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# Patient involvement in treatment decision-making: a sub-analysis of the 'MS in the 21<sup>st</sup> Century international unmet needs survey' comparing patient and healthcare professional perspectives

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## BACKGROUND

- Shared decision making and improved communication between healthcare professionals (HCPs) and patients have been shown to lead to better clinical outcomes and treatment satisfaction in multiple sclerosis (MS).<sup>1,2</sup>
- The 'MS in the 21<sup>st</sup> Century' initiative, established in 2011, includes MS specialists and patient advocates and is focused on improving education and communication between HCPs and patients.<sup>3</sup>
- An electronic survey was conducted to compare HCP and patient perceptions of unmet need in these key areas: patient support, shared treatment decision-making, disease progression and communication.

## OBJECTIVE

- To examine the influencing factors and extent of patient involvement in treatment decision-making and to explore whether HCP perceptions are aligned with these findings.

## METHODS

- Comparable HCP and patient surveys were conducted at multiple international congresses between 2016 and 2017:
  - A 10-question electronic survey, developed by the Steering Group to evaluate HCPs' opinions on unmet needs in MS management, was conducted at six international neurology congresses.
  - The equivalent patient survey was conducted at three international congresses and the Merck MS Patient Ambassador Summit 2017.
- Overall results from a dataset of 162 HCPs and 108 patients with MS (PwMS) were presented in 2017.<sup>4</sup>
- Here, we present a sub-analysis, based on a larger data set, of the questions relating to treatment decision-making, including the most important factors to HCPs and patients and perceived levels of patient involvement.

