Updated: Jan 2026

Research Network Welcome Training

An introduction to Patient and Public Involvement (PPI)

This training is mandatory for all Research Network members who wish to get involved in Research Network activities.
On average, it takes **1 hour** to complete.

Table of Contents

1. Introduction

In this training we'll describe what it means to be part of the Research Network, including:

- the principles of Patient and Public Involvement (PPI) in research,
- which parts of the research process you can be involved in,
- how you can join the Research Network,
- the support you'll receive.

You can use this training in 2 ways:

1. to find out more about the Research Network and PPI in research.
2. to complete your induction training and become a Research Network member.

As you work through this training there are activities for you to check your understanding of PPI. If you decide you'd like to become a member of the Research Network and get involved in PPI activities, then you'll need to complete a quiz after. This is to see if you've understood the purpose of the Research Network and we can better support you in your role as a member.

Key - This symbol indicates that there's an activity for you to try.

Any questions?

Please contact the Research Network team with any questions, we'd love to hear from you. Call on 0208 438 0844 or email researchnetwork@mssociety.org.uk.

Activity 1: Check your understanding

Give yourself a score from 1-5 on how confident you feel about each statement in the table below. 5 = very confident

Once you've completed this training document, come back to this table and see how your scores have changed. If there are any areas where you still have questions, don't hesitate to ask us!

Learning objective	Confidence before training	Confidence after training
I understand the steps of the research process.		
I can explain why patient and public involvement is important in the research process.		
I know the difference between involvement, participation and engagement.		
I can explain my role as a member of the Research Network.		
I know what support is available to me through the Research Network.		
I know how to get involved in the Research Network.		

2. About the Research Network

The Research Network is a group of over 300 people affected by MS. Some are living with MS; others are unpaid carers or close family members of someone with MS.

Research Network members help make sure the research we fund meets the needs of people affected by MS. There are so many different ways you can get involved, such as:

- reviewing research funding applications
- taking part in focus groups with researchers
- sharing feedback on research project plans
- helping researchers write questionnaires, lay summaries, leaflets etc.

You're an expert by experience

Many researchers don't have direct experience of being affected by MS, and so we need you to tell them what things are important to the MS community. Nobody knows what it's like to live with MS better than you!

MS is a varied condition, and everybody experiences symptoms differently. Because of this, we need to hear from lots of people with a range of experiences.

We want you to tell us how we can improve our research studies so that they're designed, delivered, and implemented with the needs of people affected by MS at their heart.

Giving us this insight into MS is invaluable in making sure that we best serve the MS community.

3. About MS research

Research we fund

We're the largest charity funder of MS research in the UK. We fund research that looks at the causes of MS and potential treatments to manage MS, stop progression and even prevent MS. This research can lead to new Disease Modifying Therapies (DMTs), or symptom management therapies, as well as developing new and better services to help people with MS.

The research process

The length of time that it takes to get from an idea to an outcome will change depending on the research. Sometimes, research projects can take many years. However, there are some basic principles and stages that all research goes through:

1. **Idea generation**
2. **Piloting** in a small number of people.
3. **Testing** in larger groups of people.
4. Assessing **cost and availability**

Symptom management research

Developing symptom management therapies or programmes are generally quicker than drug development. Examples of such symptom management research include:

- Resources to self-manage bowel problems
- Adapted sports as exercise or physiotherapy options
- Wearable digital devices to help with mobility
- Digital apps to help manage fatigue

Case study: How researchers developed the FACETS Fatigue management programme

Idea generation: Cognitive Behavioural Therapy is an effective treatment for Chronic Fatigue Syndrome. Researchers thought the same techniques may be helpful in managing MS-related fatigue.

