

Research Network distance learning pack

A quick introduction to patient
and public involvement



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1. Introduction

This distance learning pack aims to articulate what it means to be part of the Research Network. It does this by explaining:

- which parts of the research process a Research Network volunteer can be involved in,
- the principles of public involvement in research,
- how you can join the network,
- the support you'll receive.



You'll find out more and have a chance to try a few activities aiming to help you become more familiar with the principles of public involvement.

If you'd like to join the Research Network, you can find out more about how to get involved on page 16 in this pack. You'll need to complete a quiz which helps you to see if you've understood the role of the Research Network.

You can use this pack in 2 ways:

- to find out more about the Research Network before deciding if you want to join
- to help you prepare for the quiz

Key



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

Any questions?

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

Getting started



Before you start, give yourself a score from 1-5 on how confident you feel about each statement in the table below. Use your scores to choose which sections of the pack you want to focus on.

Learning objective	Confidence before	Confidence after
I understand the steps of the research process.		
I can explain why 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.		



Once you've completed the distance learning pack, 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!

2. Tell me more about the Research Network

We're really pleased you want to be involved in the Research Network.

The Research Network is a group of over 250 individuals who've been affected by MS. Some members have a diagnosis of MS; others are unpaid carers or close family members of someone with MS.

Research Network members help to make sure the research we fund meets the needs of people affected by MS. They review grant applications, take part in focus groups with researchers, participate in consultations and questionnaires, and share their experiences of MS with the public and in the media.



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. It's all about research

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. We're also working to improve care and services for people with MS.

We fund research that'll help us find new treatments or therapies to manage and stop MS. These treatments can be 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:

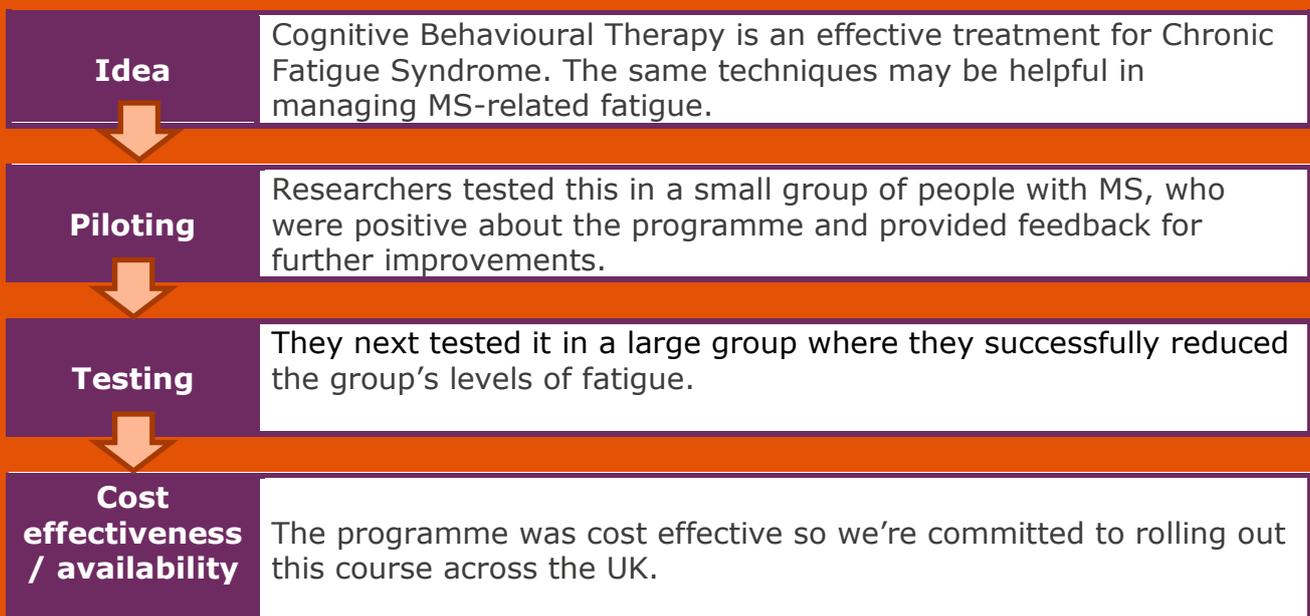


We've outlined how this process is used in symptom management and drug development research below.

