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A sub-analysis of global mapping data on the availability of online educational resources for multiple sclerosis patients

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BACKGROUND

- The MS in the 21st Century initiative, formed in 2011, is composed of a Steering Group of international multiple sclerosis (MS) specialists and people with MS (PwMS). The initiative's current focus is to improve education of, and communication between, healthcare professionals (HCPs) and PwMS.
- In 2016 and 2017, to inform the development of educational programmes and resources, MS in the 21st Century conducted a series of mapping exercises to capture the existing educational offerings for PwMS.
- Here, for the first time we present an analysis of the availability and distribution of resources within the three least covered information themes 'resources for families', 'MS stages and progression', and 'communication with HCPs'.

OBJECTIVE

- To report and compare the availability and distribution of resources for the following themes: 'resources for families', 'MS stages and progression', and 'communication with HCPs'.
- To analyse the breakdown of specific sub-topics within these three themes.

METHODS

- Desktop research was undertaken using country-specific URLs of the Google search engine, and was designed to obtain results that were as representative as possible of the resources a patient in each country would have access to online. Providers were identified in 51 countries across the globe, by using search terms that were based on a list of pre-determined provider types (Table 1).

Table 1: Categorisation of topics, overarching topics and stakeholder types

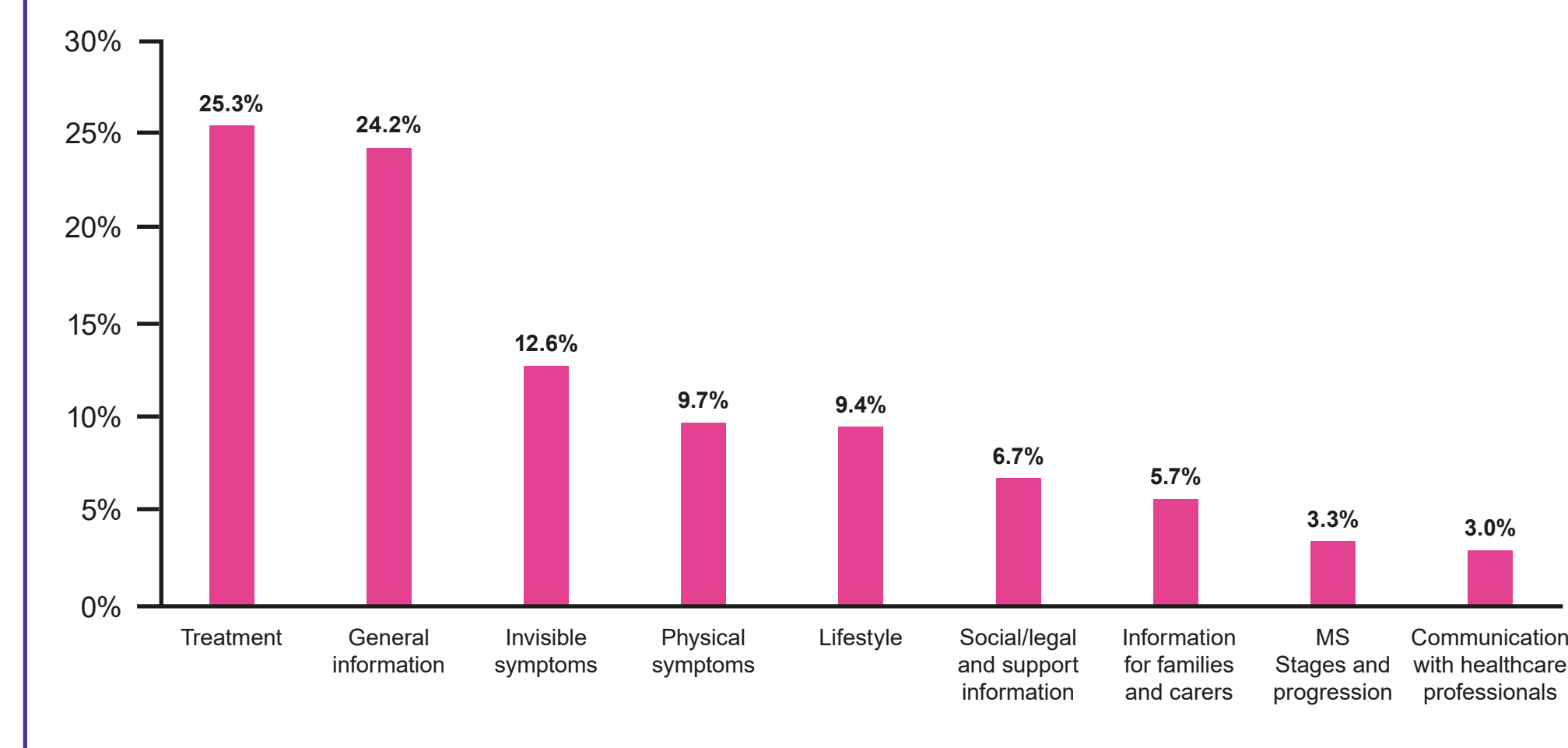
MS Resource sub-topics			
Consultation checklist; Dealing with your consultation and healthcare provider; Patient and healthcare professional disease management care plan; How to avoid misinformation	Cognition; Fatigue; Headache; Heat sensitivity; Mental health; Numbness; Pain; Sleep problems	Clinically isolated syndrome (CIS); Diagnosis; Primary progressive MS; Relapsing remitting MS; Secondary progressive MS	Insurance and healthcare; Social/legal and employment rights; Telling people you have MS; Working/studying with MS
General guide; Guide for the newly diagnosed; The biology of MS	Diet; Exercise/physical activity; Lifestyle (general); Posture; Travelling with MS	Bladder/bowel problems; Mobility/falls; Spasticity/spasms and sensations; Speech; Swallowing; Tremors; Vision	Clinical trials; Disease-modifying treatments; Functional electrical stimulation (FES); Other treatments (eg, holistic, alternative); Physiotherapy; Rehabilitation event; Scientific information; Self-management; Side effects
Information for carers/families; Talking to children/teens about MS; Guide for children; Guide for teens/young adults; Pregnancy and family planning; Sexual function			
Overarching themes (for each MS resource sub-topic)			
Communication with healthcare professionals	Invisible symptoms	Physical symptoms	
General information on the disease	Lifestyle	Social/legal and support information	
Information for families and carers	MS stages and progression	Treatment	
Provider type			
Patient group/association	Online media	Government or public health providers	Other educational platforms
Pharmaceutical company	Specialist clinic	Health insurance providers	Social media