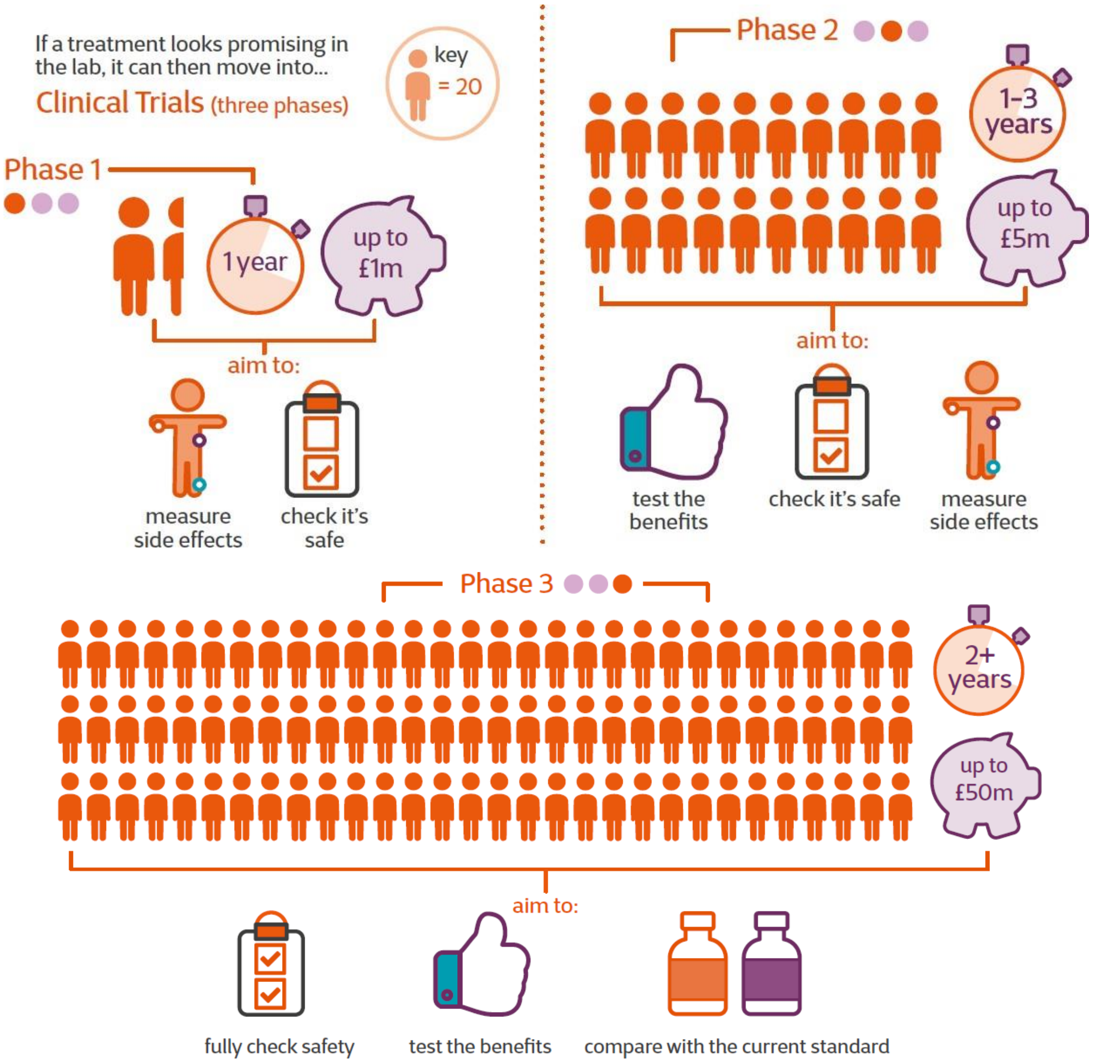
Piloting: Researchers tested this in a small group of people with MS, who were positive about the programme and provided feedback for further improvements.

Testing: Researchers next tested it in a large group where they successfully reduced the group's levels of fatigue.

Assessing cost: The FACETS programme was also cost effective so we committed to rolling out this course across the UK.