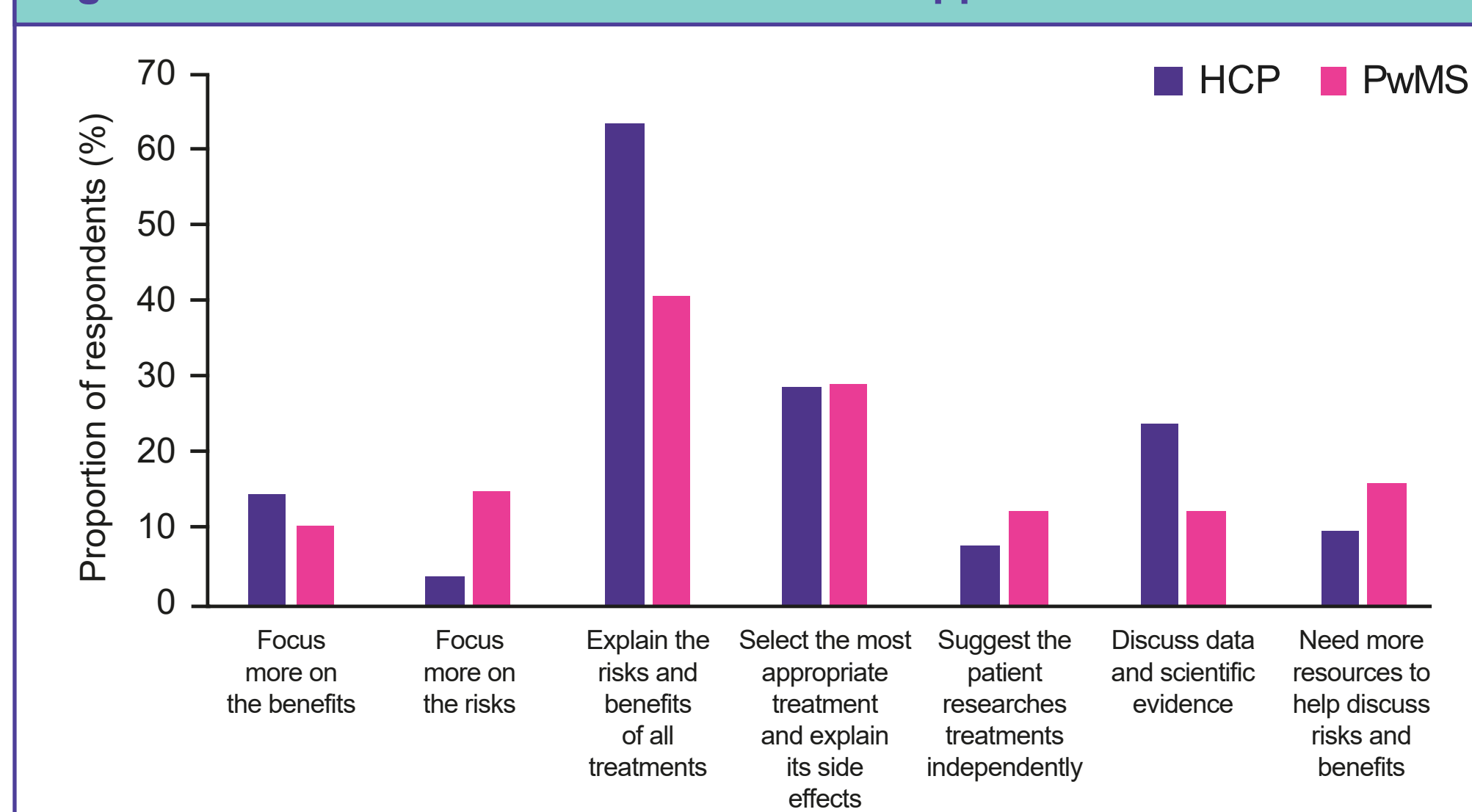
## RESULTS

- The dataset included responses from 233 HCPs and 120 PwMS. The questions weren't compulsory and respondents could select one or more answers to the questions.