Symptom management research

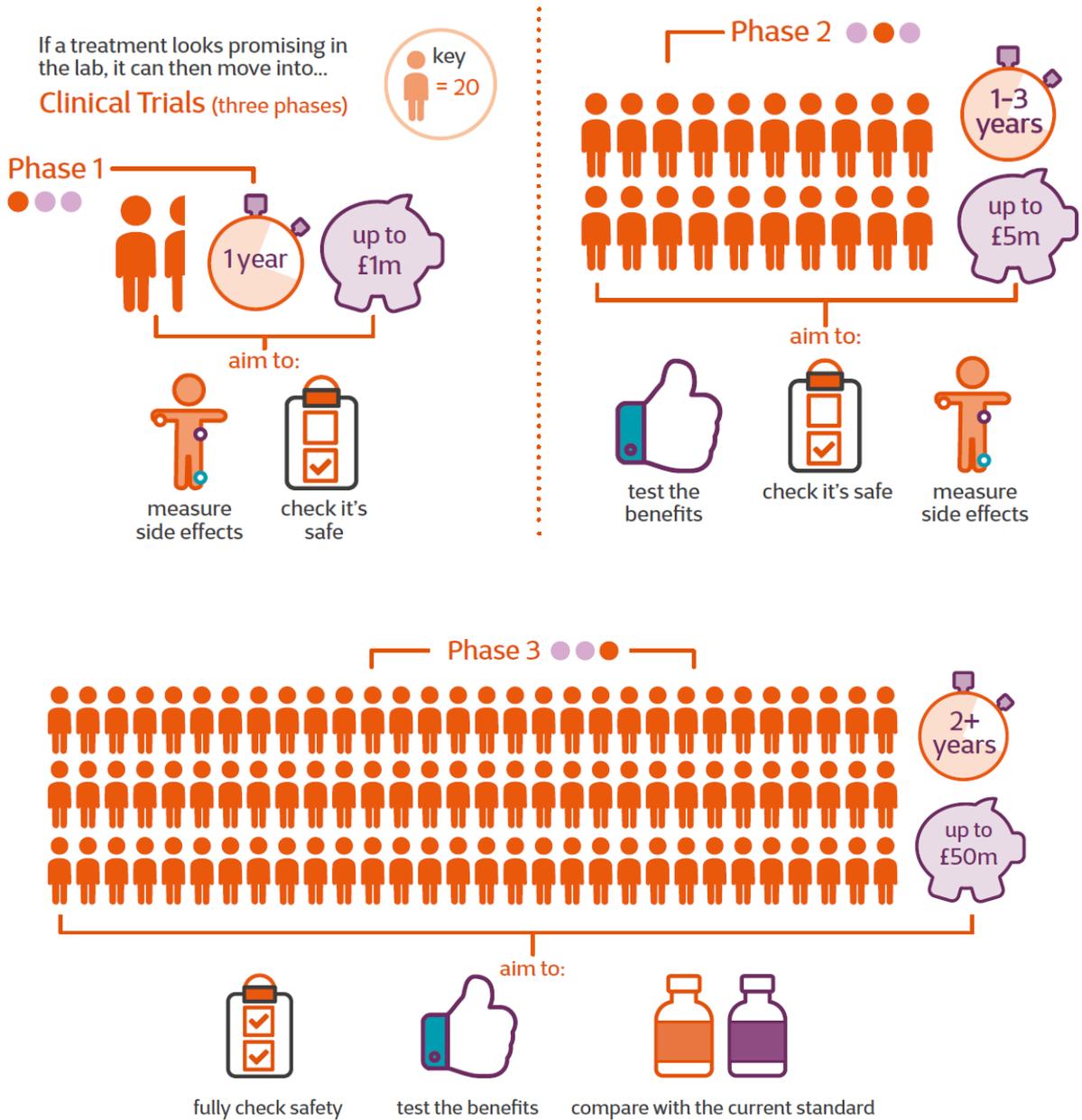
Developing symptom management treatments is generally quicker than drug development.

Here's how researchers developed the FACETS Fatigue management programme:



Drug development

It can take up to 17 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 lab, the drug must then be tested in humans using clinical trials:



If the clinical trials are successful, the researchers then apply for a licence from the European Medical Agency. 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.



Did you know...?

We're working alongside researchers to shorten the research process by investing in repurposed drugs and developing multi-arm trials.

Repurposing Drugs

Simvastatin is a medication used to treat high cholesterol and lower blood pressure, so we know that it's well tolerated by the body.

We think it could also help protect nerve cells in MS.

Because it's already widely used, we didn't have to redo the phase 1 safety checks, so we went straight into phase 2 testing. This saved us lots of time and money.



Multi-arm Trials

The MS SMART trial tested 3 drugs at the same time in people with secondary progressive MS.

Up till now, most trials only test 1 drug at a time.



By testing more than one drug at a time, we can run faster and cheaper trials. This means that we can find out what drugs work for MS more quickly.

4. Principles of patient and public involvement

What's 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.

The impact of involvement

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. It was interesting to meet experts in MS research and hear about treatments that are being used or have been trialled in managing fatigue. I have enjoyed every minute."

Kay-Anne Sheen, 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 for MS fatigue moving forwards."

Dr Anthony Harrison, King's College London



Activity: Patient and public involvement scenario

Over to you! Choose your preferred response(s) for each question then have a look at page 17 where we've added more information about each response. This isn't a quiz, it's just a chance for you to experience what it's like to be a member of the Research Network who's reviewing a research proposal.



Scenario: You and four other Research Network volunteers are reviewing a researcher's proposal. They are asking participants to attend a meeting in person at 9.30am on a Tuesday morning in central London.