Drug development

It can take about 15 years to get from a research idea to a successful treatment option, and there are a number of stages that must be completed in this process. For example, after generating an idea for a new drug and successfully testing it in the laboratory (which is known as the 'pre-clinical' phase), the drug must then be tested in humans using clinical trials:



If the clinical trials are successful, researchers then apply for a licence from the Medicines and Healthcare products Regulatory Agency (MHRA). This license shows that the treatment is safe, effective and that the benefits outweigh the possible side effects.

The treatment must then be approved for cost-effectiveness to be made available on the NHS. This approval comes from the National Institute for Health and Care Excellence (NICE) for England, Wales and Northern Ireland, and from the Scottish Medicines Consortium for Scotland.

If you're interested, we've also shared a video on YouTube which takes you through the steps above. You can watch the video here.

Case study: Testing repurposed drugs in our Octopus Trial

We're working alongside researchers to shorten the research process by investing in repurposed drugs. These are drugs that have already been licensed for other conditions and are being tested for their use in MS. So, in 2023 we launched Octopus!

Octopus
Advancing clinical trials
for progressive MS

Octopus is our multi-arm, multi-stage (MAMS) trial for people with primary and secondary progressive MS. We're testing two repurposed drugs at the same time which show potential to protect and/or repair nerves. We've got the flexibility to drop drugs that don't look promising, and slot in new drugs as they're discovered. This saves us lots of time and money.

This is the first time this kind of trial has been done for MS anywhere in the world. Most trials only test one drug at a time.

We run a Patient and Public Involvement (PPI) group within this trial, and PPI representatives are members of several of the trial management committees. On the next page we'll cover what PPI is, but here is a quote from one of our members:

"I'm on the Octopus trial's PPI group. I find out how the trial is going, bring up any issues, and suggest improvements to the way information is communicated with people on the trial. Being a family member of a person with MS gives me a little distance, so that I can bring a different perspective to discussions."
Katherine, Research Network member.

4. Principles of Patient and Public Involvement (PPI)

What is Patient and Public Involvement?

To make sure the MS community is an active partner in research, we involve patients, carers and members of the public in the research process. Involvement can improve the quality and relevance of research.

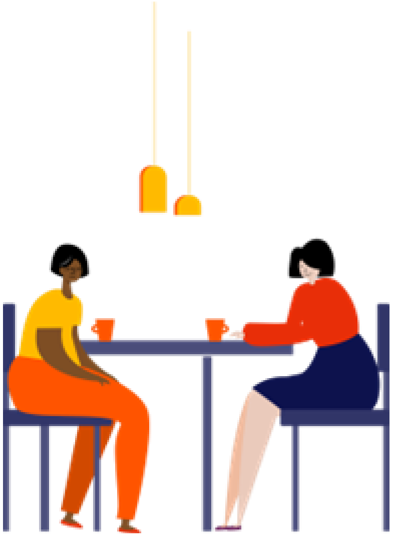
Researchers face many challenges when designing their studies, such as getting funding, gaining ethical approval, recruiting participants, or proving how their work will have an impact. By speaking to researchers, you can help them to solve some of these challenges.

Case Study: MS Fatigue Project Stakeholder Event

The aim of this project was to review the research on treatments for fatigue in MS. The researchers ran two events to hear what people affected by MS thought about the findings, and which treatment they would ideally like to see as standard on the NHS.

"We helped to organise two focus groups for people with MS fatigue, to gather views on two treatments. We were particularly involved in designing the publicity for these events in terms of what pictures and information would attract people with MS, and what they would need to know, such as accessibility to the venue. My opinion was often asked for in the discussions, which has made me feel included and valued as an equal part of the team."
Kay-Anne, Research Network member

"Patient and public involvement was invaluable after reviewing behavioural and exercise treatments for people with MS fatigue. For example, we discovered that only a few people had experience of existing interventions, which they felt limited their understanding of what was available. These meetings meant that we could integrate these views with our research findings to develop a more tailored exercise and cognitive-behavioural treatment."
Dr Harrison, King's College London



Activity 2: Patient and Public Involvement scenario

Now, it's over to you! Read the scenario below and then answer the following three questions. You'll find the answers on the following page.