## APPROACHES TO TREATMENT DISCUSSIONS

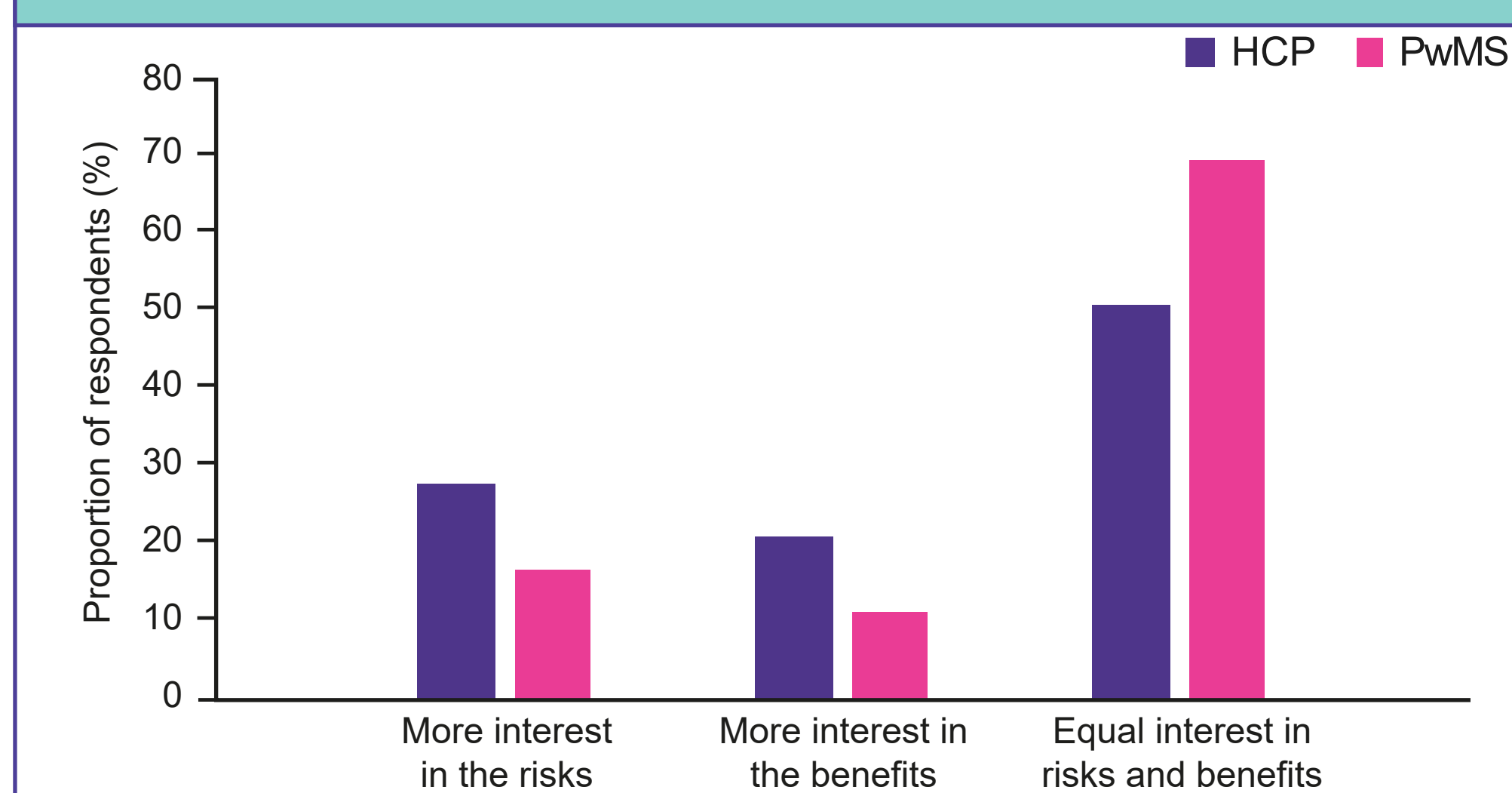
- The majority of both HCPs (63.5%, n=66) and PwMS (40.6%, n=43) stated that their treatment decision discussions covered both the risks and benefits of all treatments (Figure 1).
- While 15.1% (n=16) of PwMS felt that HCPs focused on the risks of treatments, only 3.8% (n=4) of HCPs agreed with this opinion. This result may indicate the impact of negativity bias on the perception of interactions (Figure 1).
- Almost one in four HCPs (24.0%, n=25) reported discussion of data and scientific evidence during the consultation, compared to just 12.3% of PwMS (n=13) (Figure 1).
- Separately, 16.2% (n=17) of PwMS reported not having discussed treatment risks:benefits with their doctors (data not shown).
- These results highlight the different perceptions that PwMS and HCPs have about their interactions. The disconnects highlighted here may reflect a difficulty for PwMS to follow complex treatment discussions during an appointment.

**Figure 1: How are risk:benefit discussions approached?**



- HCPs tend to underestimate how many patients have an equal interest in the risks and benefits of treatment, with just 51.0% of HCPs (n=53) reporting this, versus 69.4% of PwMS (n=75) (Figure 2).

