

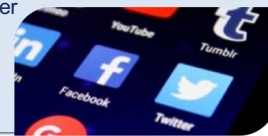


# The role of social media in MS treatment decisions: a qualitative interview study.

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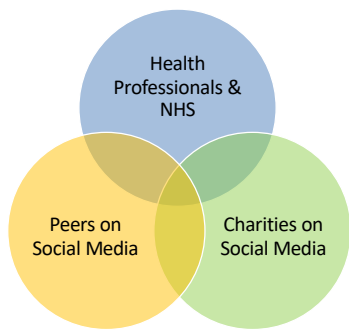
## 1 Background:

People with MS are faced with increasingly complex choices and difficult trade-offs between efficacy and potential side effects. Research shows that choosing a DMT is not a purely rational experience. Despite information provided by Health Professionals (HPs) or charities, patients can still feel that they have unmet information needs. Other people's real-life experiences (often accessed via social media) can help with the decision-making process, by providing both factual and emotional content. Online Support Groups (OSGs) are often used to research treatments, but there is limited research for other platforms such as Facebook or Twitter. People who participate in OSGs report a range of positive and empowering aspects from emotional support to increased information, as well as some disempowering aspects (e.g. misinformation, inappropriate behaviour). Feeling better informed has also been linked to an increase in confidence in discussions with HPs.



## 2 Aims:

This research aims to explore how people with MS use social media to assist with treatment decisions, the role that social media plays alongside health professionals, and whether empowerment processes play a part.



"The place that I hang out wouldn't be as good if there wasn't the mix of the MS Trust, and the, the research as well as the people, it wouldn't be good if it was just people's opinions"

## 4 Results:

Participants used social media to initiate and confirm treatment decisions and anticipate future decisions:

- Usage is higher at point of diagnosis
- Social media is valued for controversial or difficult to access treatments (CBD or HSCT)

Peers, Charities and HPs are all trusted yet insufficient sources of information. These sources are combined to assist decision-making:

- Peers offer first-hand lived experience
- Charities offer accessible information in lay terms
- HPs have expertise (although they lack personal experience of the disease)

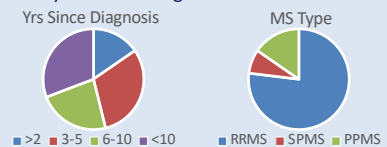
Participants identify positive aspects (24/7 access, improved knowledge and confidence) as well as some negatives (misinformation and negativity) which are overcome through discriminating use.

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## 3 Methodology:

Thematic Analysis of qualitative semi-structured interviews. Diverse sample of 13 participants recruited through social media.

- 9 Female / 4 male
- Aged 26 to 60 (mean=45.3)
- Mean 6.8 years since diagnosis.



"It's a bit like the ratings on Amazon. I might buy a product if it's got two or three negative reviews if the majority of reviews have been positive. It's a bit like that on the forum groups"

"Your neurologist can prescribe the drugs and understand what they do, but they don't, they don't take it themselves. They don't know how you feel when you're on them"

"If you're talking about something in social media it creates a feeling of normality, that your questions are not unusual or daft, that other people feel the same, and consequently I would have more confidence in going forward to a health professional"

"I follow my own [Facebook treatment group], the Tysabri one, erm, and I follow another one for Lemtrada, because I've always looked at that as maybe a possibility if I had to come off mine"

## 5 Discussion:

The data from this study confirm prior research on the role and benefits of OSGs, and of first-hand peer accounts in treatment decisions. In addition to previous research, this study highlights the importance of Facebook and Twitter, as well as emphasising the role that charities play online. It also shows that participants are comfortable navigating multiple and contradictory sources. However, as the sample was recruited through the MS Trust social media feed, there could be limits to the generalisability of these findings to those who already engage with such media. Healthcare Professionals should encourage patients to discuss information found on social media and may benefit from reviewing treatment-specific forums for new DMTs in order to demonstrate an understanding of real-life experiences of patients on the treatments they recommend. Charities should continue to invest in their social media presence, and where feasible might consider including health professionals as part of their social media feeds.

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## 6 Conclusion:

Information from HPs is necessary and valued, yet insufficient to support informed decision-making. Social media in the form of peer accounts and information from charities, provide access to wider information to assist treatment decisions. Social media users with MS employ a variety of strategies such as cross-referencing and crowd-sourcing in order to overcome the risk of misinformation. Social media are seen as empowering, and lead to greater confidence in interactions with HPs.

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**References:**  
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