- Provider websites were then explored in full and all relevant pages were recorded as resources in the database and categorised by format, topic, provider type, and country (Table 1).
- Resources were categorised into 52 different sub-topics which were grouped into eight overarching themes for analysis (Table 1).
- This research was purely quantitative and at no point were the resources or stakeholders assessed in terms of quality or level of patient engagement.

RESULTS

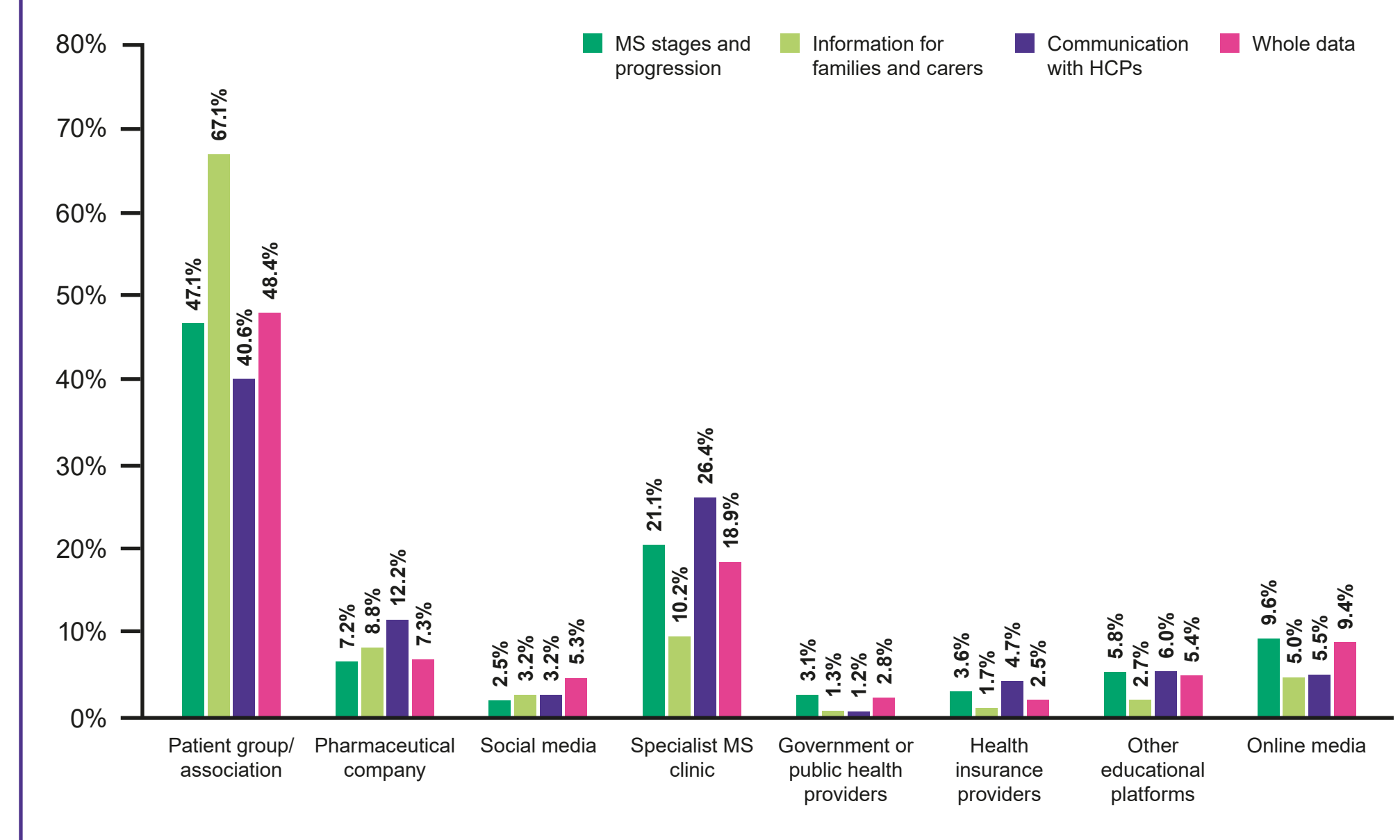
- A total of 1,308 providers from 51 countries were mapped, resulting in the identification of 13,321 individual educational resources.
