

# A Patient-based Digital Tool to Detect Early Signs of Changes in MS Symptoms and Progression: Your MS Questionnaire

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## Introduction

**WHY?** There is an unmet need as discussion of symptoms between people living with multiple sclerosis (plwMS) and healthcare professionals (HCPs) can be unstructured and lead to uncertainty in recognising subtle worsening of (MS)<sup>1</sup>

**HOW?** Your MS Questionnaire (YMSQ; [www.yourms.com](http://www.yourms.com)) was developed with input from plwMS, patient advocacy groups and HCPs, and is based on the MSProDiscuss™ – a physician-completed digital tool ([www.msprodiscuss.com](http://www.msprodiscuss.com))<sup>2,3</sup>

**WHAT?** YMSQ is a **patient-completed questionnaire** that asks for information on relapses, symptoms and impacts experienced within the past 6 months. The purpose of this questionnaire is to **facilitate a discussion between HCPs and plwMS** to better understand patient history, symptoms and impacts experienced by the patient

## Objectives

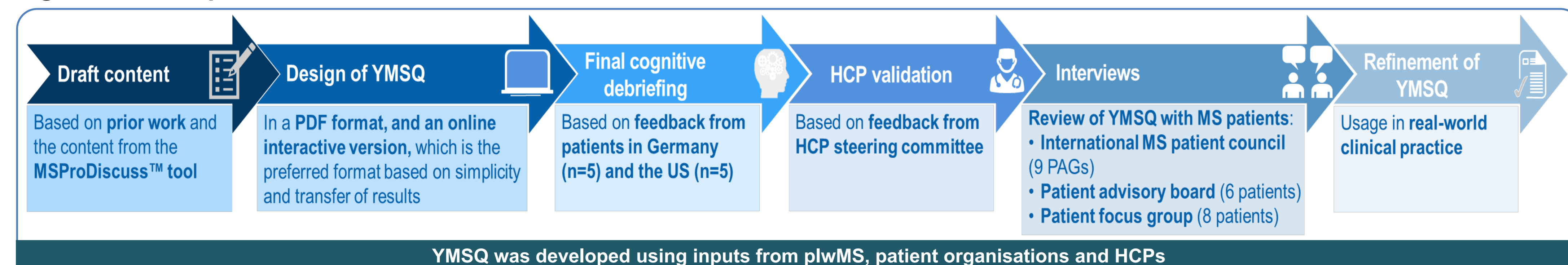
- To develop a patient-based tool, Your MS Questionnaire (YMSQ), that is completed by plwMS
- To evaluate the usability of YMSQ in helping both plwMS and HCPs in clinical practice, and to understand whether the plwMS have experienced any changes in their disease

## Methods

### Development of YMSQ

- YMSQ was designed based on MSProDiscuss™ to capture the experience of plwMS regarding changes in their MS symptoms and their impact on daily living over the past 6 months
- The questions were identified as relevant through qualitative and quantitative research with experienced HCPs and using inputs from plwMS and patient organisations
- YMSQ was initially developed as a paper version; however, due to the COVID-19 pandemic and to support telemedicine, plwMS were provided with the option to complete an online or paper version prior to the consultation (Figure 1)