This isn't a test, it's just a chance for you to get a sense of what it's like to review a research proposal.

Scenario: You're reviewing a researcher's proposal. They're planning an online focus group meeting with people affected by MS. They've invited their local contacts and have asked everyone to attend 9-11am.

Question 1: What concerns might you have about the logistics of this meeting? Select all that apply.

a. Nothing at all, the invite looks great
b. Joining a meeting for 2 hours could be difficult
c. Some people may have work or childcare commitments 9-11am, so may not be able to attend
d. Meetings first thing in the morning can be difficult for those with MS
e. Not everyone knows how to join and interact in an online meeting
f. Something different to what's listed above

Question 2: What could you suggest to the researcher to make the meeting more accessible? Select all that apply.

a. Ask the attendees for their availability to find a time that suits everyone
b. Offer guidance on how to join an online meeting, and give the option to join using a phone number
c. Incorporate breaks into the meeting, or shorten the meeting time
d. Ensure that the invitation is sent to people affected by MS across the UK, to ensure that they're hearing from a diverse group
e. Offer financial reimbursement for people's time, internet access, childcare costs or other reasonable costs
f. Something different to what's listed above

Question 3: What impact could these changes have? Select all that apply.

a. The researcher will have better attendance at their meeting
b. They will hear from a more diverse group of people
c. Their research will be more relevant to the wider MS community

Answers: Patient and Public Involvement scenario

Question 1:
One of the key points of public involvement is that there's not one specific answer or correct viewpoint - that's what makes your input so valuable. Everybody has been affected by MS differently. Whether that's the symptoms experienced or the journey to diagnosis.

The important thing is if you have any concerns you should raise them with us or the researcher.

Question 2:
You have personal experience of MS and so you're an expert in the condition. If there are things that could be changed to make the meeting better, please do let us or the researcher know.

Question 3:
You're helping the researcher to better involve people affected by MS in their work. By having a more diverse group, they'll produce research that is more relevant to the MS community.

Engagement, participation or Involvement?

These 3 terms are often referred to in research, but what's the difference?

Engagement

Engagement happens when a researcher shares information and knowledge about their work with the public. This could be at conferences, science festivals, or in the media.

Participation

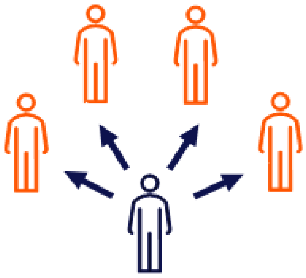
Participation is when the researcher gathers information and data from the public. Study participants may be asked to give blood, complete a questionnaire, or take a medication. Study participants are in the trial but don't influence the study design.

Involvement

This is where you work in partnership with researchers throughout the research project, from initial idea to sharing results. Activities include giving feedback on the wording of information leaflets for the public, reviewing study plans, and commenting on how much is being asked of participants.

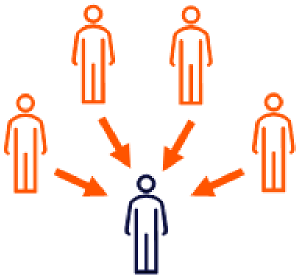
The Research Network focuses on involvement activities only.

Engagement



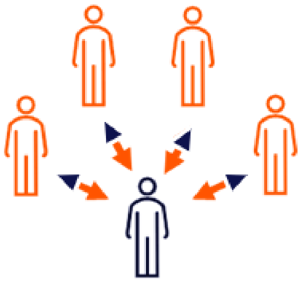
The researcher (blue) shares information with the public (orange).

Participation



The researcher (blue) gathers information and data from the public (orange).