- The most common resource themes were 'treatment' (25.3%, n=3372) and 'general information' (24.2%, n=3228) (Figure 1).

Figure 1: Distribution of resources across overarching themes



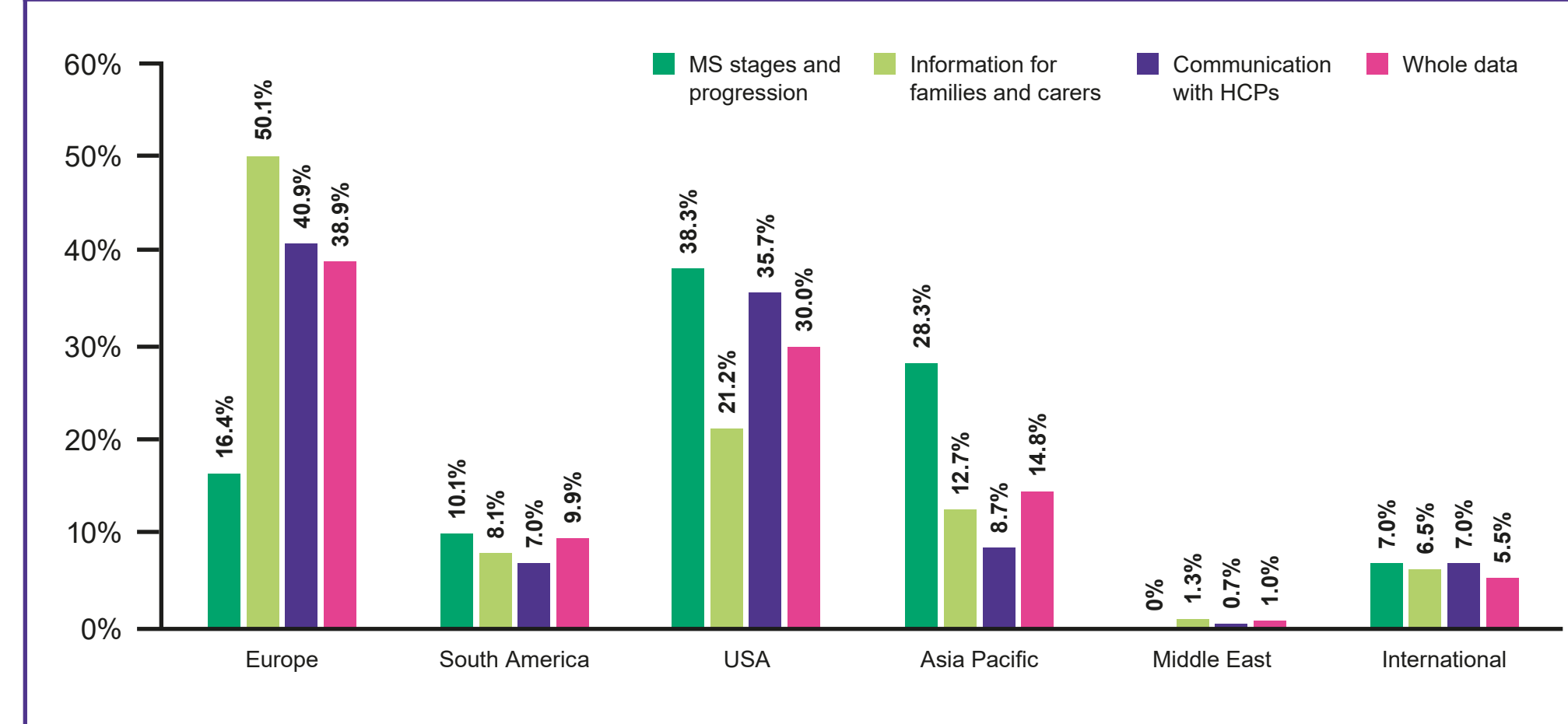
- The least common resource themes were 'information for families and carers' (5.7%, n=753), 'MS stages and progression' (3.3%, n=446), and 'communication with HCPs' (3.0%, n=401) (Figure 1).
- When examining the providers of these resource themes, patient groups/associations produced around two-thirds of resources on the theme of 'information for families and carers' (67.1%) compared to less than half of the 'MS stages and progression' (47.1%) and 'communication with HCPs' (40.6%) themes (Figure 2).

