

MS in the 21st Century mapping study identifying the global educational offerings for multiple sclerosis patients

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Introduction

- 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.
- The Phase 1 study mapped the educational resources for MS across Europe and Canada². In Phase 2, human immunodeficiency virus (HIV) was selected as a comparator disease and its educational resources, within Europe and Canada, mapped³. These data provided a measure of relativity to compare the availability of MS resources against.
- In Phase 3, the educational resources available for PwMS in the USA, Latin America, Middle East and Asia-Pacific regions were mapped⁴.
- For the first time, we present here the combined data for Phase 1 and Phase 3 to examine the availability and distribution of MS resources at a global scale.

Objectives

- To report global findings of a comprehensive mapping exercise to identify the scope, diversity and number of online educational materials for PwMS.
- To analyse the stakeholders that produce these resources and the topics they cover.

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 what resources a patient in each country would have access to online. Stakeholders were identified in 51 countries across the globe, by using search terms that were based on a list of pre-determined stakeholder types (Table 1).
- Stakeholder websites were then explored in full and all relevant pages were recorded as resources in the database and categorised by format, topic, stakeholder and country (Table 1).
- Resources were categorised into 52 different therapy topics which were grouped into eight overarching topics 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.

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

MS Resource Topics			
Consultation checklist; Dealing with your consultation and healthcare provider; Patient and healthcare professional disease management care plan	Cognition; Fatigue; Headache; Heat sensitivity; Mental health; Numbness; Pain; Sleep problems	Clinically isolated syndrome (CIS); Diagnosis; Primary progressive MS; Progressive relapsing 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 children; Guide for teens/young adults; Guide for the newly diagnosed; How to avoid misinformation; The biology of MS	Diet; Exercise/physical activity; Lifestyle (general); Posture; Pregnancy and family planning; Sexual health; 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			
Overarching topics (for each MS resource topic)			
Communication with healthcare professionals	Invisible symptoms	Physical symptoms	
General information on the disease	Lifestyle	Social/legal information	
Information for families and carers	Stages and progression	Treatment	
Stakeholder type			
Patient group/association	Online media	Government or public health providers	Other educational platforms
Pharmaceutical company	Specialist clinic	Health insurance providers	Social media

Results

- A total of 1308 stakeholders from 51 countries were mapped, resulting in the identification of 13321 individual educational resources.
- Europe produced the greatest number of resources (31.3%, n=4168) followed by North America (30.7%, n=4087). International stakeholders contributed 16.1% of resources (n=2147) (data not shown).
- 'Patient groups/associations' were the most common stakeholder type (27.1%, n=354) followed by 'online media organisations' (22.2%, n=290). 'Pharmaceutical companies' were the least common stakeholder type representing only 2.8% (n=37) of stakeholders (Figure 1).
- There was significant variation in the number of resources produced by these stakeholders. Despite representing 22.2% (n=290) of stakeholders, 'online media organisations' only produced 9.4% (n=1248) of resources (1:0.4). Similarly, 'social media user' stakeholders only produced 5.3% (n=707) of resources despite making up 13.1% (n=172) of stakeholders (1:0.4) (Figure 1).
- Despite being the least common stakeholder type, 'pharmaceutical companies' produced 7.3% (n=976) of the resources (1:2.6). 'Patient groups/associations' produced 48.4% (n=6451) of resources which, despite being the most common stakeholder type, is still more than expected (1:1.8) (Figure 1).

Figure 1: Distribution of stakeholders (and the resources produced by them) by stakeholder type

