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A mapping study comparing educational resources for multiple sclerosis patients across the USA, Latin America, Middle East and Asia-Pacific regions

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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.¹
- In 2016, to inform the development of educational programs and resources, MS in the 21st Century conducted a mapping exercise to capture the existing educational offerings for PwMS in Europe and Canada (Phase 1).² This Phase 1 study showed that resources were provided by a broad range of stakeholder types, with some topics (i.e. 'treatment') more represented than others (i.e. 'communication with healthcare professionals').
- The aim of Phase 1 was to determine whether there is a deficit in the existing educational offerings for MS. In Phase 2, human immunodeficiency virus (HIV) was selected as a comparator disease and its educational resources, within Europe and Canada, were mapped.³ These data provided a measure of relativity to compare the availability of MS resources against.
- The data presented here represents Phase 3 of the study.

OBJECTIVES

- To identify the number, format, and topic of educational resources accessible by PwMS, and the stakeholder types from which they arise within the regions of USA, South America, Middle East and Asia-Pacific.
- To analyze the distribution of different resources across the regions.

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 34 countries across the USA, South America, Middle East, and Asia-Pacific, by using search terms that were based on a list of pre-determined stakeholder types (Table 1).

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

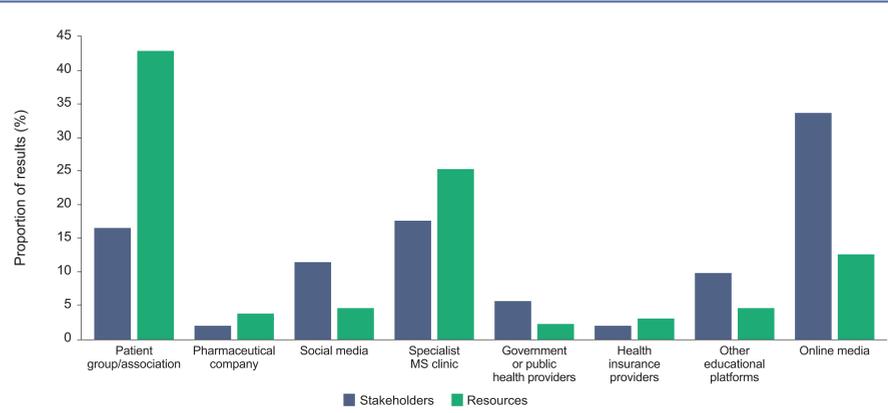
MS Resource Topics			
Consultation checklist; Dealing with your consultation and healthcare provider; Patient and healthcare professional disease management care plan	Cognition; Fatigue; Headache; Heat sensitivity; Mental health; Numbness; Pain; Sleep problems	Clinically isolated syndrome (CIS); Diagnosis; 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

- Stakeholder websites were then explored in full and all relevant pages were recorded as resources in the database and categorized by format, topic, stakeholder and country (Table 1).
- Resources were categorized 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.

