30th November 2017

Public Involvement Request Form

Request for Public Involvement

The MS Society involves people affected by MS in all areas of our work, taking full advantage of their unique insight, experience and knowledge. Our Research Network ensures that the research we fund is relevant to people affected by MS, and that researchers take into account their needs.

What is the Research Network?

The Research Network is a diverse group of approximately 250 people living with MS or is a (non-professional) carer or close family member of someone with MS. 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 your research project?

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

* Commenting on grant applications prior to submission to a funding body
* Offering suggestions to you on the suitability of 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 to provide a lay perspective throughout the research process.

How do I submit a request for Research Network involvement?

* Please read the guidance below
* Complete the request form (page 5 onwards of this document)
* Email to [researchnetwork@mssociety.org.uk](mailto:researchnetwork@mssociety.org.uk) with the subject heading ‘Request for public involvement’

Please note: due to resource constraints the MS Society cannot guarantee support for every request we receive.

For all enquiries about involving people affected by MS in your research:

Please contact our Public Involvement Manager at

[researchnetwork@mssociety.org.uk](mailto:researchnetwork@mssociety.org.uk) or 020 8438 0844.

Completing the Public Involvement request form

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

Section 3

In this section you need to clearly describe your research project in accessible language. You can attach supporting documents. Is your description intelligible for an audience without a scientific background?

* Background to the work, organisation(s) involved, and the funding body
* Research to be undertaken and how this fits with MS Society’s priority areas as identified in the [James Lind Alliance priority setting partnership](https://www.mssociety.org.uk/research/explore-our-research/our-research-priorities/how-we-decide-what-to-fund) or in our [Research Strategy](https://mss-cdn.azureedge.net/-/media/b57a2336d0204380b231e5fe8619a8bb.pdf?la=en&sc_revision=d101146c98e543ecb13b879f1d8ee7a7&hash=AAB91A26CD3147104C0BD91361BE6DCBAC902440&hash=AAB91A26CD3147104C0BD91361BE6DCBAC902440).
* How your research will benefit people affected by MS in the future.

Section 4 & 5

Please explain what kind of involvement activity you would like to run with Research Network members. What do you hope to achieve from this involvement activity?

* Please clearly describe the impact that you feel their contribution can make to your work. This is really important; if Research Network members feel they have a real opportunity to have an impact then they are much more likely to want to be involved.

Section 8

Please indicate if you would us to try to involve only people who meet certain criteria (e.g. those experiencing a specific symptom, or using a specific treatment). Do you want to involve people with a certain type of MS? Do you want to speak only to people who have MS themselves, or carers as well?

Section 9

For any potential venue, please take into account accessibility for people who may be disabled. For example, is there wheelchair access to the meeting rooms, toilets, car parking?

Section 10

Our Research Network members are not paid. If you would like to hold a meeting, are you able to reimburse reasonable travel expenses for attendees? Please bear in mind that some people may need to be accompanied by their carer.

Section 11

Please describe any support you are able to offer to Research Network members. This might include an induction to the project, advance reading, training (if necessary) or mentoring for example, and being available to answer any queries.

Section 12

Sharing results and assessing the impact of our public involvement activities is very important to us. Please consider how you could share the impact of Research Network involvement on your research project. For long term involvement, you will be asked to provide regular updates, which we may also share through the Research Network newsletter and/or our Research blog.

Public Involvement Request Form

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| --- | --- |
|  | Lead Applicant for the study |
| Full name |  |
| Title |  |
| Post held |  |
| Department, Institution and postal address |  |
| Phone number |  |
| Email |  |

|  |  |  |
| --- | --- | --- |
| Please list other applicants involved in the research. | Applicant | Institute |
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| --- | --- |
| 1. Title of project |  |
| 2. Does this project have funding? If not, which funding scheme are you planning to apply to? When is the application deadline? |  |
| 3. Please give a lay description of your study.  If you wish you can provide this in a separate document attached with this form.  This should be 1-2 pages. |  |
| 4. Please describe *how* you would like to involve people affected by MS.  Examples include involving people:   * In planning and developing a project proposal * In reviewing a project proposal you have already developed, before it is submitted to a funding body. * In a project if it is awarded funding, for example in an Advisory Group, members of a steering committee, or in its dissemination.   You may have other ideas too. |  |
| 5. What is the purpose of involving people affected by MS in this way? |  |
| 6. Is this an ongoing or a one-off opportunity?  If it is long term, when will the involvement start and end?  How often will Research Network members be required?  (e.g. number of meetings per year) |  |
| 7. When would you like to hold this involvement activity?  Please highlight any deadlines you are working towards, or possible dates you have in mind for meetings. |  |
| 8. How many people do you want to involve? (minimum and maximum)  Would you like to involve Research Network members with particular experiences? (e.g. carers, type of MS, symptoms, specific treatments, gender, age) |  |
| 9. Does this activity require physical attendance at meetings? If so, where will the meetings take place?  Please describe your facilities for people with disabilities. |  |
| 10. Are you able to reimburse expenses for Research Network members? |  |
| 11. How will you support the Research Network members involved in their role?  Who will be their main point of contact from your team? |  |
| 12. How and when will you share the impact of involvement with the people you involve, and with the MS Society? |  |

Thank you for taking the time to think about how you will involve people affected by MS in your research.

Please now return this form to [researchnetwork@mssociety.org.uk](mailto:researchnetwork@mssociety.org.uk)