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Comparing patient and healthcare professional perceptions on multiple sclerosis management and care – where do their priorities differ? Results from a qualitative survey

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Introduction

- The MS in the 21st Century initiative, formed in 2011, is composed of a group of international multiple sclerosis (MS) specialists.
- In 2016, the group was expanded to include MS patient advocates, thus creating a Steering Group that provided a combined perspective from healthcare professionals (HCPs) and people with MS (PwMS).
- The Steering Group's current focus is to improve education and communication between HCPs and PwMS. Other study groups have shown that shared decision making and improved communication resulted in better clinical outcomes and influenced patient satisfaction with treatment.^{1,2}
- In 2016, a Steering Group workshop aimed to identify where HCPs' and patients' perspectives differed within key areas of unmet needs, treatment burden, patient engagement and priorities of care.
- Following this workshop, the Steering Group decided to investigate whether there were differences in priorities and perceptions between the groups and how this may affect disease management.

Objectives

- To compare the priorities of HCPs and PwMS with respect to MS management and care.
- To identify disparities between HCP and PwMS perceptions on communication barriers and unmet needs in MS care.

Method

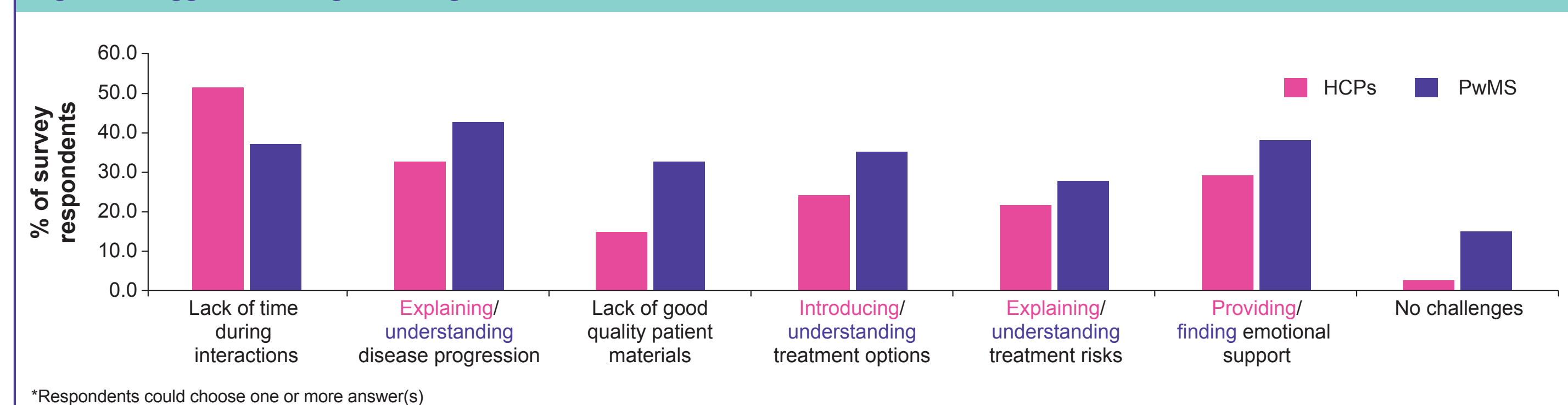
- A 10-question electronic survey was developed by the Steering Group to evaluate HCPs' opinions on unmet needs in MS management. Respondents were able to select multiple answers to 9 out of the 10 questions.
- This survey was then conducted at 4 international neurology congresses – ECTRIMS 2016, CMSC 2017, CONy 2017 and EMSP 2017.
- An equivalent patient survey was conducted at EMSP 2017, CMSC 2017 and the Merck MS Patient Ambassador Summit 2017.
- The surveys emphasised aspects of patient support, including at diagnosis, shared treatment decision making, and disease progression and communication.