RESULTS

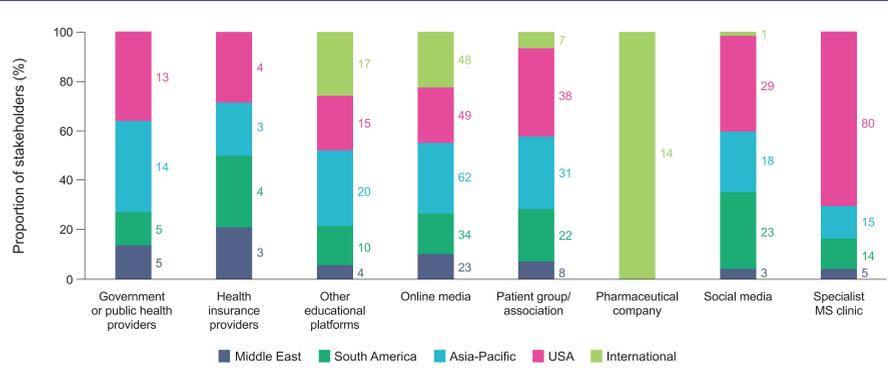
- A total of 641 stakeholders from 34 countries were mapped, resulting in the identification of 8,139 individual educational resources.
- The USA provided the highest number of stakeholders (35.6%, n=228), followed by Asia-Pacific (25.4%, n=163) and South America (17.5%, n=112), with the Middle East providing the fewest (8.0%, n=51). A number of stakeholders covered multiple regions and so were classed as International (13.6%, n=87) (data not shown).
- While 'online media' was the most commonly identified stakeholder type (33.7%, n=216), these stakeholders produced proportionally fewer resources (12.8%, n=1,043) (Figure 1).
- Conversely, while 'patient groups/associations' only accounted for 16.5% (n=106) of all stakeholders mapped, they produced 42.8% of the total resources (n=3,480) (Figure 1).
- The average number of resources per stakeholder in Phase 3 was 12.7. 'Patient groups/associations' (32.8) and 'pharmaceutical companies' (23.2) produced the greatest number of resources per stakeholder, while 'online media' (4.8) and 'social media' (5.0) produced the fewest (Figure 1).

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



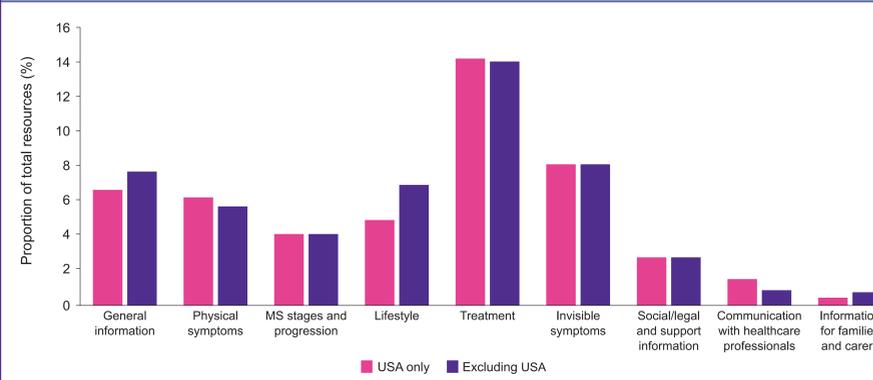
- As well as being the most numerous stakeholder type, 'online media' also had the most even distribution across the regions (Figure 2).
- The least distributed stakeholder type was 'pharmaceutical companies', which were all classified as international stakeholders (Figure 2).
- The majority of 'specialist MS clinic' stakeholders identified were located in the USA (70.2%, n=80) (Figure 2).

Figure 2: Distribution of stakeholder types across regions (including those classed as international)



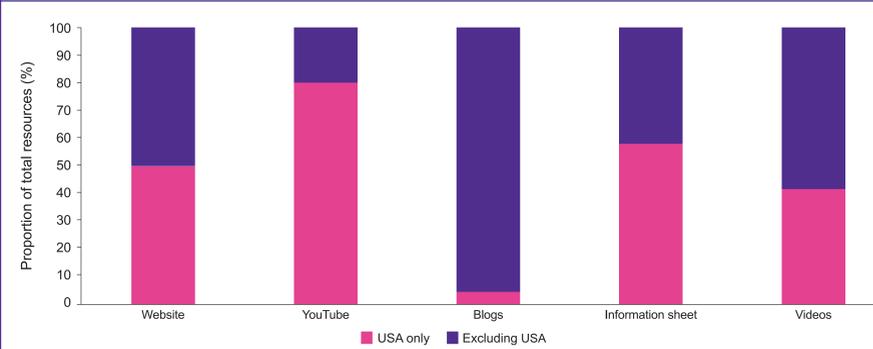
- As a region, the USA, produced almost as many resources as the rest of the regions combined (USA: 49%, n=3,990; non-USA: 51%, n=4,149) (Figure 3).
- The overarching topics covered by resources from the USA are almost identical to those covered across the other regions (Figure 3).
- The largest difference in resource numbers was in the topic of 'lifestyle', which was covered slightly more in the non-USA regions (6.9%, n=561) than in the USA (4.9%, n=398) (Figure 3).
- The most commonly covered overarching topic was 'treatment' (28.2%, n=2,292), followed by 'invisible symptoms' (16.2%, n=1,321) (Figure 3).
- The least commonly covered overarching topics were 'information for families and carers' (1.3%, n=103) and 'communication with healthcare professionals' (2.4%, n=199) (Figure 3).

