MRI in MS survey – insights into access, understanding and interest by people with MS



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Disclosures

LC, EV, AD, DS and WV are employees of icometrix WV is a shareholder of icometrix

Introduction

 MRI scans have become the main tool to monitor disease progression and treatment effect in MS

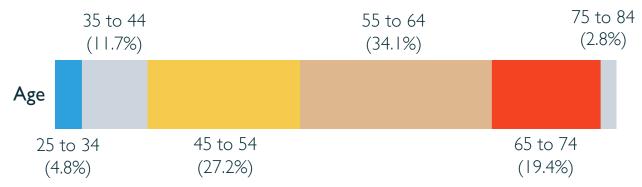
- While studies showed more than 2/3 of patients aim to play an active role in their disease management [1] some strong MRI-related knowledge gaps have been reported [2]
- In order to help MS patients to be more active in their disease management, more studies need to investigate the MRI-related knowledge, attitudes, information needs and experiences of MS patients

I. Heesen, C., Köpke, S., Solari, A., Geiger, F., & Kasper, J. (2013). Patient autonomy in multiple sclerosis—possible goals and assessment strategies. *Journal of the neurological sciences*, 331(1-2), 2-9. 2. Brand, J., Köpke, S., Kasper, J., Rahn, A., Backhus, I., Poettgen, J., ... & Heesen, C. (2014). Magnetic Resonance Imaging in Multiple Sclerosis—Patients' Experiences, Information Interests and Responses to an Education Programme. *PloS one*, 9(11), e113252.

Methodology



- We launched a worldwide survey which was answered by 876 people with MS (PwMS), predominantly located in the US and Canada (91.4%)
 - 80.0% Female
 - Age:

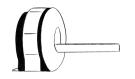


 Survey consisted of questions concerning MRI access, viewing, knowledge and information needs

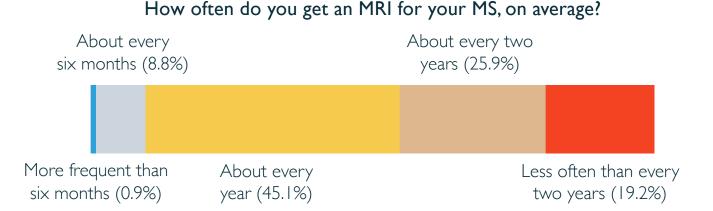
^{*} We did not include answers such as 'Not Sure / Prefer not to say' into the analyses

* One subject aged under 24 participated in the survey

Results – MR scan frequency



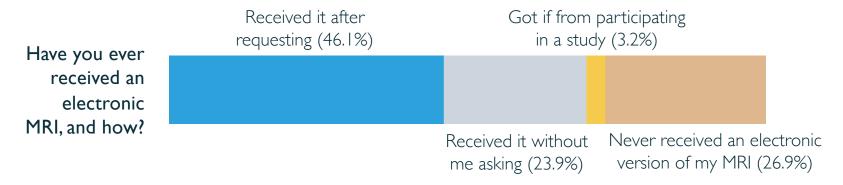
- Only 0.6% (n = 5) of PwMS have never had an MRI performed for the purpose of diagnosing or treating.
- Only 54.9% (n = 474) undergo an MRI scan every year or more frequently



Results – MR image access



• Almost 27% (26.9%, n = 228) of patients have never received an electronic version of their MRI from their clinic or radiology lab



• Of those patients that received an electronic version of their MRI, 79.9% (n = 560) got it on a CD-Disk, 15.6% (n = 109) through their clinic's patient portal, 4.0% (n = 28) through a direct download into their computer or other device and 0.6% (n = 4) on a USB-drive

Results - MR image viewing and knowledge



- Of PwMS that received an electronic version of their MRI
 - 70. 5% (n = 431) looked at their MR images on their own
 - Of those people, only 13.3% (n = 57) claimed to completely understand their MR images:

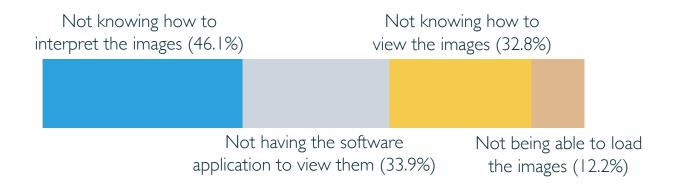
How well did you understand the images in your MRI?



Results - MR image viewing



- 70.2% (n = 99) of the PwMS that have access to an electronic MRI but have not looked at it on their own, would like to do so
- Reasons for not viewing the electronic MR images on their own were (n=225):



Results - information needs



• 98.2% (n = 836) of PwMS are interested in knowing about changes between their MRIs

- 94.7% (n = 767) of PwMS wanted to know if their MRI scan was performed according to clinical MS guidelines
- 96.6% (n = 714) of PwMS would be willing to share their MRIs with researchers

Conclusion

- Only a small proportion of PwMS reported complete understanding of MR images, illustrating the importance of MRI education
- In order to support PwMS to look at their MRI scans on their own, education plays a crucial role but clear instructions and easy access are also important
- Almost all PwMS expressed interest in knowing whether a scan was performed according to guidelines, and whether any changes were present compared to their previous MRI scan