Figure 2: Distribution of resources across provider types



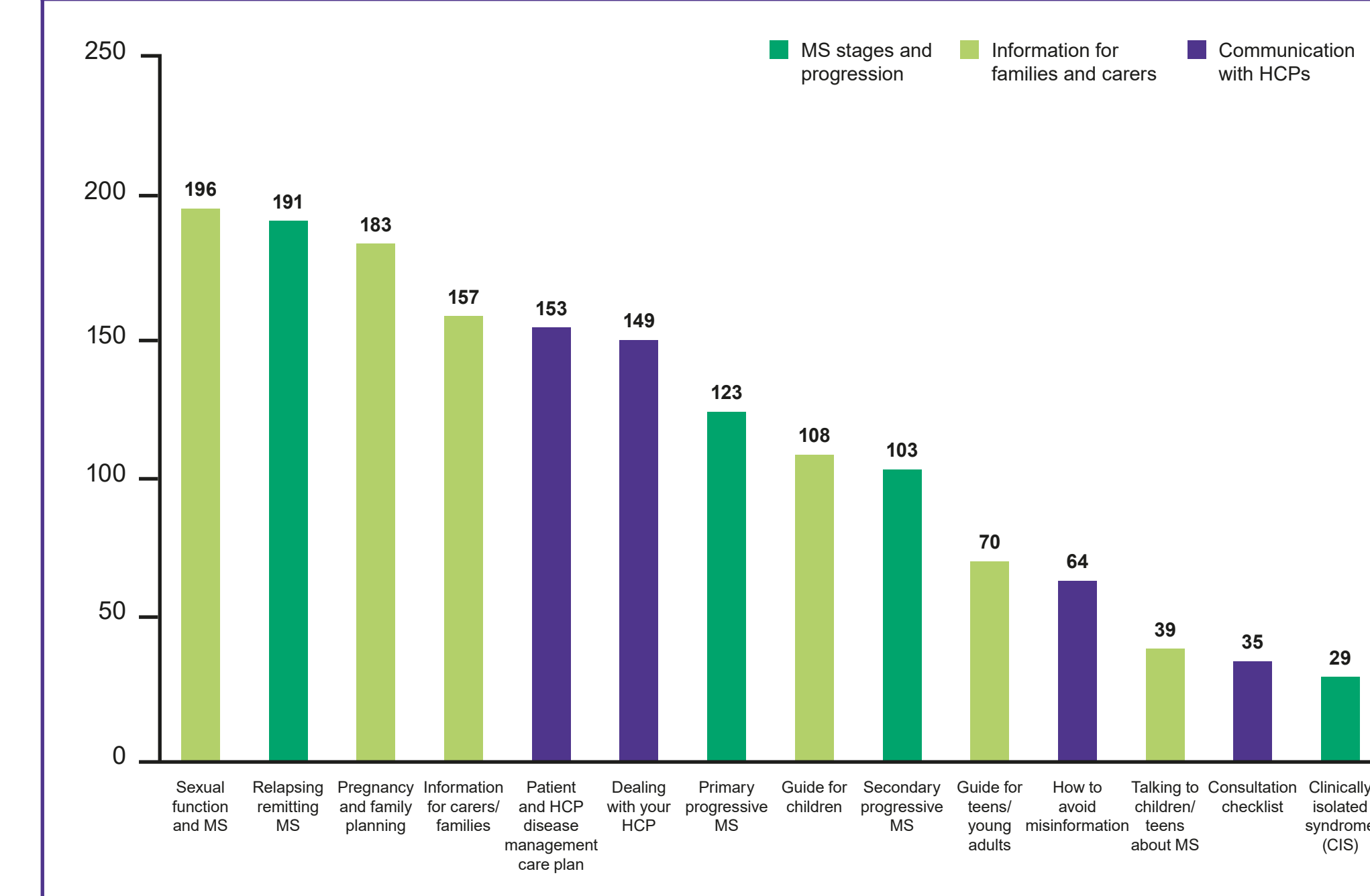
- The proportional breakdown of resource providers for the theme of 'MS stages and progression' closely match the breakdown for the full data set with a mean deviation of only 1.1% across the eight different provider types (Figure 2).
- Conversely, the geographic distribution of resources across the theme 'MS stages and progression' deviates from the rest of the data. Only 16.4% of the resources on this topic came from European providers compared to 38.9% of the whole data set and half of the 'information for families and carers' resources (50.1%) (Figure 3).