Figure 1. Development of YMSQ

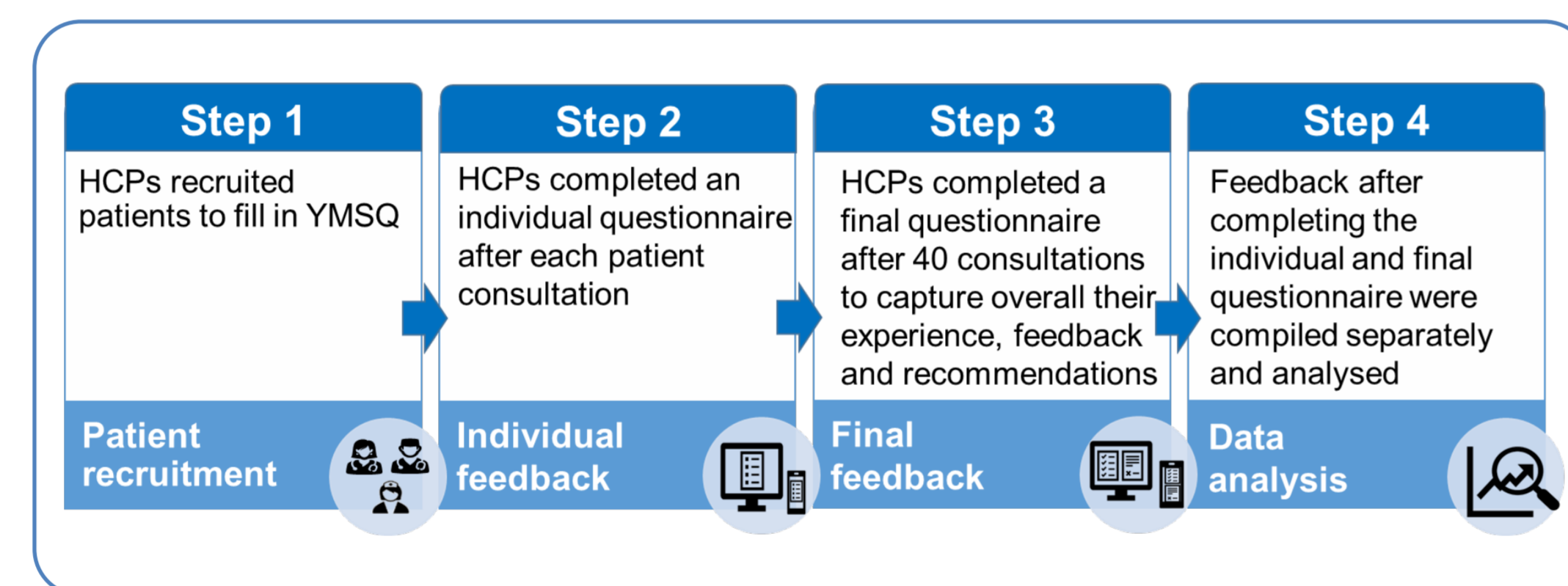


HCP, healthcare professional; MS, multiple sclerosis; PAG, patient advisory group; PDF, Portable Document Format; plwMS, people living with MS; US, United States; YMSQ, Your MS Questionnaire

### YMSQ usability testing: A two-part HCP survey (Figure 2)

- Individual questionnaire (15 questions):** After every patient consultation, feedback was collected for usability and usefulness, comprehensibility, patient and HCP satisfaction and usability in conjunction with MSProDiscuss™
- Final questionnaire (15 questions):** After 40 patient consultations (a minimum of 10), in-depth feedback was collected on usefulness, integration into clinical routine and recommendations for improvement areas
- HCPs had the option to provide their response with one of four categories: strongly agree, agree, disagree, strongly disagree