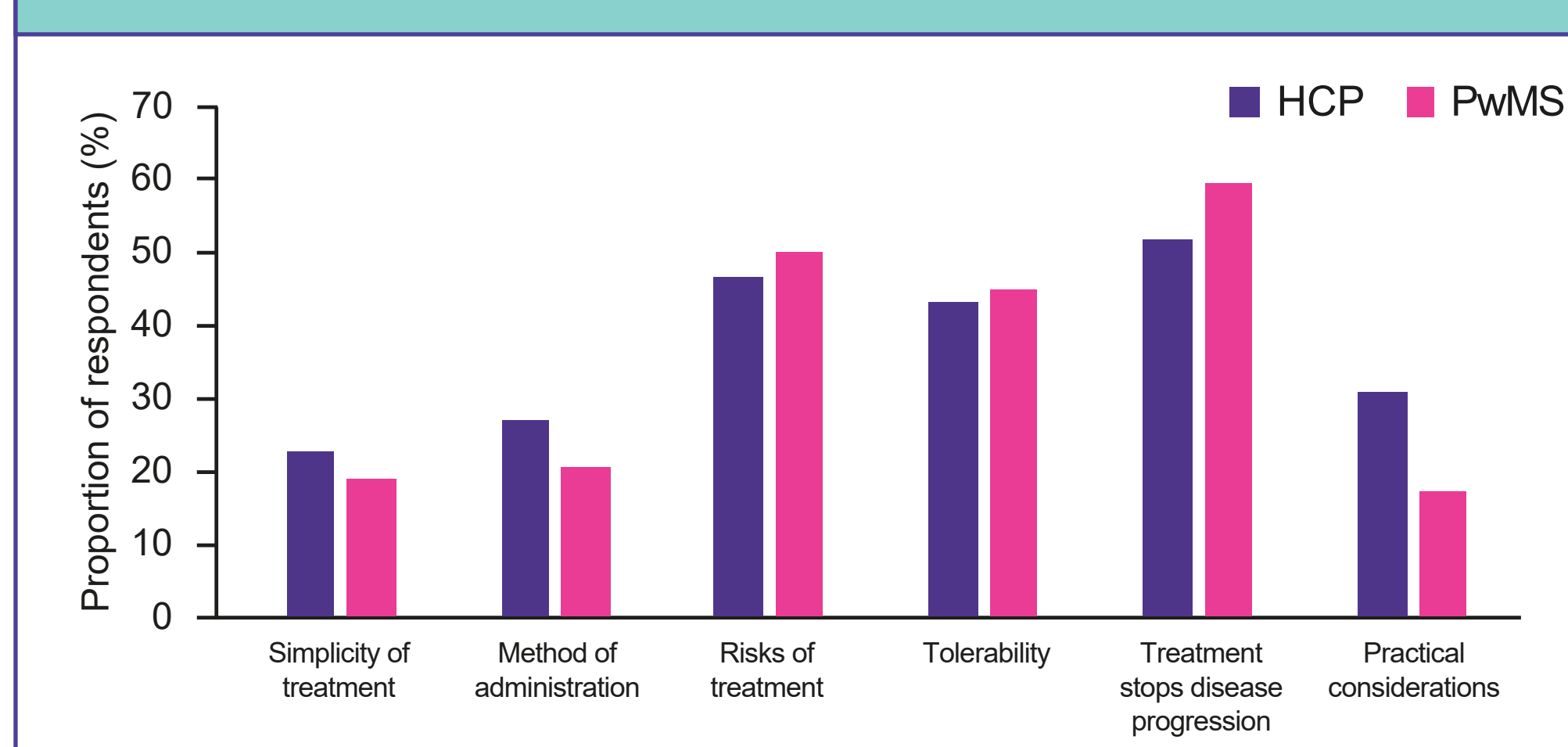
**Figure 2: Are patients more interested in understanding the risks or benefits of treatments?**



## FACTORS INFLUENCING TREATMENT DECISIONS

- According to both PwMS and HCPs, the most important factor influencing treatment decision-making was whether 'treatment stops disease progression' (60.0%, n=72 and 52.0%, n=79, respectively). The second most important was 'risks of treatment' (46.7%, n=71 and 50.0%, n=60, respectively) followed by 'tolerability' (43.4%, n=66 and 45.0%, n=54, respectively) (Figure 3).
- HCPs overestimated how important the factors associated with treatment burden are to PwMS i.e. 'simplicity of treatment' (23.0%, n=35 and 19.2%, n=23, respectively); 'method of administration' (27.0%, n=41 and 20.8%, n=25, respectively); and 'practical considerations' (30.9%, n=47 and 17.5%, n=21, respectively) (Figure 3).