Figure 3: Distribution of resources across MS therapy topics



- While the most common resource format, 'website', was evenly split between the USA and non-USA regions (USA: 50.1%, n=2,718; non-USA: 49.9%, n=2,708), there was a big difference in the split of the next two most common resource formats ('YouTube' and 'blogs') (Figure 4).
- The majority of 'YouTube' resources came from the USA (80.6%, n=458), while the majority of 'blog' resources came from outside of the USA (94.9%, n=464) (Figure 4). More non-YouTube 'video' resources were found outside of the USA (58%, n=188) (Figure 4).

Figure 4: Distribution of MS resources across the top 5 resource formats (left to right)



DISCUSSION

- These results may be representative of patient-driven demand for reliable sources of information. 'Patient groups/associations' and 'specialist MS clinics' contributed nearly 70% of the total resources despite making up less than 35% of the stakeholders. Both of these stakeholder types typically represent reliable sources of accurate MS information.

- Conversely, while general stakeholder types, such as 'online media' and 'social media', represented large proportions of identified stakeholders, both of these stakeholder types contributed significantly fewer resources proportionally.
- The large proportion of 'specialist MS clinic' stakeholders found in the USA suggests that these stakeholders represent an important source of information for patients in this region.
- The similar numbers of resources found within and outside the USA might be representative of the importance of the internet as a global tool for accessing information. While our study methodology categorized resources based on their intended geographic audience, the vast majority of them would be accessible to anyone in the world. As such, the relative prevalence of English-language resources would be expected.
- One of the most interesting differences between these Phase 3 data and our Phase 1 data is that the Phase 3 resources seem to be more specialized. In Phase 1, 35.3% of resources were classified as 'general information', compared to only 14.4% in Phase 3.²
- 'Invisible symptoms' was the second most covered topic in these Phase 3 data, whereas it was only the fifth most covered in Phase 1;² this topic had previously been identified by the Steering Group as an under-served part of the educational landscape.
- The two topics with the least amount of resources in Phase 3, 'information for families and carers' and 'communication with healthcare professionals', were also the two least represented topics in the Phase 1 regions.²
- The difference in resource formats between the USA and the rest of the Phase 3 regions represents the importance of considering regional differences when creating educational resources. The prevalence of YouTube resources in the USA, when juxtaposed against the distribution of other 'video' resources, suggests that rather than being less interested in audio-visual resources, the other regions are simply more varied in their chosen video platforms (i.e. vimeo, dailymotion etc).
- However, the lack of 'blogs' as a format in the USA suggests a potential gap in this region for promoting more patient-driven creation of educational resources.

CONCLUSION

- These Phase 3 data showed that the educational resources available online for PwMS differ by topic, format, and stakeholder. While there were some important regional differences, there was a surprising amount of uniformity across many of the areas.
- These Phase 3 data differed significantly in places from our previously published Phase 1 data from Europe and Canada, providing potential for further analysis of these data at the global level.
- The topics of 'communication with HCPs' and 'information for families and carers' are under-represented across all of our data; however, further research will be needed to determine whether the resources available on these topics cover the needs of MS patients or if they represent genuine gaps in the educational landscape.

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