Development of Your MS Questionnaire: A Patient-completed Digital Tool to Monitor Multiple Sclerosis Disease Symptoms and Their Impact on People's Life

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Gavin Giovannoni[1], Enrique Alvarez[2], Olaf Hoffmann[3], Celia Oreja-Guevara[4], Patrick Vermersch[5], Mudeer Khwaja[6], Bianca Stadler[7], Jo Vandercappellen[6], Tjalf Ziemssen[8]

[1]Blizard Institute, Barts and The London School of Medicine and Dentistry, Queen Mary University of London, London, UK; [2]University of Colorado School of Medicine, Aurora, CO, USA; [3]Department of Neurology, Alexianer St. Josefs Hospital, Potsdam, Germany; [4]Multiple Sclerosis Center at the University Hospital San Carlos, Madrid, Spain; [5]Univ. Lille, Inserm UMR U1172 LilNCog, CHU Lille, FHU Precise, Lille, France; [6]Novartis Pharma AG, Basel, Switzerland; [7]Novartis Pharma GmbH, NÜRNBERG, Germany; [8]Department of Neurology, University Clinic Carl-Gustav Carus, Dresden, Germany

Introduction

- Your Multiple Sclerosis Questionnaire (YMSQ; www.yourms.com) is a patient-completed digital tool to capture their perceptions of changes in multiple sclerosis (MS) symptoms, disability progression and impact on daily living over the past 6 months
- A tool to facilitate conversations between physicians and patients was identified as an unmet need during the development and validation of MSProDiscuss™, a physician-completed tool[1]
- Insight gathering from people living with MS (PlwMS) aimed to ensure the tool's 15 questions would be adapted in a patient-friendly manner

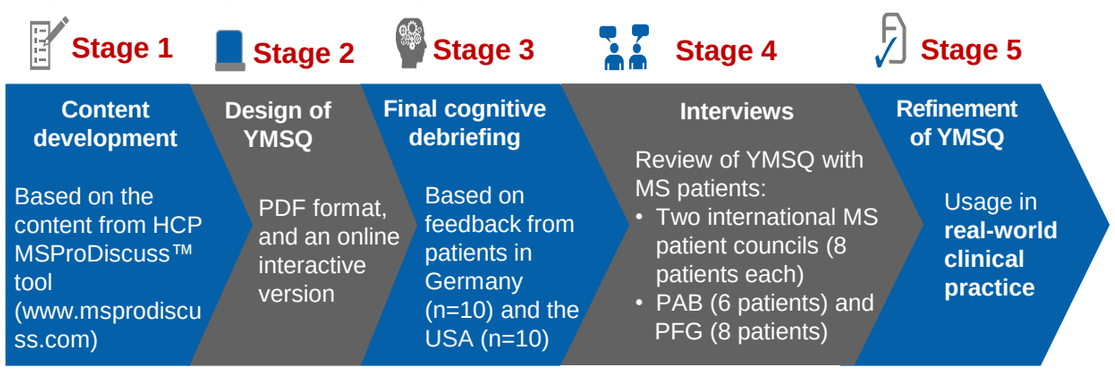
Objective

- To describe the steps involved in the development of the YMSQ, particularly feedback from PlwMS

Methods

Overview of stages of YMSQ development (Fig. 1)

Figure 1: Stages of YMSQ



MS, multiple sclerosis; PAB, patient advisory board; PFG, patient focus group; USA, United States of America; YMSQ, Your Multiple Sclerosis Questionnaire.

Final cognitive debriefing

- Two rounds of telephonic interviews with patients aged ≥18 years and diagnosed with relapsing-remitting MS or secondary progressive MS were conducted by trained and qualified interviewers

Patient councils/advisory board meetings

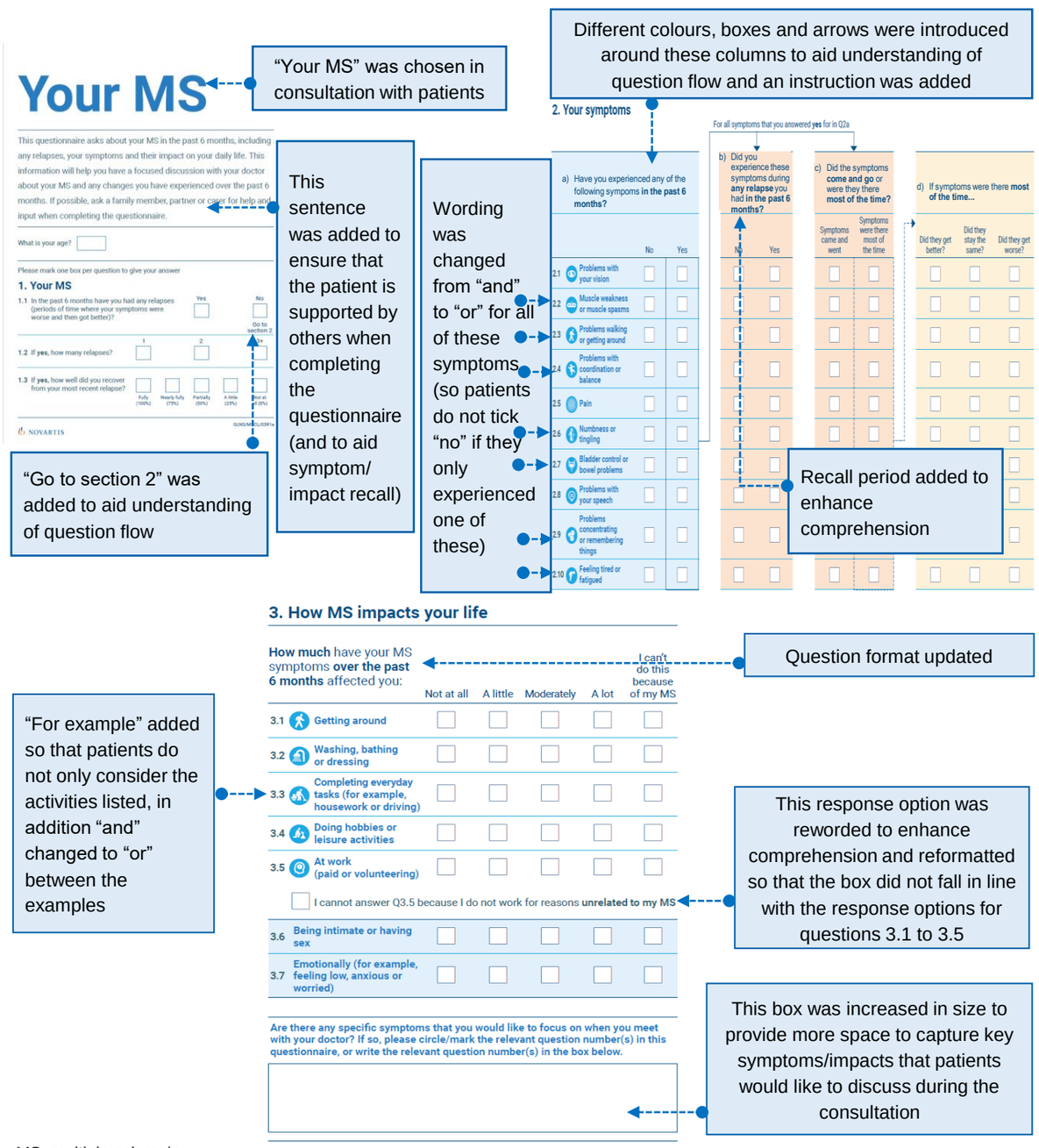
- Participants provided general feedback on the draft tool, potential improvements and recommendations for changes to the YMSQ