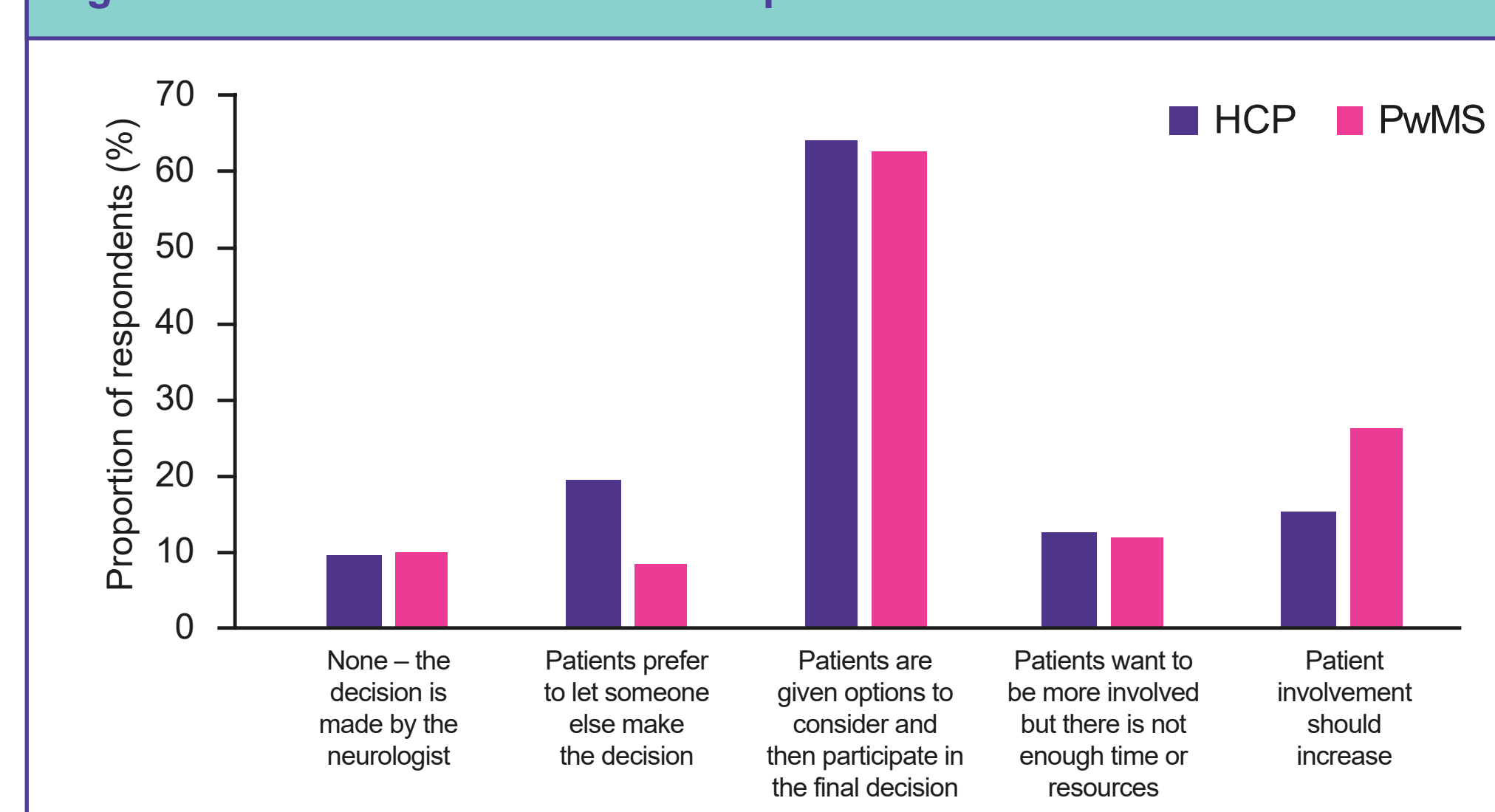
**Figure 3: What is most important to patients when making treatment decisions?**