Figure 3: Distribution of resources across geographic region



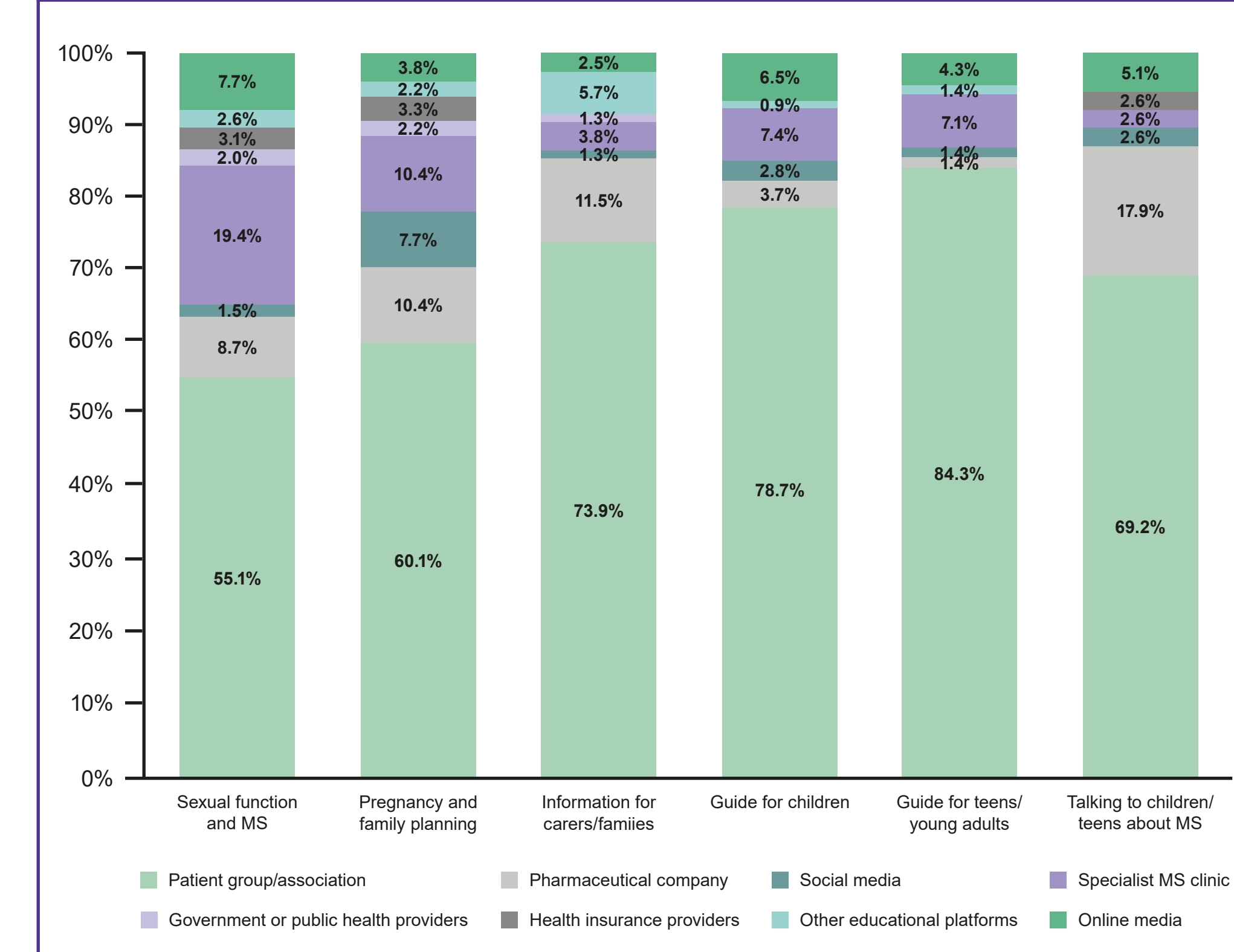
- Similarly, 28.3% of the resources on the theme of 'MS stages and progression' came from providers in the Asia-Pacific region which is almost double the proportion of resources that this region contributed to the whole data set (14.8%) (Figure 3).
- Of the sub-topics that make up the specific themes analysed here, the three most common were 'sexual function and MS' (n=196), 'relapsing remitting MS' (n=191), and 'pregnancy and family planning' (n=183) (Figure 4).