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. Getting to a meeting in central London could be difficult
- c. Travelling during rush hour will make this more challenging
- d. Not everybody lives in or near London, so may not be able to attend
- e. Meetings first thing in the morning can be difficult for those with MS
- f. Travel will be reimbursed, but traveling during peak hour will cost the researcher more, meaning that less money will be spent on the research
- g. 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. Offer dial-in details so that people can join the meeting by phone
- b. Start the meeting later in the day to avoid rush hour and allow more time for people to start the day
- c. Ensure that the teleconference invitation is sent to people affected by MS across the UK, to ensure that they're hearing from a diverse group
- d. Something different to what's listed above

Question 3: What impact could these changes have on the meeting? 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

Involvement, participation, or engagement?

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

Involvement

This is where you're actively involved in planning research projects and research organisations. Activities include giving feedback on the wording of information leaflets for the public, reviewing study procedures and commenting on how much is being asked of participants, study management, or helping us to decide which research to fund. You could influence any part of the research process. The Research Network focuses on involvement activities.

Participation

Research study participants actually provide the researcher with data. This may be through completing a questionnaire, taking a medication, or going for scans. Study participants follow the trial procedure but don't influence how the study is designed.

Engagement

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



Photograph credit: Amit Lennon

Activity: Which type of activity is this?



Label each activity as involvement, engagement, or participation.
Remember this isn't a test. You'll find the answers to this activity on page 18.

Activity	Involvement, engagement, or participation?
1. Reviewing a research proposal	
2. The local MS group shares research findings	
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	

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

Stages of the research process you could be involved with

You can get involved in lots of different projects throughout the research process. Here are some examples:



5. Getting involved in the Research Network

What's the time commitment?

As little or as much as you like! We contact Research Network members by email when there's a new opportunity to get involved. You can express interest in as many or as few activities as you like.

Some opportunities are short and can be done from home, others could last several years and could involve attending or dialling into meetings. See the table below for some ways you might get involved.

Activity	Average time commitment	Where?
Reviewing research grant applications	You'll be given a deadline in advance, giving you a few weeks to read and comment on the research proposal in your own time. This may take you 2-4 hours.	At home
Completing surveys/questionnaires and reviewing documentation for accessibility and ease of understanding	Up to a couple of hours	At home
Participating in meetings or focus groups to discuss the importance of a proposed research question to people affected by MS, or helping researchers to develop a study protocol	A few hours to read any preparatory material at home in your own time in advance, and then a few hours at the meeting or focus group.	The meeting may be in person (often in central London but not always), or you may be able to phone or video conference
Contributing to research communications, writing for our research magazine (Research Matters), interviewing researchers, or taking part in filming opportunities	Varied, but generally a few hours	Mostly at home, but you may be able to visit the researcher at their university (if you want)
Joining an advisory group to oversee the running of a research project	Attending/ dialling in to a meeting every few months for a couple of years. Each meeting may last an hour or two. You may be asked to read material ahead of the meetings.	At home or in person

How will I be supported?

- We reimburse out-of-pocket expenses and will arrange travel for you if you're going to a meeting in person
- Meetings are held in accessible venues
- We try to offer dial-in opportunities if you can't physically attend the meeting
- You can choose to receive papers to read by email or by post. We'll always send papers in plenty of time ahead of the meeting.
- You can always contact us by phone or email with questions and for guidance and support.
- 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'll listen to your feedback and welcome your ideas of how we can improve our involvement activities.
- 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.

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.

When you're appointed to a role, we'll provide more support specific to the activity.

How do I get involved?

To join the Research Network, you'll need to fill in this form.

You'll be sent a quiz to complete. Once this is complete you'll be registered as a member of the Research Network and you'll be ready to take part in Research Network activities that interest you.

You'll be sent details about these activities by email, and you can register your interest in as many or as few opportunities as you like.

For some activities, you'll need to complete a short application form which asks:

- why you're interested in the role,
- your relevant experience,
- what you think the role will involve

The application form helps us to find the Research Network members who would best fit the role, especially when there's a lot of interest.

We often follow up the application form with a phone call. We'll discuss your relevant experience and make sure that you fully understand the role. We don't want to appoint someone to a position that they don't feel comfortable with.

We're here to support you so be sure to ask us any questions you may have. You'll also receive regular Research Network updates by email, telling you about what is happening in the Research Team at the MS Society and any exciting news about MS research.



Remember to go back to the table on page 4 to see if your scores have changed. Do contact us if there's anything you're still unclear about.



Photograph credit: Ginny Lattul

6. Feedback on this resource

Tell us what you think about this guidance by completing this short [survey](#). Your feedback will help us to improve our resources when they're reviewed.

7. Answers

Activity: Patient and public involvement scenario

Here's some additional information for the questions that you answered on page 10.

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 to raise them with the researcher or the Public Involvement Officer.

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.

Activity: Which type of activity is this?

Here are the answers to the questions that you answered on page 12.

Activity	Involvement, engagement, or participation?
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 that they hear from a more representative and diverse group.