Figure 2. YMSQ usability testing

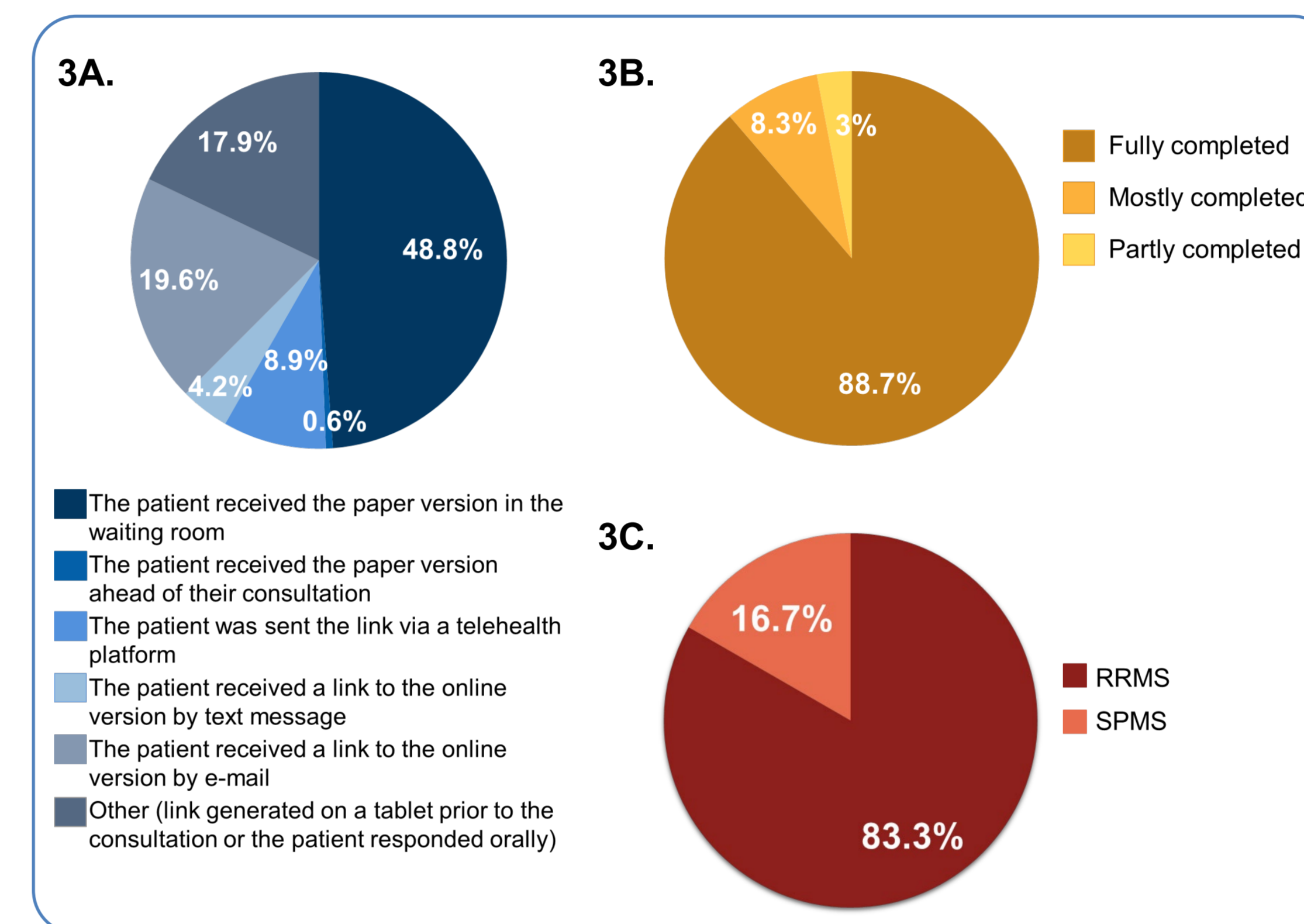


HCP, healthcare professional; MS, multiple sclerosis; YMSQ, Your MS Questionnaire

## Results

- Usability testing of YMSQ is ongoing with HCPs across eight countries. Up to the data cut-off for the interim analysis (12 February 2021), nine HCPs from four countries (US, China, Spain and Italy) completed the testing based on 168 MS patient consultations where YMSQ was used
- Distribution channels for YMSQ, completion status of YMSQ and patient distribution according to YMSQ are presented in Figure 3

