Systematic mapping of the global educational offerings for multiple sclerosis patients on the topic of disease progression

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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 focus is to improve education of, and communication between, healthcare professionals (HCPs) and PwMS, with a view to ultimately supporting more effective shared decision-making and improving overall patient engagement and outcomes.
- In 2019, to inform the development of future educational programmes and resources, a systematic mapping exercise was conducted to identify online resources on the topic of disease progression, to allow for the identification of unmet educational needs.

Objective

- To report, for the first time, the global findings of a mapping exercise to identify the diversity and distribution of online educational resources for PwMS on the topic of MS disease progression.

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 that a PwMS in each country would discover while searching for information on the topic of disease progression.
- Twelve keyword search terms were developed to reflect the types of information that PwMS might search for (**Table 1**).

Table 1: Mapping search parameters

Search terms						
Definition	and	multiple sclerosis	and	disease progression	and	worsening
Talking about						
Coping with						
Understanding prognosis of						
Working or studying with						
Lifestyle						
Clinically isolated syndrome						
Primary progressive						
Secondary progressive						
Relapsing remitting						
Progressive relapsing						
Stages						

Countries

Argentina, Australia, Belgium, Bolivia, Brazil, Canada, Chile, Colombia, Czech Republic, Denmark, Ecuador, Egypt, Finland, France, Germany, Greece, Guatemala, Hong Kong, Hungary, India, Indonesia, Ireland, Israel, Italy, Japan, Malaysia, Mexico, Netherlands, New Zealand, Norway, Pakistan, Peru, Philippines, Poland, Portugal, Romania, Russia, Saudi Arabia, South Korea, Spain, Sweden, Switzerland, Taiwan, Thailand, Turkey, UAE, UK, USA, Venezuela, Vietnam

Languages

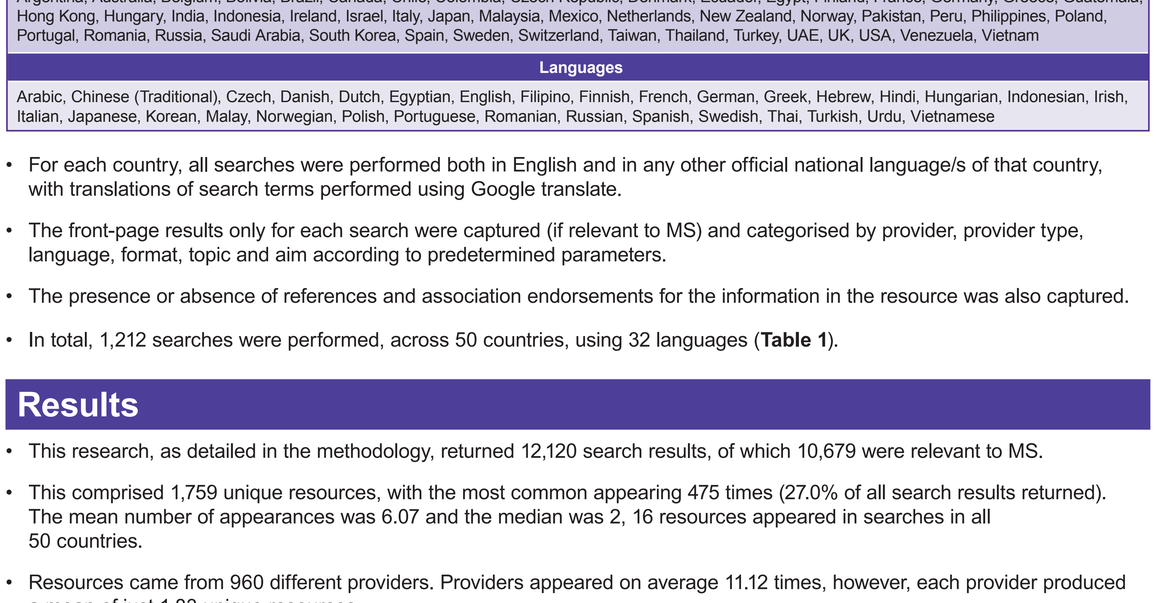
Arabic, Chinese (Traditional), Czech, Danish, Dutch, Egyptian, English, Filipino, Finnish, French, German, Greek, Hebrew, Hindi, Hungarian, Indonesian, Irish, Italian, Japanese, Korean, Malay, Norwegian, Polish, Portuguese, Romanian, Russian, Spanish, Swedish, Thai, Turkish, Urdu, Vietnamese

- For each country, all searches were performed both in English and in any other official national language/s of that country, with translations of search terms performed using Google translate.
- The front-page results only for each search were captured (if relevant to MS) and categorised by provider, provider type, language, format, topic and aim according to predetermined parameters.
- The presence or absence of references and association endorsements for the information in the resource was also captured.
- In total, 1,212 searches were performed, across 50 countries, using 32 languages (**Table 1**).