Results

Patient support, including at diagnosis

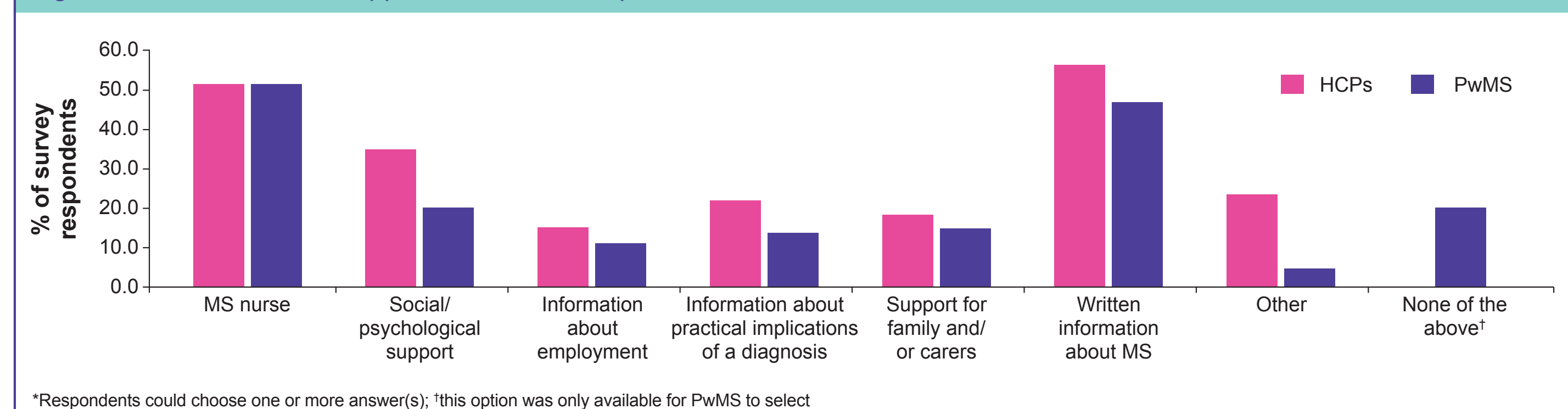
- A total of 162 HCPs and 108 PwMS completed the survey. Respondents could select one or more answers to the questions.
- The majority of HCPs (97.5%, n=158) and PwMS (85.2%, n=92) reported at least one communication challenge at diagnosis (Figure 1).
- Lack of time with the patient was the communication challenge most frequently reported by HCPs (51.2%, n=83), and PwMS agreed that this is a significant barrier (37%, n=40) (Figure 1).
- Along with lack of time during interactions, the communication challenges most frequently reported by PwMS were: difficulty in understanding their disease and how it might progress (42.6%, n=46), finding emotional support (38%, n=41), understanding their treatment options (35.2%, n=38), and lack of good quality patient materials (32.4%, n=35) (Figure 1).

Figure 1. Biggest challenges at diagnosis?



- One in five PwMS (20.4%, n=22) stated that their clinics offer no additional support (MS nurse and holistic information) for MS patients outside of contact with their doctor (Figure 2).
- The most common additional support provided by clinics according to both HCPs (51.9%, n=84) and PwMS (51.9%, n=56) was the support of an MS nurse. Both HCPs and PwMS reported that a minority of clinics offer information about employment and family and/or carers support. Of note, 35.2% (n=57) of HCPs stated that their clinic provided psychological support whereas, only 20.4% (n=22) of PwMS stated that in their clinic (Figure 2).
- Only 56.8% (n=92) of HCPs and 47.2% (n=51) of PwMS reported that their clinics offered any written resources about MS (Figure 2).

Figure 2. What additional support is available for patients in the clinic?



Shared treatment decision making

- PwMS were of varied opinion with respect to how involved they would like to be in decisions about their treatment, indicating the requirement for personalised communication. While 32.4% (n=35) of PwMS indicated that they were happy to let their doctors make decisions about their treatment, 38.9% (n=42) said they liked to participate in the final decision and 23.1% (n=25) said they would like to be more involved but a lack of time prevents them (Figure 3).

Figure 3. How much involvement do you have in making treatment decisions?