## PATIENT INVOLVEMENT IN TREATMENT DECISIONS

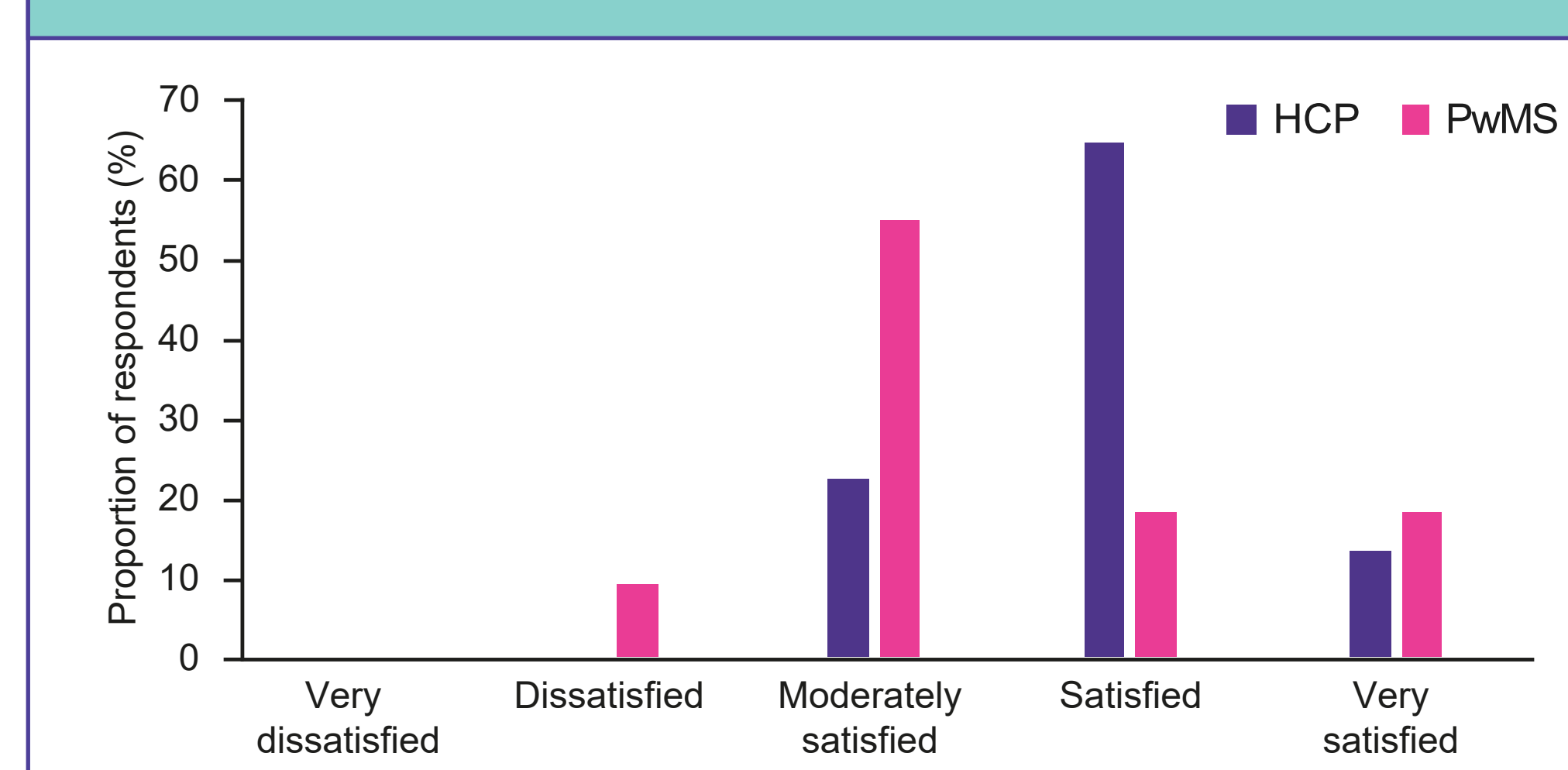
- The majority of both HCPs and PwMS reported that patients are being included in the final decision about their treatment (64.1%, n=66 and 62.6%, n=67, respectively). However, HCPs underestimated the desired level of patient involvement (Figure 4).
- While 19.4% (n=20) of HCPs felt that patients preferred to let them make the decision, only 8.4% of PwMS (n=9) stated that this is the case (Figure 4).
- Similarly, while only 15.5% (n=16) of HCPs stated that patient involvement should increase, 26.2% (n=28) of PwMS indicated that they should be more involved (Figure 4).

