MS Society logo has letters M S in orange followed by the word Society written in white inside an orange triangle. 

Research Network logo is an orange wheel shape with the words 'Research Network' in dark blue. Public Involvement Request Form

Updated 2024

We involve people affected by MS in all areas of our work, taking into account their unique insight, experience and knowledge. Our Research Network members help ensure that the research we fund is relevant to people affected by MS, and that researchers consider their interests and needs.

# What is the Research Network?

The Research Network is a diverse group of over 300 people affected by MS. This includes people living with MS, as well as family, loved ones, and unpaid carers. They are trained to use their personal experiences of MS to help improve the quality and relevance of research.

# How can the Research Network be involved in my research project?

Research Network members can be involved in a number of ways, including:

* Commenting on project proposals prior to submission to a funding body (the MS Society or other UK funders). Or inviting them to be a co-applicant on the application.
* Helping you understand what it means to live with MS. And discussing the relevance and importance of your research questions or future plans.
* Offering suggestions on the suitability of your proposed methods, for example through a focus group.
* Helping you develop information materials such as leaflets, posters, webpages, and questionnaires prior to their use.
* Sitting on a steering group, or joining the study team, to provide a lay perspective throughout the research process.
* Helping you strengthening your communication, engagement and dissemination strategy or plans.

# How do I submit a request for Research Network involvement?

Please read the guidance below and complete the request form. Email this to [researchnetwork@mssociety.org.uk](mailto:researchnetwork@mssociety.org.uk) with the subject heading ‘Request for public involvement’.

Please note, we only recruit Research Network members via our monthly email. So depending on when we approve your request, **it can take up to 6 weeks** from then to find interested members. We also can’t guarantee support for every request we receive.

## For other public involvement queries

Please contact our Public Involvement Manager:

[researchnetwork@mssociety.org.uk](mailto:researchnetwork@mssociety.org.uk)

020 8438 0844

# What should I include in my Public Involvement request form?

Please read these guidance notes carefully before completing your request form.

## Section 1

Clearly describe your research project in accessible, lay language. This should be **no more than one page of text.** You can include figures or attach supporting documents. Consider covering:

* Background to your work, the aims, the plan and potential outcomes.
* How your research will benefit people affected by MS in the future.

## Section 2

Explain what kind of involvement activity you would like to run with Research Network members, how they can contribute, and what you hope to achieve. See examples on the previous page of how they could get involved.

It’s really important you **clearly describe the impact** that Research Network members can make on your work. If they feel valued and can make an impact, then they’re more likely to want to be involved.

## Section 3

Describe how and where you will involve people. Will this be online or in person? If in person, where? Will this be a group conversation or one-to-one? Will there be an opportunity to comment on documents in their own time?

## Section 5

Equality, Diversity and Inclusion (EDI) is at the heart of all our work. We want Research Network members to feel included and empowered in their role, while also feeling they can be themselves. Whether involvement is online or in-person, please explain how you’ll:

* Support members in their role, e.g. induction, training, mentoring, direct point of contact
* Address any barriers to involvement e.g. family, work, technology, language, education
* Take into consideration accessibility needs e.g. disabilities, mobility, cognition, technology

## Section 6

Our Research Network members aren’t currently paid for their time and contribution by the MS Society. We ask that you fully reimburse all expenses and offer some form of reimbursement for their time, if possible. This is to recognise and value their contribution to MS research. You may wish to follow the [NIHR public contributor payment policy.](https://www.nihr.ac.uk/nihr-public-contributor-payment-policy)

## Section 7

Sharing results and assessing the impact our public involvement activities is very important to us. Please consider how you will share the impact of Research Network involvement on your research project. We may ask you to provide updates, so we can share this with our Research Network or the wider MS community.

# Public Involvement Request Form

|  |  |
| --- | --- |
|  | Lead Applicant |
| Full name |  |
| Title |  |
| Institute and department |  |
| Email |  |

|  |  |  |
| --- | --- | --- |
| Other applicants involved in the research | Applicant | Institute |
|  |  |
|  |  |
|  |  |

|  |  |
| --- | --- |
|  | Key information |
| Lay title of the project |  |
| Does this project have funding? | Yes / No  If no, which funding scheme will you apply to? When is the application deadline? |

**+ See previous page for guidance on how to complete the following questions.**

**1. Please write a lay summary of your project.**

**2. Describe how you’d like to involve people affected by MS, and the impact they could have.**

**3. When and where would you like to hold this involvement activity?**

Highlight any deadlines, timeframes, possible meeting dates and locations.

Describe the time commitment expected from the Research Network members.

**4. Who do you want to involve? And how many people?**

Would you like people with particular experiences or interests? E.g. carers, type of MS, symptoms, specific treatments, gender, age. If so, explain why.

We can’t guarantee we can meet your request, but we’ll try.

**5. How will you consider EDI in your involvement activity?**

**6. How will you reimburse Research Network members for their time or expenses?**

**7. How and when will you share the impact of involvement with the people you involve, and with the MS Society?**

**We’re the MS Society.**Our community is here for   
you through the highs, lows   
and everything in between.   
We understand what life’s   
like with MS.

Together, we are strong   
enough to stop MS.  
[mssociety.org.uk](http://mssociety.org.uk/)

Contact us  
MS National Centre 020 8438 0700  
[info@mssociety.org.uk](mailto:info@mssociety.org.uk)  
MS Helpline Freephone 0808 800 8000   
(weekdays 9am-9pm)  
[helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

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[twitter.com/mssocietyuk](http://twitter.com/mssocietyuk)

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