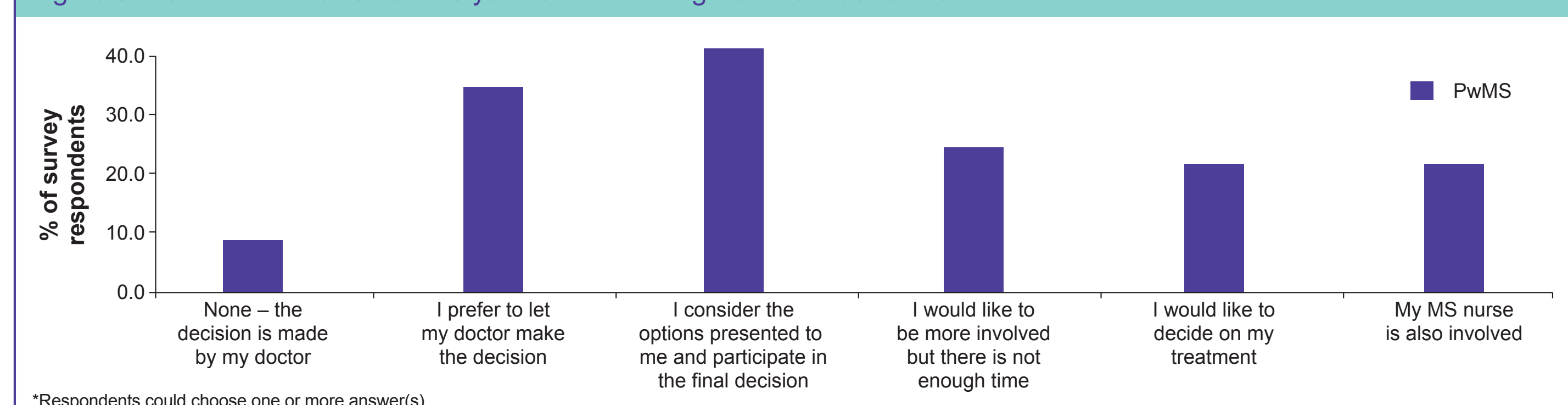


Figure 4. How do HCPs approach risk:benefit discussions?

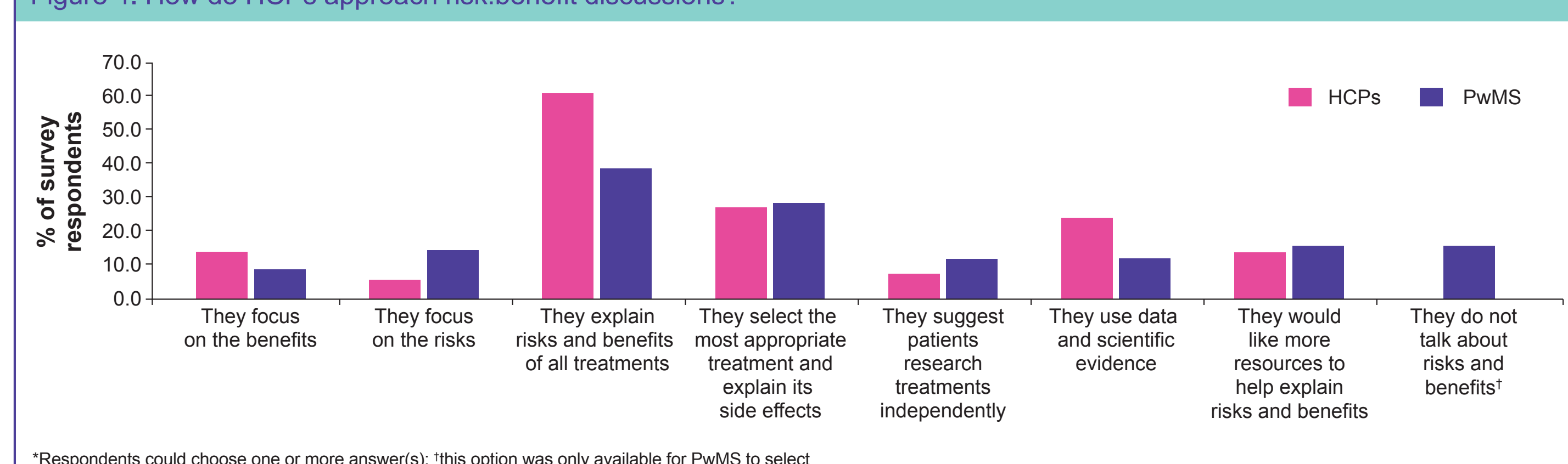
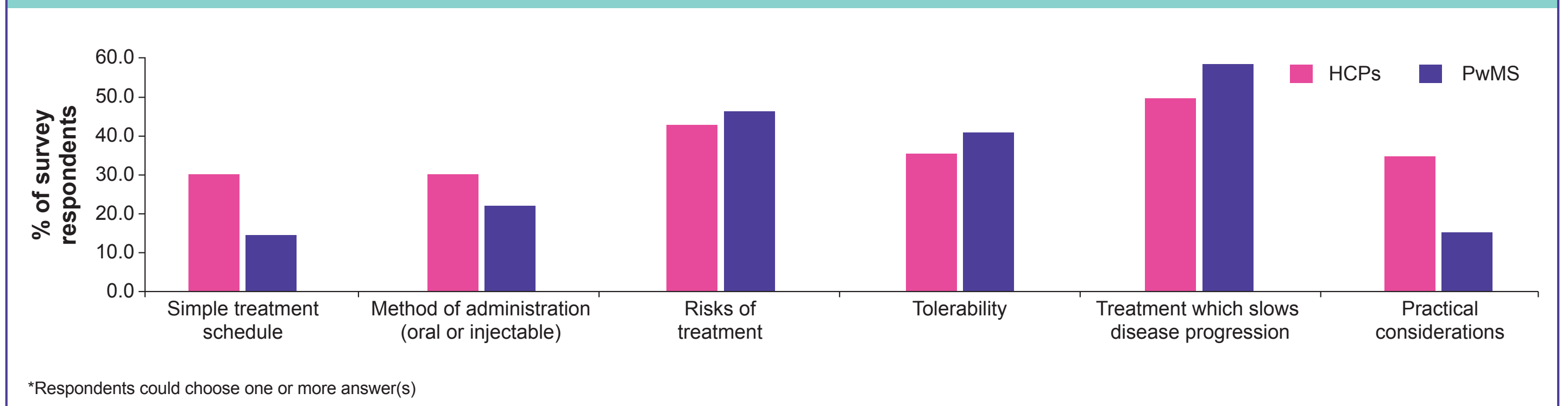