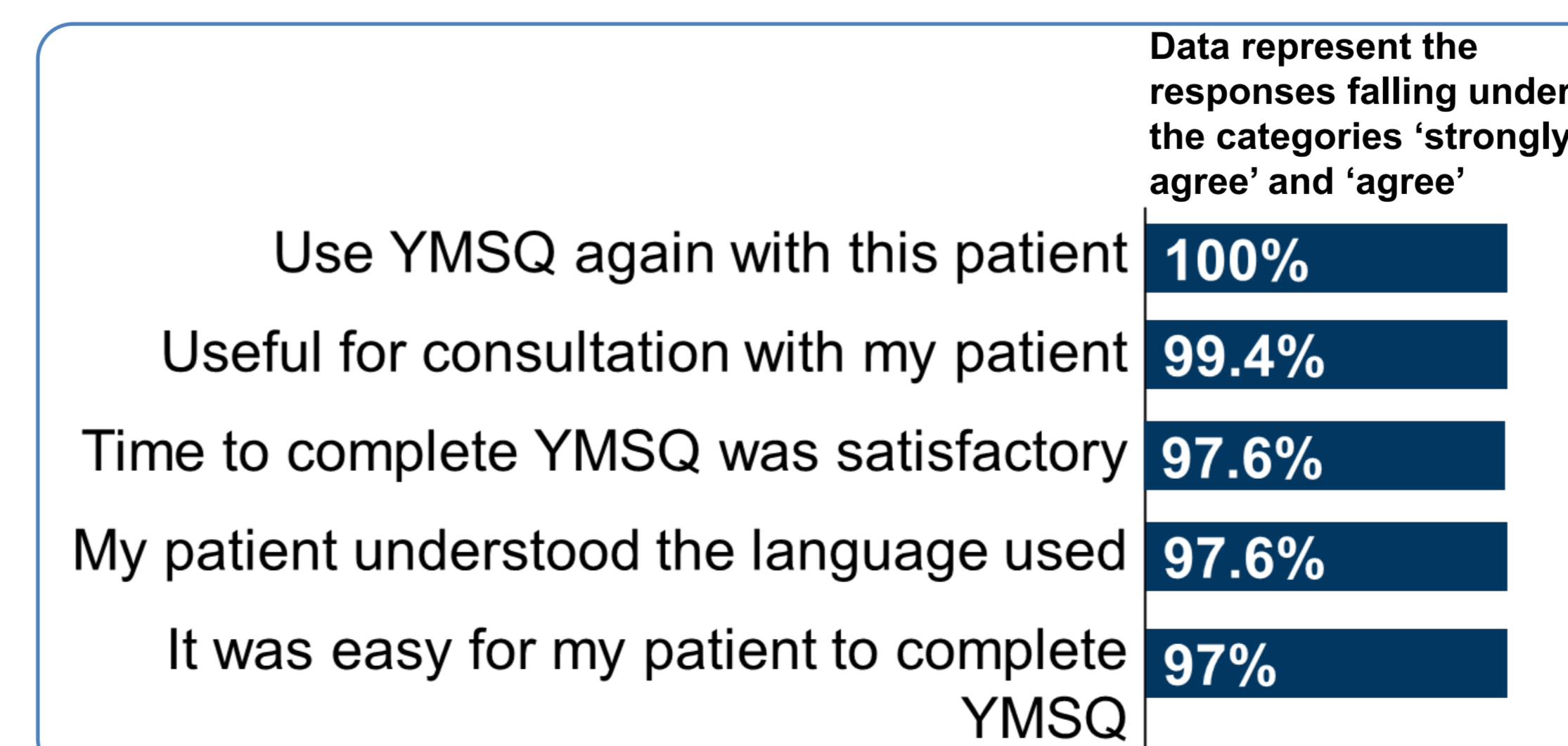
Figure 3A. Distribution channels for YMSQ, 3B. Completion status of YMSQ\*, 3C. Patient distribution in completed YMSQ



\*'Mostly' refers to >50% of the questionnaire, while 'Partly' refers to <50% of the questionnaire. MS, multiple sclerosis; RRMS, relapsing-remitting MS; SPMS, secondary progressive MS; YMSQ, Your MS Questionnaire

- The majority of HCPs agreed or strongly agreed that YMSQ was useful in their practice and was easy for plwMS to use and understand (Figure 4)
- The use of YMSQ positively influenced the clinical practice; it was helpful in engaging patients with their MS
- The majority of HCPs (80%) were willing to integrate YMSQ in addition to MSProDiscuss™ in routine clinical practice

Figure 4. HCPs' feedback based on the 168 individual questionnaires



HCP, healthcare professional; MS, multiple sclerosis; YMSQ, Your MS Questionnaire

## Conclusions

- YMSQ was developed with input from plwMS, patient advocacy groups and HCPs, based on the MSProDiscuss™, a physician-completed digital tool
- YMSQ facilitates a discussion between plwMS and HCPs on changes in MS symptoms and ways in which they impact daily activities within the past 6 months, enabling a holistic approach to MS patient management
- Based on the initial results from the usability testing of YMSQ in real-world clinical practice, HCPs found it useful and are willing to use it again with the same patients
- When completed before consultations, YMSQ may benefit plwMS and HCPs by enabling a better-structured conversation and a better-informed consultation, with practical uses in telemedicine

Your MS Questionnaire is freely available online at [www.yourms.com](http://www.yourms.com)

## References

- Davies F et al. *Int J MS Care*. 2016;18(5):257-264.
- Tolley C et al. *JMIR Med Inform*. 2020;8(4):e17592.
- Ziemssen T et al. *J Med Internet Res*. 2020;22(2):e16932.

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