**Figure 4: How much involvement do patients have in treatment decisions?**



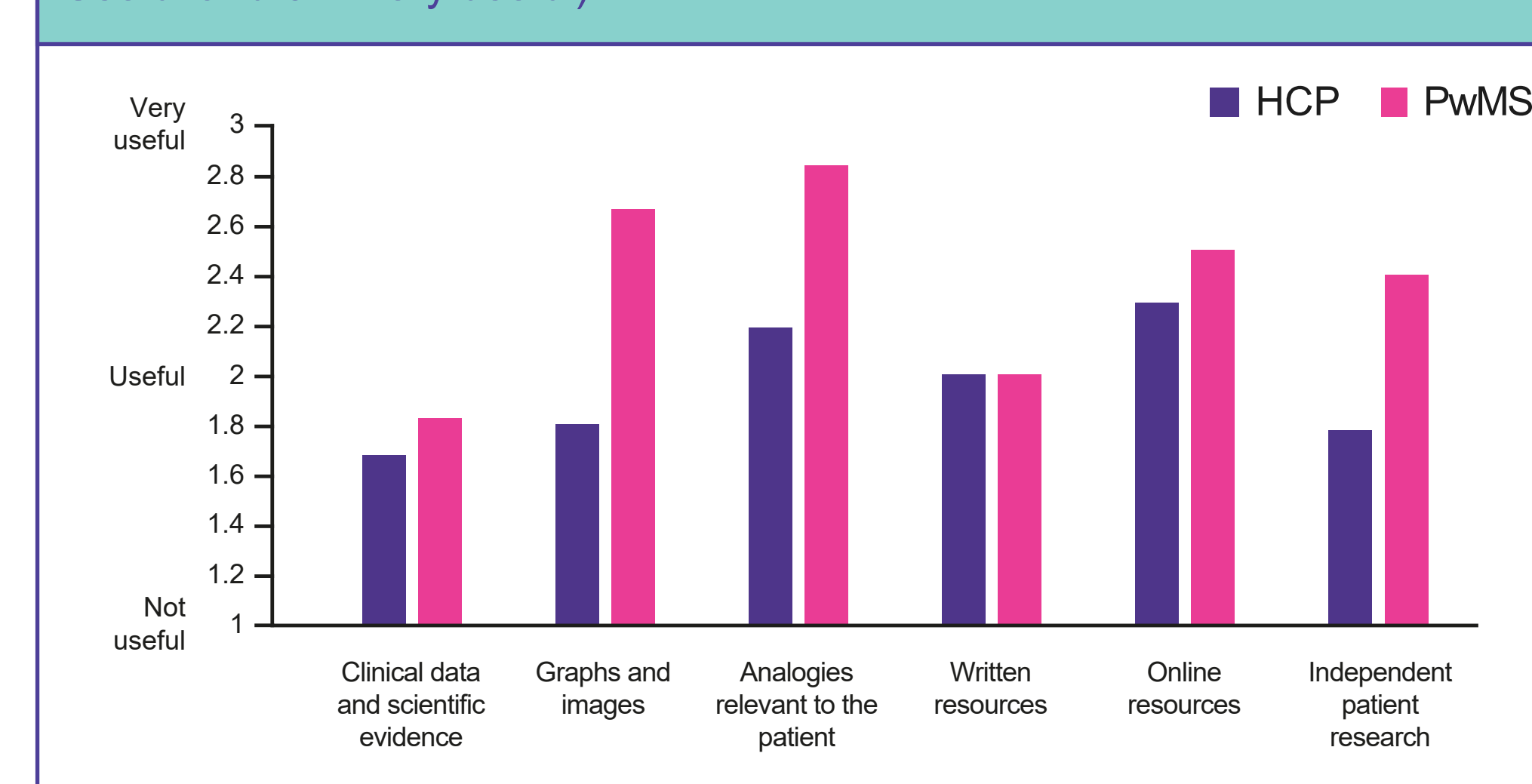
- Following initial analysis of the original dataset in 2017 a follow up question was added to the survey to determine how these differences in opinion about involvement affect patient satisfaction.
- Of the PwMS, 63.6% (n=7) reported being either 'dissatisfied' or only 'moderately satisfied' with their level of involvement (Figure 5).
- Inversely, 77.8% (n=35) of HCPs felt that their patients were either 'satisfied' or 'very satisfied' with their level of involvement (Figure 5).