Results

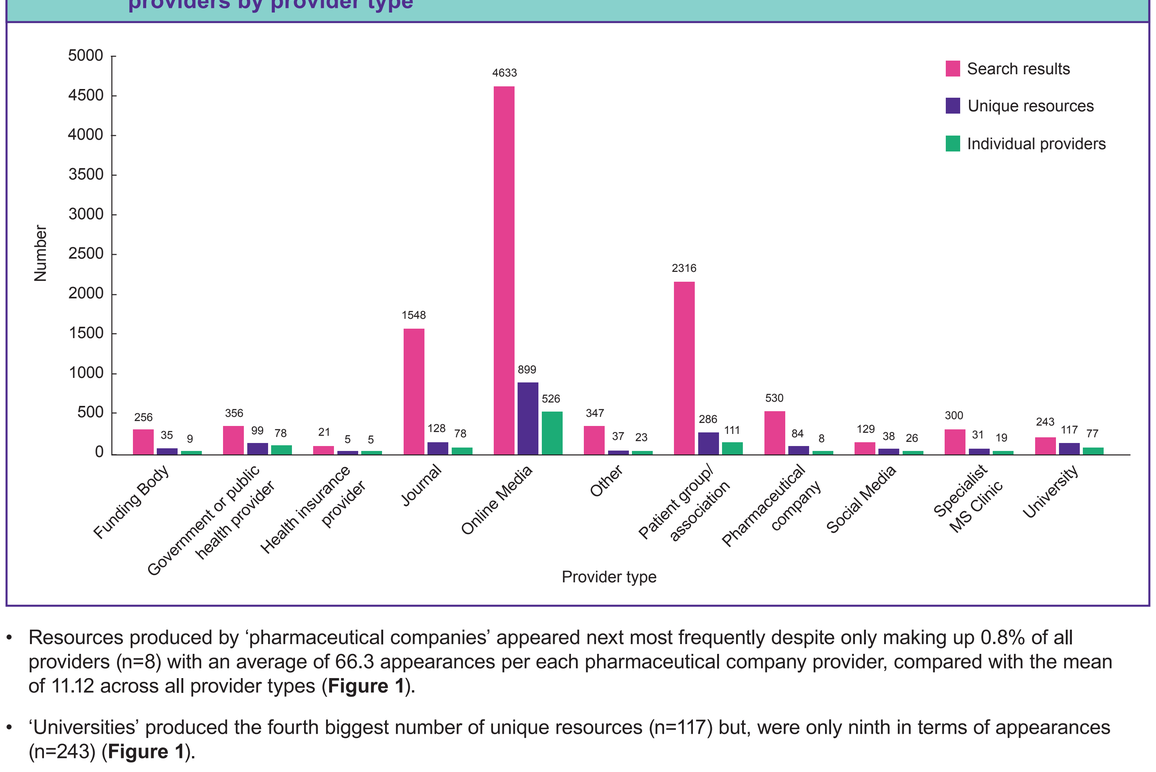
- This research, as detailed in the methodology, returned 12,120 search results, of which 10,679 were relevant to MS.
- This comprised 1,759 unique resources, with the most common appearing 475 times (27.0% of all search results returned). The mean number of appearances was 6.07 and the median was 2, 16 resources appeared in searches in all 50 countries.
- Resources came from 960 different providers. Providers appeared on average 11.12 times, however, each provider produced a mean of just 1.83 unique resources.
- The top three provider types both in terms of number of appearances and in number of unique resources produced were 'online media' (4,633 and 899 respectively), 'patient group/association' (2,316 and 286 respectively), and 'journals' (1,548 and 128 respectively) (**Figure 1**).

