BACKGROUND
Access to timely and appropriate information is a critical component of informed decision-making for people with MS and their family members. While specialists remain the preferred source for many, the Internet is rapidly becoming the primary information source for people with MS aged under 40. In fact, between 64%-82% of people with MS seek health-information online. As the Internet has grown in prominence, and given the increasing array of therapies and treatments, there has been a rapid increase in the frequency of therapies and interventions to manage MS, how has the health-seeking landscape changed?

OBJECTIVE
To explore the experiences of people with MS in finding, assessing and integrating research-based health information from the Internet.

METHOD
We conducted focus groups and an online discussion forum based on the focus group format.

Participants
Participants, recruited via purposive sampling, had to be diagnosed with MS or a family member of a person with MS. 90 participants (47 females; 13 males; 51 people with MS; 9 family members) took part in either a focus group (27/60) or the online forum (33/60) (see Table 1).

RESULTS

The Internet and...
While most participants described using the Internet to gain information about MS treatments, it was rarely used as the sole source. Most described integrating their Internet searching with information from health professionals, MS Societies and family and friends.

Too much information
Many described being inundated with information, not just information available online, but from the media, family and friends, health professionals and pharmaceutical companies. Some participants described reaching information overload.

The Internet and... Online forum participant
It is up to us to filter through and go with information that we are comfortable with because we just get it put at us every day at noon.

Focus group participant
I reached a point of over-saturation. I snap at the end of it because it was just too much information and just too overwhelming to handle.

Focus group participant

Unbiased, up to date, personally applicable
Most participants expressed a strong desire for unbiased information from independent sources that was up to date and personally applicable to their circumstances. There were sceptical about the quality of information available online although the Internet was seen as an up to date source. Some said it was hard to find personally applicable information on the Internet.

In general, MS is too complex and varies too much for each person to apply information I find online to myself.

Online forum participant

Pros and cons of the Internet
Participants described that searching for information online can often be overwhelming, confusing and sometimes scary. Some, but not all, participants described interactive websites such as forums and blogs as particularly negative. For others, the Internet was a vast, valuable resource and they were confident in their ability to seek out high quality and meaningful information.

These days I will use the Internet solely to read about any new breakthroughs in research.

Online forum participant

Self-regulation of information
Participants described a range of information-seeking strategies to address their comfort levels with the amount of information they receive, their information preferences, attitudes about reliability and their attitudes towards the Internet. We term this concept self-regulation.

I only fully trust the information I find after I have chatted to my neurologist, chatted to family and friends and found satisfactory findings, e.g. people's success stories.

Online forum participant

CONCLUSION
The Internet is an important source of information for many, yet equally scepticism exists about the trustworthiness of many websites. While invaluable to some for fact-checking and to connect with people with MS it can also be overwhelming, scary and negative. Relating online information to personal circumstances was difficult for some.

People with MS and their family members are using a range of self-regulation strategies to filter information from the Internet and to integrate with other sources. The findings suggest that with the advent of the Internet the MS health landscape has moved from unmet need to information overload.

ACKNOWLEDGEMENTS
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REFERENCES

INFORMATION-SEEKING BY PEOPLE WITH MS

Table 1. Participant characteristics

<table>
<thead>
<tr>
<th>People with MS (n)</th>
<th>Family member (n)</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus groups</td>
<td>Online forum</td>
<td>Online forum</td>
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<tr>
<td>--------------------</td>
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</tr>
<tr>
<td>21 (16F:5M)</td>
<td>6 (2F:1M)</td>
<td>27 (2F:1M)</td>
</tr>
<tr>
<td>48.6 +/- 11.6 (median +/− SD)</td>
<td>57 (median +/− SD)</td>
<td>27-66 (median 27-66)</td>
</tr>
<tr>
<td>11.7 +/- 5.9 (median +/− SD)</td>
<td>10 (median +/− SD)</td>
<td>1-39 (median 1-39)</td>
</tr>
<tr>
<td>Mild = (11 (48%): Moderate = 10(28%): Severe = 8 (14%): Unclassifiable = 4 (12%))</td>
<td>Yes = 24 (89%): No = 3 (11%)</td>
<td>Yes = 30 (91%): No = 3 (9%)</td>
</tr>
</tbody>
</table>

*Participants with reports on MS with the year in which they were diagnosed. Family members reported the year when in which their family member with MS was diagnosed.

**Participants with reports on their own disease severity using a modified disease steps questionnaire[5]. Family members reported the disease severity of their family member with MS. "Mild" equates to EDSS 0-1. "Moderate" equates to EDSS 2-5. "Severe" equates to EDSS 6-9 [7]. One online forum participant had two immediate family members with MS and gave separate scores for each.

<table>
<thead>
<tr>
<th>Focus groups</th>
<th>Online forum</th>
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<tr>
<td>8.5 (range 22-73)</td>
<td>48.6 (range 27-66)</td>
</tr>
</tbody>
</table>

*Participants with reports on MS with the year in which they were diagnosed. Family members reported the year in which their family member with MS was diagnosed.

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