**Figure 5: How satisfied are patients with their level of involvement in treatment decisions?**



- As well as wanting more involvement in treatment decisions, PwMS also indicated an interest in having more resources available to them to help make these decisions.
- When asked about the usefulness of various formats of information, PwMS uniformly reported a greater degree of usefulness, than HCPs, for each type of information (except for written resources) (Figure 6).

**Figure 6: What forms of information are useful to patients when making treatment decisions? (3 point scale where 1 = Not useful, 2 = Useful and 3 = Very useful)**



## CONCLUSIONS

- One of the main findings from this data was the disparity in perception of how treatment benefits and risks are explained. It is essential to ensure that HCPs understand their patient's priorities and to have the training, tools and time to better these discussions.
- Improved communications between HCPs and PwMS in daily practice may help to address this disconnect. HCPs should be aware of how factors such as negativity bias can influence patients' perceptions of their interactions.
- There were striking differences between patient and HCP perceptions of involvement in treatment decision-making. With the patients reporting a desire to have greater involvement in deciding treatment, it is important that they have the education and empowerment to approach these discussions.
- A greater emphasis around joint education of HCPs and PwMS, as well as the production of more patient-focused educational resources, might help to address some of the problems with communication, and help increase shared-decision making during appointments.

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## DISCLOSURES

Celia Oreja-Guevara receives honoraria from: Biogen Idec, Novartis, Sanofi Genzyme, Almirall, Merck Serono. Dawn Langdon receives funding for travel to scientific meetings from Bayer; serves on a Steering Committee for Bayer; has served/serves as a consultant to Merck Serono, Novartis, and Bayer; served on speaker contract with Bayer, Novartis, and Biogen Idec; and receives educational grants and sponsorship from Bayer. Peter Rieckmann receives honoraria for lectures from: Almirall, Apple Healthcare, Baxter, Bayer, Biogen Idec, Boehringer-Ingelheim, Cerner, Daiichi Sankyo, Genpharm, Genzyme, Medtronic, Merck Serono, Novartis, Pfizer, Roche, Sanofi-Aventis, Siemens AG and Teva. He receives research grants from: Bayer, EMD Serono, Novartis, Teva, MS Society of Canada, Canadian Institute of Health Research, Hertie Foundation, Oberfranken-Stiftung and German Neurology Foundation. He is on an advisory board or steering committee for: Abbvie, Bayer, Biogen Idec, Novartis, Merck Serono, Teva, German Multiple Sclerosis Society and Canada Drug Review. Elisabetta Verdun Di Cantogno is an employee of Merck KGaA.

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