Figure 1: Total number of search results, number of unique resources and number of unique providers by provider type



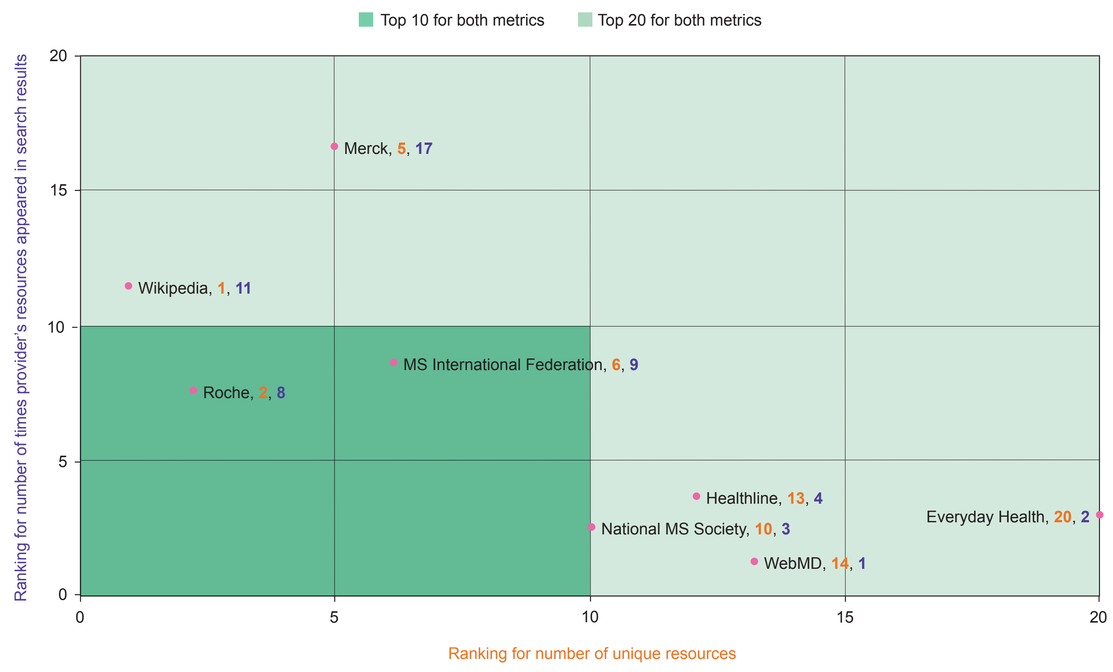
- Resources produced by 'pharmaceutical companies' appeared next most frequently despite only making up 0.8% of all providers (n=8) with an average of 66.3 appearances per each pharmaceutical company provider, compared with the mean of 11.12 across all provider types (**Figure 1**).
- 'Universities' produced the fourth biggest number of unique resources (n=117) but, were only ninth in terms of appearances (n=243) (**Figure 1**).
- The results showed no evidence of correlation between the number of search results and either the number of providers or combined number of unique resources produced by a provider type. Despite 'online media' resources making up the highest overall number of search results, this was still 11.4% fewer search results than would be expected, based on the number of individual providers in the group, and 7.7% fewer than would be expected based on the number of unique resources (**Figure 2**).

Figure 2: Difference between proportion of search results and proportion of unique resources, or providers, by provider type