Figure 5. What is most important to patients when making treatment decisions?

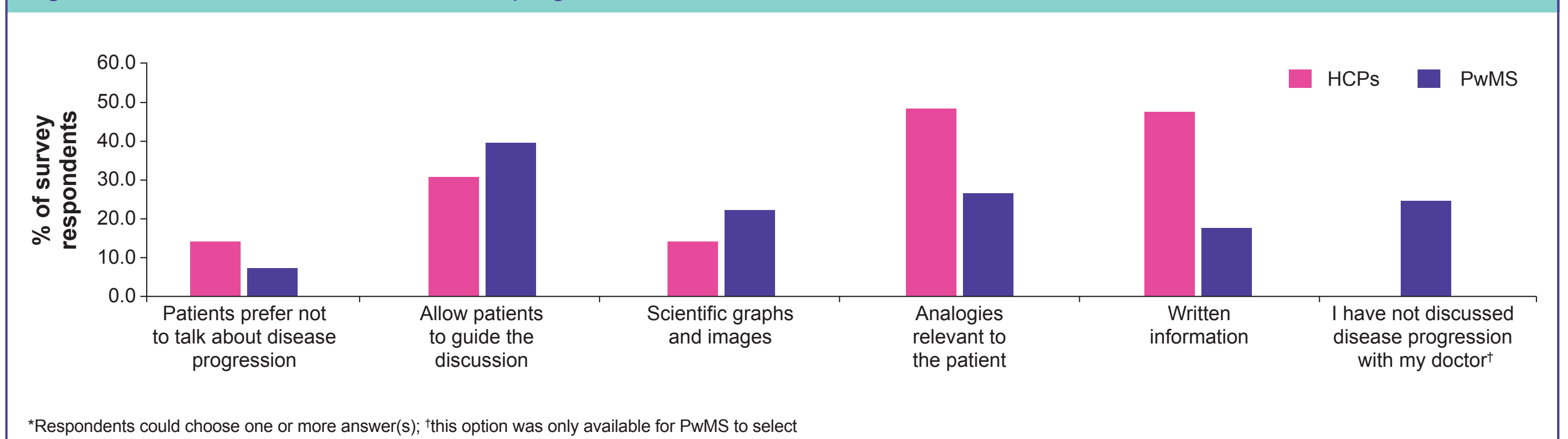


- Some PwMS (15.7%, n=17) reported that their neurologist does not discuss the risks and benefits of treatment options with them. The same number (15.7%, n=17) of PwMS indicated that they would like more resources to help explain risks and benefits (Figure 4). A higher number of HCPs than PwMS reported that they explain the risks and benefits of all treatments (61.1%, n=99 and 38.9%, n=42 respectively).
- Both HCPs and PwMS agreed that the most important treatment consideration for patients was that it slows disease progression (49.4%, n=80 and 58.3%, n=63 respectively); however, responses were relatively evenly distributed over a number of other priorities. Treatment decisions are clearly influenced by numerous factors and, as such, need to be highly personalised decisions between patients and their doctors (Figure 5).
- Interestingly, HCPs overestimated the importance of factors PwMS deemed least important (simple treatment schedule, method of administration and practical considerations) and underestimated the factors that PwMS deemed most important (risks of treatment, tolerability and treatment which slows disease progression) (Figure 5).