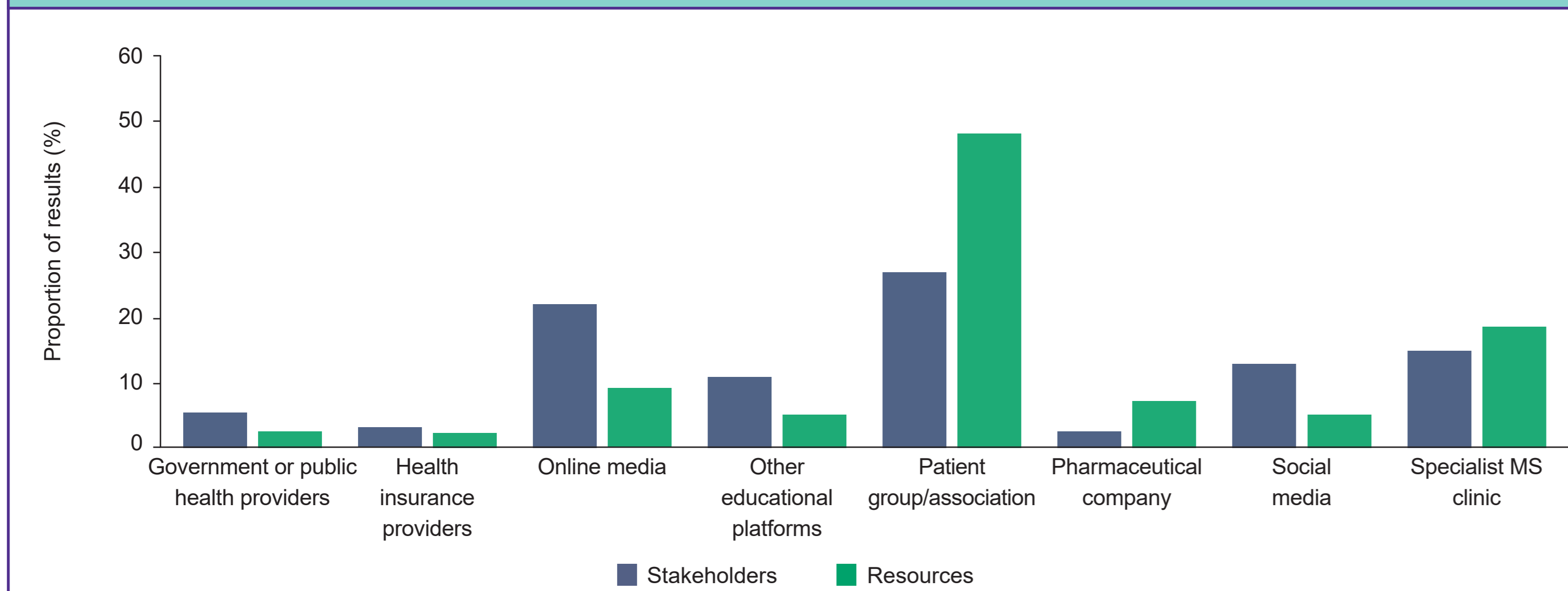
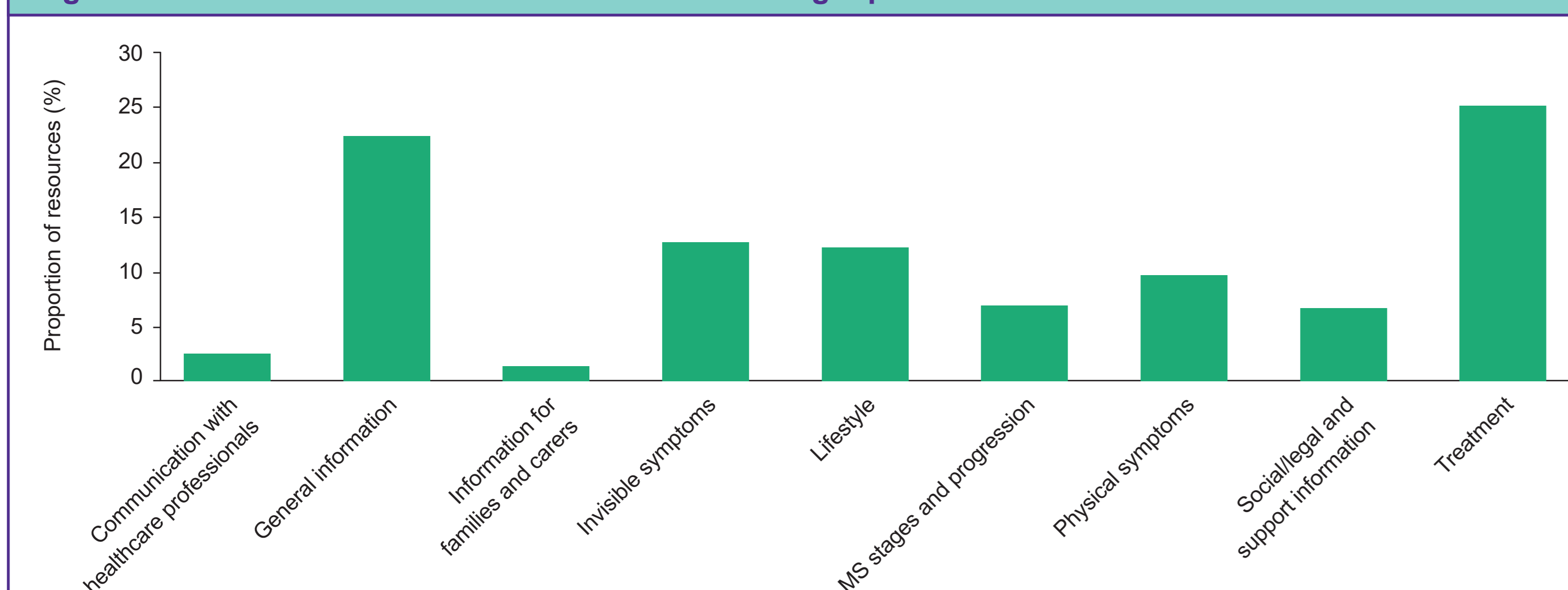


