

Social networks in multiple sclerosis – research study results

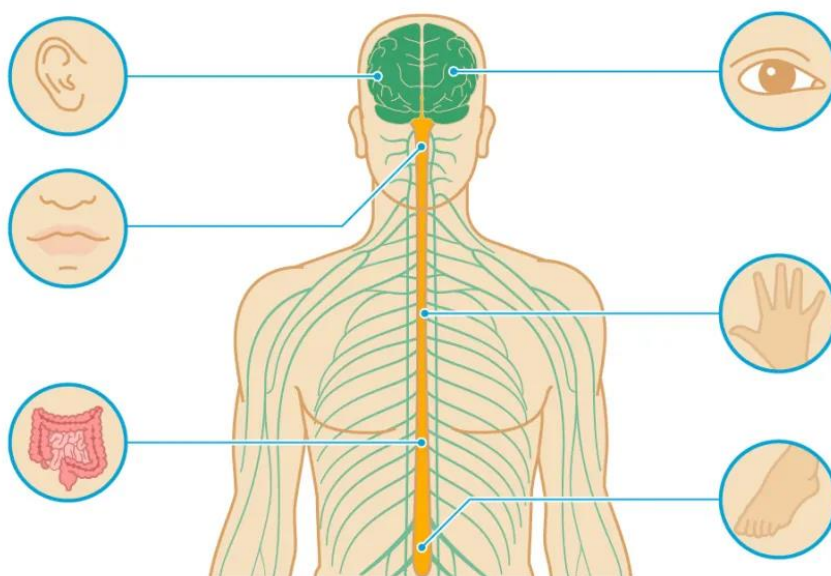
Earlier this year or last year you participated in the research study, '**Associations between social networks, health and social media in multiple sclerosis**'. Thank you very much for offering your valuable time to contribute to this research. I am pleased to let you know that the study has now ended and the data has been finalised. I am sharing the results with everyone who took part.

Background

Neurological conditions are long-term diseases or injuries which affect the brain and spinal cord. They include stroke, dementia, multiple sclerosis (MS) and traumatic brain injury (TBI).

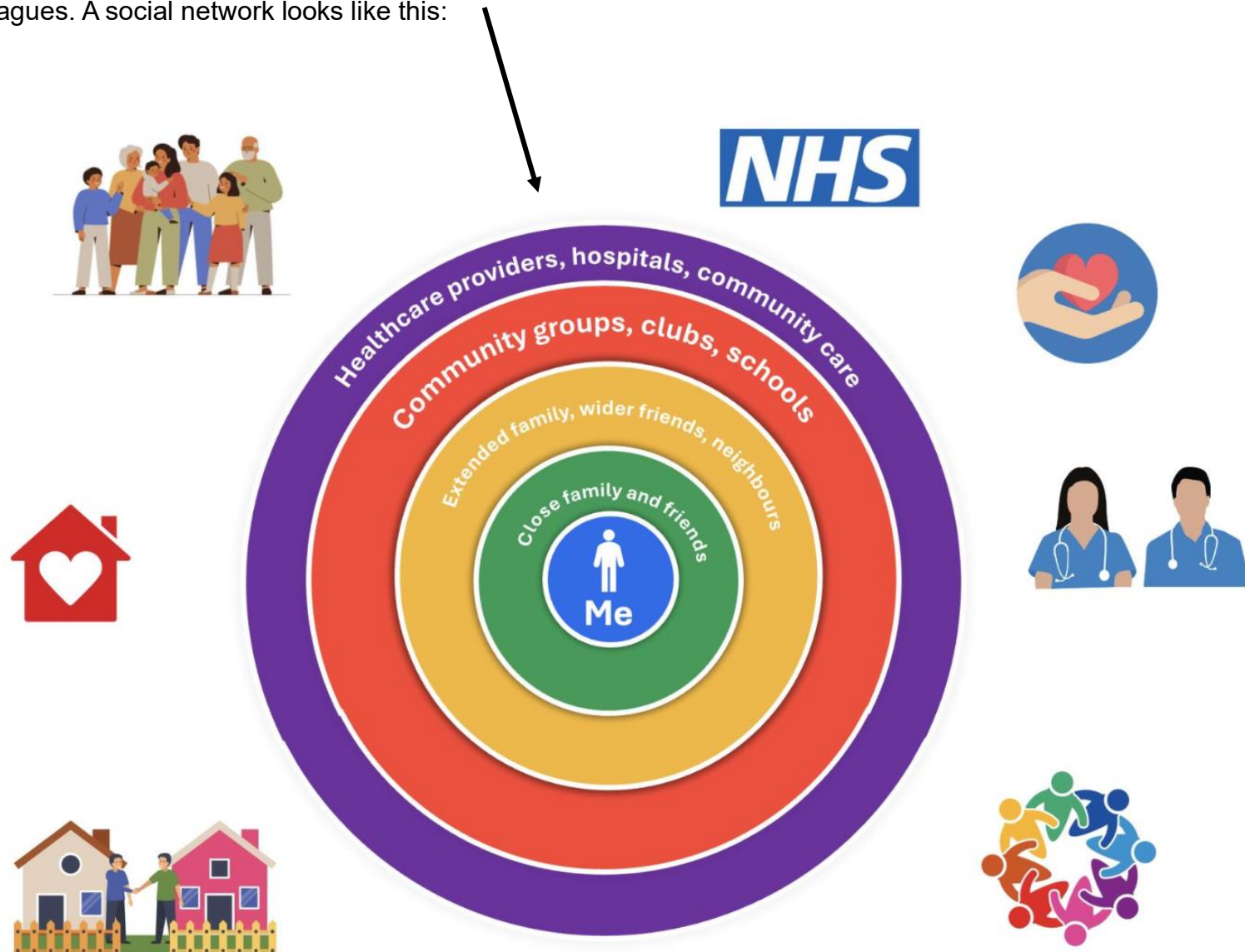
Neurological conditions can lead to a range of **physical symptoms** including muscle weakness, pain, fatigue and difficulties with balance. They can also affect **thinking skills** like problem solving, decision making, language and memory. These thinking skills are called '**cognition**'.