Disease progression and communication

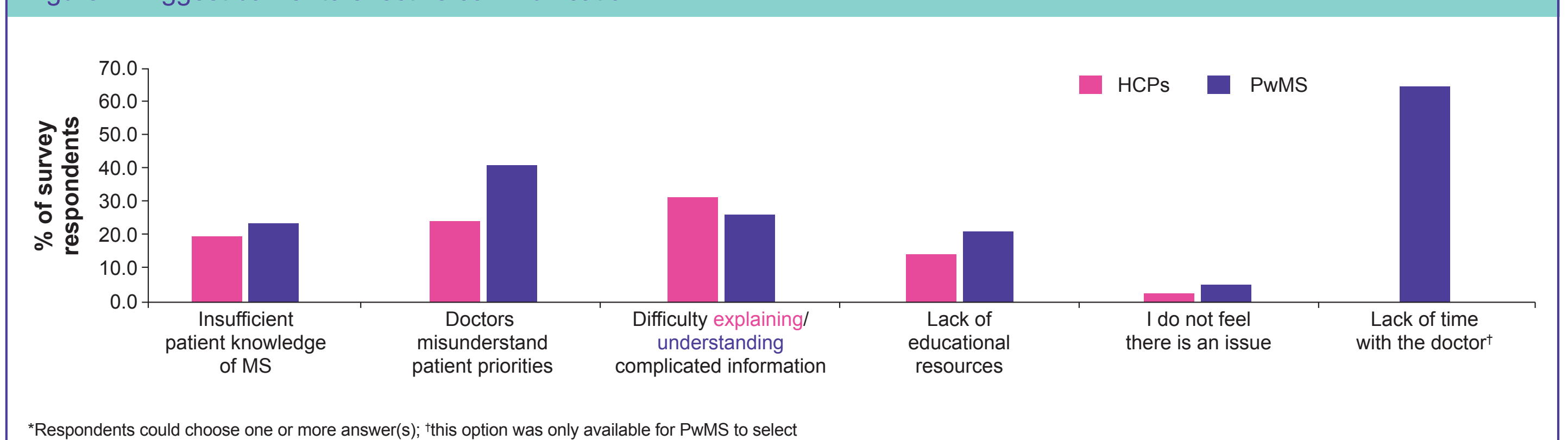
- Nearly 1 in 4 PwMS (24.1%, n=26) have not discussed disease progression with their doctors. Interestingly, while 13.6% (n=22) of HCPs said that disease progression was a topic that their patients preferred to avoid, only 6.5% (n=7) of PwMS agreed (Figure 6).

Figure 6. How do HCPs discuss disease progression?



- A large majority of PwMS (84.3%, n=91) indicated that they would benefit from more resources, both printed and online, to help explain their disease (graph not shown).
- HCPs felt that the greatest barrier to effective communication with patients was accurately explaining and helping them to understand complicated information (30.9%, n=50). PwMS also expressed difficulty in understanding information (25.9%, n=28), but felt that a lack of time with doctors (64.8%, n=70) was a much bigger barrier (Figure 7).
- A large proportion of PwMS (40.7%, n=44) reported that an important barrier to communication was doctors misunderstanding patient priorities. Accordingly, a much smaller proportion of HCPs (24.1%, n=39) reported this as an issue (Figure 7).
- The majority of PwMS (91.6%, n=99) valued the concept of joint educational programmes to improve the education of and communication between patients and HCPs (graph not shown).
- One of the survey questions asked whether patients show more interest in understanding the risks or benefits of treatments. It did not receive enough responses from HCPs to warrant analysis here..

Figure 7. Biggest barrier to effective communication?



Conclusions

- This survey highlighted a number of challenges that HCPs and PwMS face which could negatively impact the standard of MS care provided/received; the results show that HCPs and PwMS often have different perceptions of their interactions. Given the importance of tailoring conversations to the patient, this disconnect is a significant barrier to efficient communication; PwMS show a much greater awareness of this issue than HCPs.
- A notable number of PwMS indicated that their clinics offer no additional support outside of contact with their doctor; only half of the MS clinics offered written materials about MS.
- One of the most striking results was the number of PwMS (1 in 4) who reported that they had not discussed disease progression with their HCP. It is essential to ensure HCPs have the training, time and resources required to facilitate these discussions, and that patients 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.
- Future surveys will focus on the areas identified where HCP and PwMS opinions differ most and aim to provide more detailed country- and discipline-specific sub-analyses.

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