Figure 2: Distribution of resources across overarching topics



- The most common resource topic covered by stakeholders was 'treatment' (25.3%, n=3372) followed by 'general information' (22.5%, n=2998) and 'invisible symptoms' (12.6%, n=1679) (Figure 2).
- The least frequent topics were 'information for families and carers' (1.5%, n=196) and 'communication with healthcare professionals' (2.5%, n=337) (Figure 2).
- The overarching topics covered by different stakeholder types varied. While 'patient groups/associations' produced 73.0% (n=143) of the resources for the least common topic 'information for families and carers', they only produced 37.0% (n=1249) of the resources for the most common topic 'treatment' (Figure 3).
- 'Online media organisations' had the greatest variation across the topics (std dev, 12.3%) compared to other stakeholder types with 'health insurance providers' the most uniform resource provider (std dev, 6.5%) (Figure 3).

- Within the overarching topic of 'treatment' there was a difference between the sub-topics (Table 1) covered by 'social media user' stakeholders compared to the rest of the stakeholder types. While 'disease-modifying treatments' was the most common topic for other stakeholders (36.1%, n=1167) 'social media user' stakeholders jointly most covered topic was 'other treatments' (29.3%, n=41) which focuses on alternative and non-traditional treatments (Figure 4).

Figure 3: Sub-analysis of overarching topics by stakeholder type

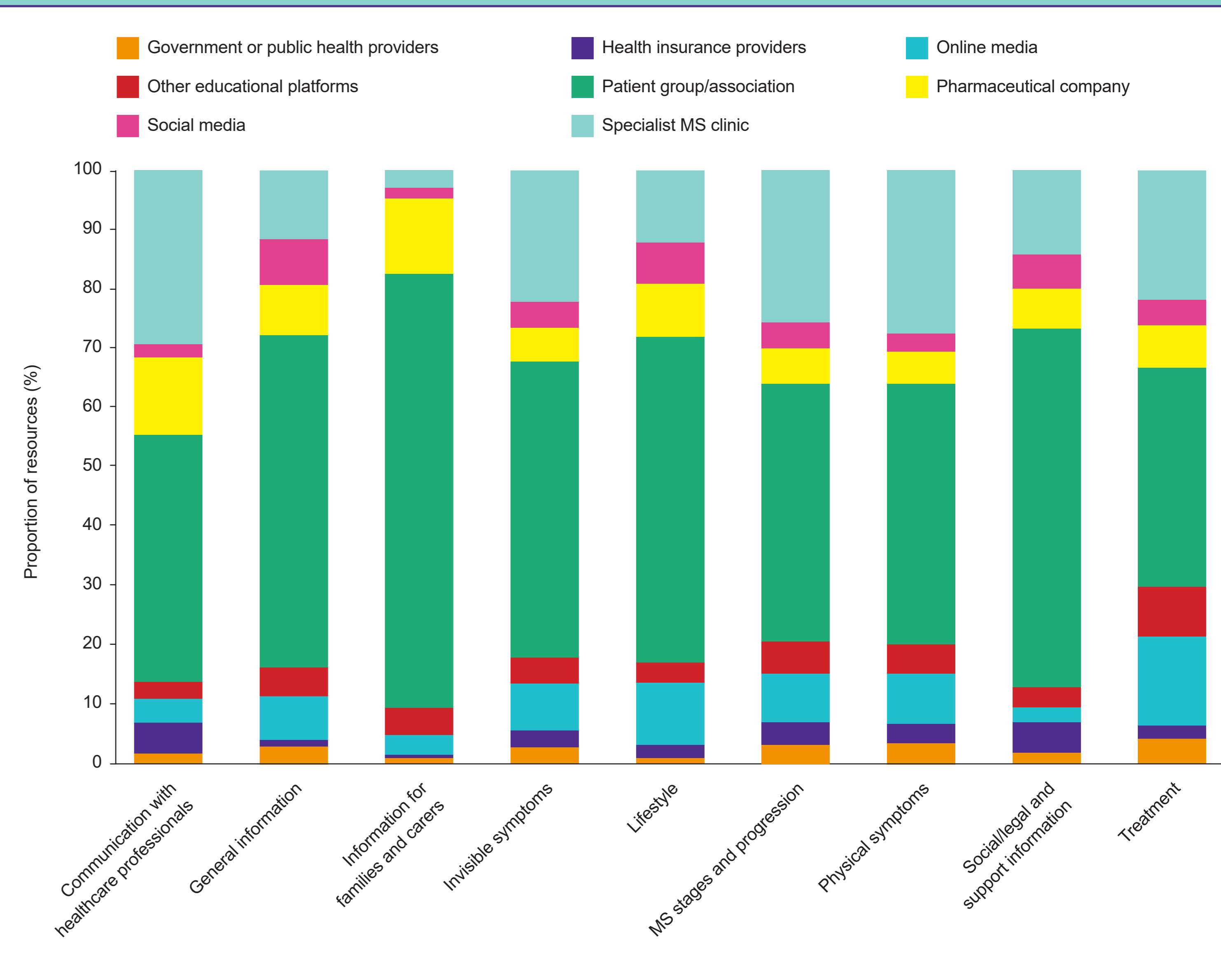
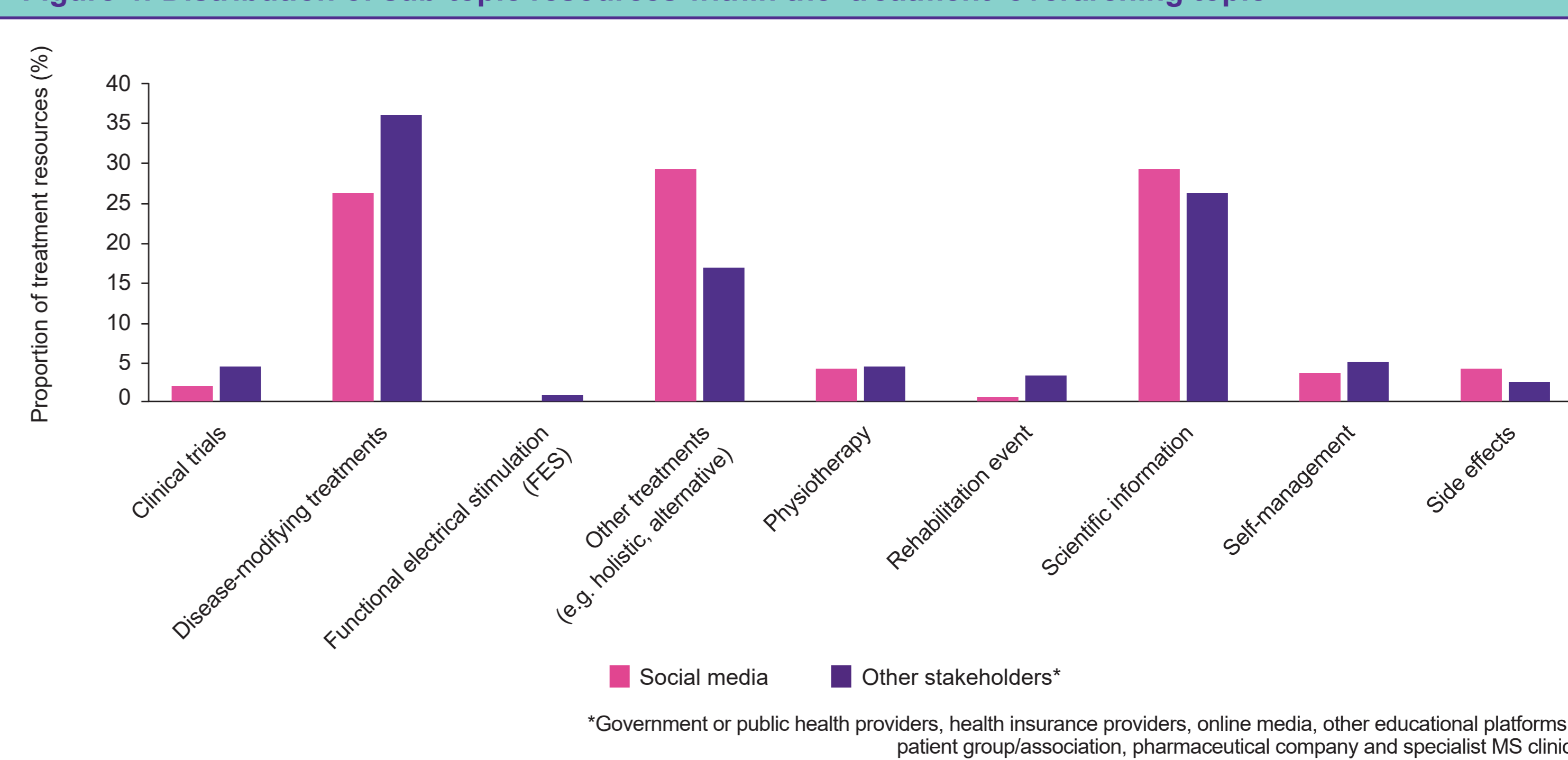


