individual awards. However, if the cost of accessing the UK MS Register exceeds £5,000, the additional costs **must** be included in the 'Consumables' budget section.

B. Lay Summary

A good lay summary is clear and accessible to people who do not have a scientific background. It is not a 'dumbed down' version of your research, but a clear, plain English explanation, which offers context and explains relevance to people affected by MS.

Your lay summary is important because it will be reviewed by a number of people affected by MS. They are not asked to comment on the quality of science.
They will comment on your project based on:
- how relevant it is to people with MS, and the potential impact;
- the extent of involvement of people with MS in the research planning and design;
- If there is appropriate consent around use of data in the project
- the clarity and quality of the writing.

Structure
Please address the following questions:

What is the aim of the project? How will it benefit people affected by MS?
This section should clearly set out the aims of the project, and focus on why they are important and relevant to people affected by MS. Please be as specific as you can about the potential benefits your work could bring. How will it move the field forward?

What is the reason for this study?
This section should clearly set out the rationale for the project, what is already known from past research, how this project is original, and what you hope to find out.

How will this project be carried out?

This section should clearly set out the methods that will be used, and explain why you have chosen to use them. If people with MS will be participants, clearly explain how you will recruit them, and what will be asked of them (and any control group).

How will your research findings be put into practice?
This section should clearly set out your plans for dissemination. Once the project is complete, how will the findings be put into practice or further developed, ensuring that people with MS benefit from your research? This section may also include any planned public engagement activities.

Lay summary development
People affected by MS from our Research Network can provide feedback on your application before you submit, focusing on how well you have communicated your research proposal and the importance of the topic to people affected by MS. This isn't part of our review process, but is intended to help you to improve your lay summary before you submit.

If you'd like to go through Lay Summary Development, you'll need to submit a completed Lay Summary Development request form to researchnetwork@mssociety.org.uk.

You must submit your completed form by the deadline below. You will receive the feedback on your summary approximately two weeks before the deadline for submitting your grant application (see table below for exact dates). You can find guidance notes and the request form on our website: https://www.mssociety.org.uk/research/for-researchers/funding

Award type	Deadline to return your lay summary development form	When you will receive feedback on your lay summary
Data discovery awards	Friday 1 April 2022	Monday 25 April 2022

C. Involvement of people affected by MS

Patient and public involvement (PPI) in research is when people with personal experience of health conditions work in active partnership with researchers or research funders such as the MS Society. We believe that involving people affected by MS strengthens the quality and relevance of MS research.

This is distinct from being a participant in a trial or study, and from public engagement. Involvement is about influencing the design and oversight of a project.

Before applying, we encourage applicants to consider involving people affected by MS in the development of proposals. This helps to:
- Ensure your research questions are relevant to their experiences
- Improve the clarity of your lay summary
- Ensure that any studies involving people are designed in a patient-friendly way and acceptable to participants with MS

We also encourage applicants to consider how to involve people affected by MS, should their application be awarded funding. For example, people affected by MS could:

- Join an advisory group to provide their perspective throughout the course of a project - advising on challenges such as low recruitment.
- Review participant information materials to be used in your research (leaflets, posters, webpages, questionnaires)
- Advise on the best ways to communicate and disseminate your findings

You may find the following resources useful to plan effective patient and public involvement:

- INVOLVE Briefing notes for researchers: http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/
- The NIHR Research Design Service patient and public involvement in Health and Social Care Research: http://www.rds-london.nihr.ac.uk/RDSLondon/media/RDSContent/files/PDFs/RDS_PPI-Handbook_web_1.pdf
- INVOLVE guidance on 'Budgeting for involvement': http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/.
- Access to Understanding 'Writing about biomedical and health research in plain English': http://www.access2understanding.org/wp-content/uploads/2014/11/Access-to-Understanding-writing-guidance_v1.pdf

Expenses for involvement should be included in the budget.