Involvement



The researcher (blue) works in partnership with the public (orange). Sharing ideas and suggestions with each other.

Activity 3: Which type of activity is this?

Label each activity as engagement, participation or involvement.

Remember this isn't a test. You'll find the answers to this activity on the next page.

As a member of the Research Network you'll be taking part in **involvement** activities ONLY, not participation or engagement activities.

Activity	Engagement, participation or Involvement?
1. Reviewing a research proposal	
2. MS researcher shares their findings with local MS group	
3. Working with the researcher to design their research, and suggesting that they give the participants a break to help manage their fatigue	
4. A researcher organises an event to present their findings	
5. Commenting on the patient information sheets for a new treatment	
6. Taking part in a new treatment trial	
7. Being invited to join a study which will involve completing questionnaires	
8. Advising a researcher to interview trial participants on the phone instead of face-to-face meetings, so that they can speak to a wider range of individuals	

Answers: Which type of activity is this?

Activity	Involvement, participation or engagement?
1. Reviewing a research proposal	**Involvement**- you can make suggestions on how it can be improved based on your experience and knowledge of MS symptoms
2. The local MS group share research findings	**Engagement**- you get to hear about this work after it's complete but not have any influence on how the research has been run
3. Suggesting to a researcher that they give the participants a break to help manage their fatigue	**Involvement**- you're using your experience of MS to improve the experience for those who will take part in the study
4. A researcher organises an event to present their findings	**Engagement**- you get to hear about this work after it's complete but not have any influence on how it's been run
5. Commenting on the patient information sheets for a new treatment	**Involvement**- you're reading these sheets as someone affected by MS, and can pick up on any parts that the researchers need to clarify
6. Taking part in a new treatment trial	**Participation**- you're taking part in this study to give the researchers data, but you can't change how the study is run
7. Completing a questionnaire about the symptoms you experience	**Participation**- you're taking part in this study to give the researchers data, but you can't change how the study is run
8. Advising a researcher to interview participants on the phone instead of face to face meetings	**Involvement**- based on your experience and knowledge of MS symptoms, you know that some people can't travel to meetings. Suggesting that the researcher is flexible and offers to call participants instead would mean hearing from a more representative and diverse group.

5. Getting involved in the Research Network

Stages of the research process

You can get involved in lots of different ways throughout the research process. Remember, involvement is where you work in partnership with researchers to influence the project.

Setting research priorities
Join consultations, focus groups or partner with a researcher to identify and prioritise research topics.

Designing research
Join meetings to develop ideas. Review research plans. Ensure project aims are important and relevant.

Help researchers write funding applications
Support with writing the lay summary or PPI plans. Or join the team as a co-applicant.

Decide what research we fund
Review and score PPI sections of research funding applications.

Shaping ongoing research
Sit on advisory groups or project teams to help direct, manage or oversee the project.

Carry out research
Work in partnership with researchers. e.g. developing questionnaires, running focus groups, interpreting the data.

Sharing results
Engage the community by writing articles or presenting research finding with researchers.

Case study: Helping design a research project looking at menopause in MS

Researchers wanted to understand whether menopause impacts MS. And how people manage menopause symptoms or look for support. So they designed a menopause study looking at information from people with MS, rather than at scans or medical tests.

"I attended a focus group to help design this study. There were women with MS from all over the UK there. Everyone had either been through menopause or were going through it at the time. We talked about our experiences and about the important questions we thought researchers should focus on."

Úna, Research Network member

Case study: Partnership with a lab-based researcher

Myelin is the protective coating that surrounds our nerve cells. When myelin is lost, nerves can become damaged and lead to MS progression. Researchers want to better understand how brain cells, called oligodendrocytes, behave and produce myelin. Their research is carried out in a lab but PPI is still just as important.

"I was partnered with a PhD student who is studying different types of oligodendrocyte cells. She clearly explains the science and there are many opportunities for me to ask questions. Partnering with her has helped me to understand the biology in a lot more depth and helped her to check that her research is a priority for people with MS. I feel that I can encourage her as well as learning a lot from the partnership.