Figure 4: Distribution of sub-topic resources within the 'treatment' overarching topic



Discussion

- 'Patient groups/associations' represented the largest number of stakeholders and produced almost half of the resources mapped, reflecting the importance of patient communities and the patient voice in MS.
- While 'pharmaceutical companies' made up the smallest number of stakeholders, they were also proportionally the largest producer of resources. This shows the importance of these stakeholders as producers of educational information. Additionally, the fact that these stakeholders are international organisations suggests that these resources will potentially have a larger reach than those produced by many other stakeholders.
- While 'online media organisations' and 'social media users' accounted for over a third of total stakeholders, the fact that these stakeholders produced proportionally the fewest number of resources suggests that MS patients rely on more trustworthy and centralised sources for educational materials.
- It is encouraging to note that 'invisible symptoms' was the third most common overarching topic as this has previously been identified by the Steering Group as an area of unmet need within MS care. Although, it should be clarified that this is largely driven by the USA and other regions cover this topic much less^{2,4}.
- The topics of 'communication with healthcare professionals' and 'information for families and carers' are uniformly under-represented around the globe. Both of these topics are heavily linked to patient satisfaction and wellbeing, which is important as these are major drivers of treatment adherence⁵.
- The large focus on 'alternative treatment' resources by 'social media user' stakeholders demonstrates the importance of directing patients towards reliable and accurate sources of information online in order to prevent misinformation.

Conclusions

- These global level data highlight the importance of different stakeholders for educational resource production; with stakeholders varying significantly in both the topics and amounts of resources produced.
- While this was a quantitative study and we are unable to comment on the quality of the information available for PwMS these data highlight a number of potential gaps in the educational landscape. The topics of 'communication with healthcare professionals' and 'information for families and carers' are under-represented across both the individual datasets^{2,4} and this global data set, and should be further investigated to determine the benefit of additional resources in these areas.
- It is important that PwMS have access to accurate and reliable patient information online and these results highlight the need to ensure that 'social media' has a positive rather than negative role in patient education.

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Gavin Giovannoni is a steering committee member for: AbbVie (Daclizumab trials), Biogen Idec (BG12 and Daclizumab trials). He has received honoraria for speaking at Physicians summit Canbox. He is a clinical advisor regarding the development of VSN16. He has received consultancy fees for advisory board meeting for GW Pharmaceuticals, and speaking at launch of Sativex in Norway.
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