Figure 4: Number of sub-topics resources within the three overarching themes



- The three least common sub-topics were 'talking to children/teens about MS' (n=39), 'consultation checklists' (n=35), and 'clinically isolated syndrome' (n=29) (Figure 4).
- While patient groups/associations produced 67.1% of resources in the overall theme 'information for families and carers' they accounted for a smaller proportion of the two biggest sub-topics in this theme 'sexual function and MS' (55.1%) and 'pregnancy and family planning' (60.1%) (Figure 5).

Figure 5: Analysis of sub-topics by provider type within the overarching 'information for families and carers' theme



- Pharmaceutical companies produced 17.9% of the resources on 'talking to children/teens about MS' despite only contributing 8.8% of resources to the overall theme. Similarly, despite only producing 3.2% of the theme resources, social media provided 7.7% of the 'pregnancy and family planning' sub-topic resources (Figure 5).

DISCUSSION

- While 'treatment' was the most common resource theme across the mapping project 'MS stages and progression' was one of the least covered. This suggests a relative absence of non-treatment related educational resources enabling PwMS to understand the potential course of their disease.
- The least covered theme across the whole mapping project was 'communication with HCPs' despite the patient-physician relation being a major driver of patient satisfaction and treatment in MS¹.
- The high proportion of 'information for families and carers' resources produced by patient groups/associations suggests that these providers have recognised this as an area of unmet need within MS and are actively working to address this.
- It is important that PwMS have access to information online wherever they live. While the internet is a global resource, the uneven distribution of 'MS stages and progression' resources indicates that PwMS in Europe are particularly under-served on this subject.
- The two most covered sub-topics within the theme of 'information for families and carers' were both focussed on relationships. These topics are clearly of interest and importance to PwMS and the information about these subjects came from a more diverse group of providers including social media.
- There are only a few dozen online resources identified globally on the topic of 'how to avoid misinformation' in MS. This may mean that HCPs have a key role to play in educating PwMS not just within appointments but helping to direct them to trustworthy and accurate sources of information online.

CONCLUSIONS

- These data highlight the importance of recognising and investigating the under-represented areas of PwMS online educational resources.
- It is essential that PwMS have access to information online wherever they live and from a variety of sources. For topics with limited resource availability globally, there is a risk that the effects on PwMS will be amplified where these limited resources are produced and distributed unevenly.
- While this was a purely quantitative study, it is important for future research in this area to investigate not just the availability but also the quality of the resources that educate PwMS.

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