Living with a neurological condition can be difficult for people, with so many medical things to manage. It is therefore important to develop therapies which can help to maximise the wellbeing of people with neurological conditions and support their **mental health**.



Social networks

An area of research which could help is social networks. Social networks are our relationships with important people, like friends, family, neighbours and colleagues. A social network looks like this:



You are in the middle, and each circle contains different types of people in your life. The circles are categorised based on how close you feel to these people and what type of role they play in your life.

We know that social networks are important for our health and wellbeing because they provide opportunities for **social support, social interaction and social connection**. They also provide opportunities for different types of activity like **work, education and hobbies**, as well as **physical movement** (travel, exercise).



For people with MS, social networks are very important. Social support and social interaction are good for **mental health**, and being more socially active can benefit **physical health** and **cognition** (thinking skills).



However, some studies have shown that people with MS might have **lower social support** and **lower social participation** compared with people without MS. Research has also shown that people with MS often have **fewer people in their social networks**, and the persons they do have in their social networks are **likely to know each other well** (i.e., they are mostly family or close friends – they are not strangers).



If we know how social networks positively influence health, we could help people with MS to make changes to their relationships, social activities and routines which could help to maintain better health. These recommendations could form a part of **treatment or therapy**.



What did we do?

We designed a new study to look at the relationships between social networks and different aspects of health in people with MS. A group of healthy adults were recruited to the study so that comparisons could be made between people with MS and the general population.

The study also aimed to look at whether PwMS' **social media use** is relevant to their social networks. Previous studies show that PwMS use social media to make social connections with other PwMS and find support and guidance. Social media could therefore influence how many people are in the social network, or how many people in the social network know each other. This has not been researched in MS before, so the study aimed to test something new.



Predictions

- We predicted that PwMS who had poorer health would have smaller social networks containing fewer people. We also predicted they would have social networks containing mostly people who know each other.
- We predicted that PwMS who frequently use social media would have larger social networks containing more people. We also predicted that they would have social networks containing a range of people who don't know each other.

We recruited 20 people with MS from a London NHS Neurology clinic, charities and therapy centres across Southeast England. We also recruited 20 people without MS from the general population. Everyone completed a face-to-face interview.



This included:

- A questionnaire about **depression and anxiety**
- A questionnaire about **fatigue**
- Three brief **cognitive tests**. These tests measured cognitive skills that can be affected in MS (information processing speed, visual memory, verbal memory)
- A questionnaire about **social networks** (who you speak to about personal matters)
- A questionnaire about **social support** and **social participation** (the activities you do)
- A questionnaire about **social media**



What did we find?

- People with MS scored higher on depression, anxiety, cognitive difficulties and fatigue compared to people without MS.
- People with MS named fewer people in their social networks compared to people without MS. However, the people they named were equally like to know each other as the social networks of people without MS.
- People with MS scored the same as people without MS on social support but lower on social participation.
- People with MS also reported lower use of social media.
- We didn't find any relationships between social networks, social media and health in people with MS. This contradicted what we expected to find.

What does this mean?

It is difficult to draw confident conclusions from these findings, because the study faced challenges which affected the final results.



We were not able to recruit all the participants we needed, meaning the study was low on '**statistical power**'. Statistical power is an issue related to the tests we perform and refers to how likely the study is to find the effects or relationships it expects. Recruiting more participants might have helped us to find the relationships we predicted.



In the future, the study could be repeated in a larger group of people with MS or using different questionnaires.

Ideas for the future

More research in social networks is important because it will help us to design new social network therapies which support the physical health, brain health (cognition) and mental health of people with MS.

Social network therapies have been trialled with people with **diabetes, cancer and respiratory conditions** and have shown positive effects on people's wellbeing. We could use ideas from these therapies to design something similar specifically for people with neurological conditions.

Social media could also be used as a part of this type of therapy to increase people's social connections. We could think about using accessible technology or digital skills training for people who do not feel confident to use the internet.



Thank you

Thank you so much for taking part in this research study. I really appreciate the time you gave to complete all of the questionnaires.

I wish you all the best for the future. If you have any further comments, questions or suggestions about the study, please don't hesitate to contact me:

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