Results

Outcomes of cognitive debriefing

- Key changes in the questionnaire following patient feedback are presented in **Fig. 2**
- Additional feedback was requested from 11 participants of which 9 reported that the YMSQ would be a valuable tool for communicating their experience of MS to their healthcare professionals (HCPs)

Figure 2: Key changes to the questionnaire based on cognitive debriefing*



MS, multiple sclerosis.
*The feedback was sought on the paper version of the questionnaire, online layout is different for use on computer/mobile/tablet.

Outcomes of patient councils/advisory board/focus groups (Fig. 3)

Figure 3: Outcomes from patient councils and advisory board meetings

Addition of information/items

Definition of relapse
- In the past 6 months, have you had any relapses *(periods of time where your symptoms were worse and then got better)*?

List of symptoms
- Mood and sexual problems

Exclusion of existing item

Question relating to previous MRI result
- Form should focus more on prepping individuals for their sessions with neurologists

Improvements

Selecting age rather than typing
- Because of dexterity issues, it would be better to be able to scroll down and select one's age rather than having to type it in

Keeping diaries
- Beneficial to make some note of symptoms if troublesome or if they feel it is worth bringing up at next appointment with neurologists

ID, identification; MRI, magnetic resonance imaging.

Conclusions

- Improvements to the YMSQ were carried out based on the key suggestions from PlwMS and patient councils
- PlwMS and patient councils were positive about the applicability of YMSQ in enhancing and structuring the conversation between PlwMS and their HCPs and as a disease monitoring tool in clinical practice
- YMSQ has been also tested for usability and usefulness with HCPs and is freely available at https://www.yourms.com

References

1. Ziemssen T et al. *J Med Internet Res*. 2020;22(2):e16932.

Disclosures

Jo Vandercappellen, Mudeer Khwaja, Bianca Stadler are employees of Novartis. **Gavin Giovannoni** is a steering committee member on the daclizumab trials for AbbVie, the BG12 and daclizumab trials for Biogen, the fingolimod and siponimod trials for Novartis, the laquinimod trials for Teva and the ocrelizumab trials for Roche. He has also received consultancy fees for advisory board meetings for oral cladribine trials for Merck KGaA, Sanofi Genzyme, and in relation to DSMB activities for Synthon BV, as well as honoraria for speaking at the Physicians' summit and several medical education meetings. He is also the Co-Chief Editor of Multiple Sclerosis and Related Disorders (Elsevier). **Enrique Alvarez** received compensation for consulting from Actelion/Janssen, Alexion, Bayer, Biogen, Celgene/BMS, EMD Serono/Merck, Genentech/Roche, Genzyme, Novartis, Sanofi, and TG Therapeutics, and for research from Biogen, Genentech/Roche, Novartis, TG Therapeutics, Patient-Centered Outcomes Research Initiative, National Multiple Sclerosis Society, National Institutes of Health, and Rocky Mountain MS Center. **Olaf Hoffmann** received consulting fees from Biogen, Merck, Novartis, Roche, and Sanofi; compensation for research from Biogen, Novartis, and Sanofi; and as a speaker from Merck, Novartis, Roche, and Sanofi. **Celia Oreja-Guevara** received consulting fees from Novartis, Alexion, and Roche; compensation for research from Alexion; and as a speaker from Novartis and Roche. **Patrick Vermersch** has received compensation for consulting and/or research and registration, travel, and accommodation for meetings from Biogen, Roche, Novartis, Sanofi, Teva, Merck and Celgene. **Tjalf Ziemssen** has received compensation for consulting and lecturing from Alexion, Biogen, Celgene, Novartis, Roche, Sanofi, and Teva and for research from Biogen, Novartis, Roche, Teva, and Sanofi.

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