We'll have 3 or 4 online meetings a year which could have the additional benefit of helping her with funding applications, and should help to improve the quality of her PPI. Also, I can help her to design materials for people in the MS community."

Stuart, Research Network member

Note on using AI

We ask that you don't use Artificial Intelligence (AI) in any activity, unless you gain permission in advance. This is essential for safeguarding scientific opinions and assessments, as well as private conversations. It's not clear whether anything put into AI tools like ChatGPT, or using meeting notetaking tools like Otter.AI remains confidential.

What's the time commitment?

As little or a much as you like. We'll email you every month with new activities to get involved in. You can express interest in as many or as few as you like.

Almost all of the activities we share you can do at home, in your own time, at your own pace. You'll just need a computer/tablet and access to the internet. Some opportunities are just a one-off, but for others you might join a research project for several years. We'll always be clear what the commitment is.

Activity	Average time commitment	What's involved
Review documents or research funding applications	1 -3 hours per document	You'll share honest and constructive feedback. You could help researchers develop their written research proposals. Or help develop materials suitable for the MS community. You can complete these reviews at home in your own time.
Participate in meetings or focus groups	1-2 hours per meeting + 1-2 hours pre-reading	You'll participate in discussions at online meetings, asking questions and raising any concerns. You might discuss the importance of the proposed research question, how reasonable the ask of participants is, or the best way to embed PPI in the project. Meetings will likely be online. But occasionally in-person.
Contributing to our research communications	Varied, but generally a few hours	Write articles for our website or MS Matters magazine. Interview researchers, or take part in filming opportunities. This is mostly online. Occasionally, you might be given the option to visit the researcher at their university.

How will I be supported?

- We provide guidance and support specific to each activity.
- We run monthly Zoom sessions where you can drop in and ask questions. Or you can always contact us by phone or email.
- We can put you in touch with another Research Network member who has done a similar role before so that you can hear about it from their perspective.
- We reimburse out-of-pocket expenses and will arrange travel for you if you're going to a meeting in person.
- We encourage researchers to reimburse you for your involvement, according to the National Institute of Health Research (NIHR) guidelines.
- Meetings will be online or held in accessible venues.
- You can choose to receive papers to read by email or by post.
- We listen to your feedback and welcome your ideas of how we can improve.
- We'll keep you updated on the activities of the Research Network.
- We'll thank you for your time, commitment, and the impact that you had on the project.

At the MS Society there are lots of different ways you can get involved and volunteer. Have a look at the Welcome Booklet on the volunteer website to find out more about what we do, what volunteering with us is like and learn about useful and important resources.

Next steps

1. Check your understanding of this training - go back to page 4 to see how your confidence scores have changed.
2. Complete the Welcome Quiz and demographic survey. It should take no more than 10 minutes. This is to check you understand the role and then we'll be in touch with some feedback. Email us at researchnetwork@mssociety.org.uk to access the quiz and survey.

Once you've completed the Welcome Quiz, you're ready to get involved in research!

We'll email you monthly with new activities for you to get involved. We also hold an optional monthly Zoom meeting, so you can ask questions, chat to other Research Network members, and sign up to activities that you feel comfortable with.

We're a research network, a community, a team. And we're here to support you!

Feedback and contacts

We're always looking to improve the way we work and the support we offer our network. So, whether you thought this training was fantastic, terrible or somewhere in between - please tell us why. And if you have some recommendations to improve, we'd love to hear these.

Email us at ResearchNetwork@mssociety.org.uk and we can work together to make it better.

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

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

Online
mssociety.org.uk
facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland
0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
mscymru@mssociety.org.uk

Multiple Sclerosis Society
Registered charity nos. 1139257 / SC041990
Registered as a limited company in England and Wales 07451571
Registered office: Carriage House, 8 City North Place, London, N4 3FU