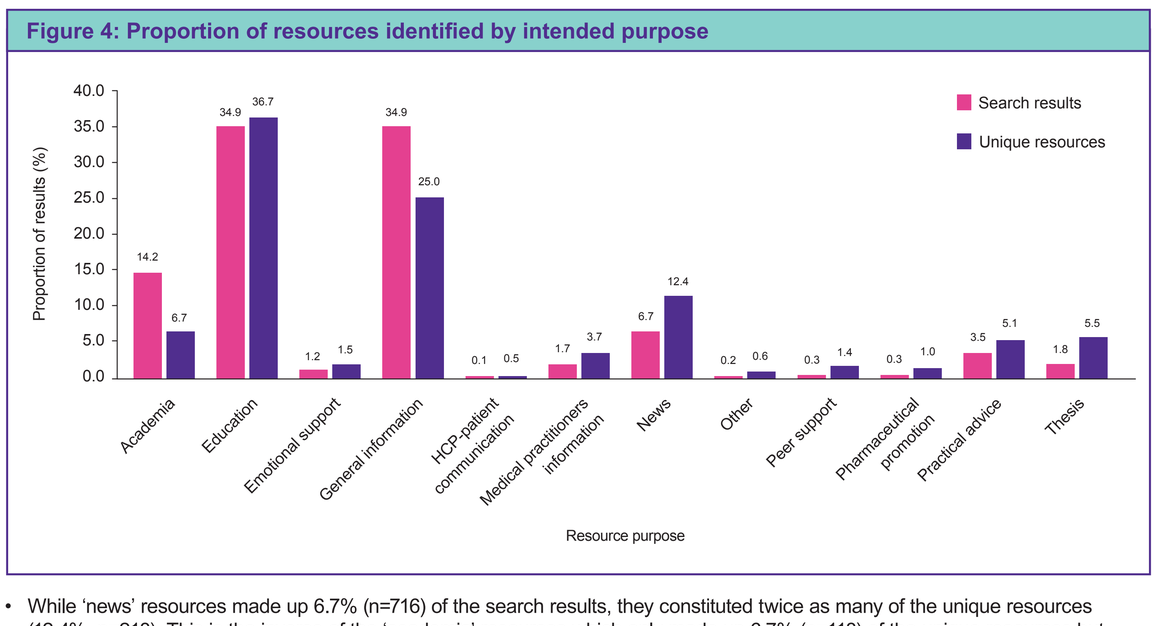
- Conversely, resources produced by the second and third most prevalent provider types, 'patient group/association' and 'journals', were found proportionally more than would be expected based on both the number of providers (+10.1% and +6.4% respectively) and number of unique resources (+5.4% and +7.2% respectively) (**Figure 2**).
- While 'pharmaceutical companies' search result numbers roughly matched the expected proportion based on the number of unique resources produced (+0.2%), they represented a much larger proportion than would be expected when compared with the number of providers (+4.1%) (**Figure 2**).
- Of the eight providers that ranked in the top 20 lists for both number of unique resources provided and number of times their resources appeared in search results, three were non MS-specific health-related websites, two were pharmaceutical companies, two were patient organisations and one was Wikipedia (**Figure 3**).

Figure 3: Individual providers with top 20 rankings for both number of unique resources and number of search results



- Only three providers ranked in the top 10 lists for both metrics (Roche, MS International Federation and National MS Society). In addition, the nine further providers that featured in just one of the two top 10 lists, did not make it into the top 20 list for the other metric (**Figure 3**).
- Interestingly, of the top 10 providers producing the most individual unique resources, only 2 were exclusively focused on MS, whereas, of the top 10 providers that appeared most frequently in searches, 5 were exclusively focused on MS (data not shown).
- When interpreting the intended purpose of the resources, 'general information' was the most frequently identified (34.9%, n=3732) closely followed by 'education' (34.9%, n=3726) (**Figure 4**).

Figure 4: Proportion of resources identified by intended purpose



- While 'news' resources made up 6.7% (n=716) of the search results, they constituted twice as many of the unique resources (12.4%, n=218). This is the inverse of the 'academia' resources which only made up 6.7% (n=118) of the unique resources but 14.2% (n=1520) of the search results (**Figure 4**).
- Resources intended to support patient-HCP communication on the topic of disease progression made up the smallest percentage of both unique resources (0.5%, n=9) and overall search results (0.1%, n=9) (**Figure 4**).

Discussion

- The large number of repeated appearances of resources and providers in search results around the globe show the international nature of the modern online landscape. This is emphasised by the fact that some resources showed up in results from every country searched. However, this is not necessarily a positive for PwMS who might benefit more from tailored local resources.
- Resources produced by 'online media' providers (comprised predominantly of news and generic health websites) made up far fewer of the total relevant search results than would be expected considering the number of unique pages and individual providers. Despite this, as a combined group, the high volume of providers in this category means that patients are still most likely to frequently encounter and interact with resources from this provider type compared with any other.
- Conversely, despite only accounting for a small fraction of providers, at an individual level, 'pharmaceutical companies' outperformed all other provider types, with a quarter of them in the top 8 overall individual providers.
- Similarly, 'patient group/association' resources also made up more search results than expected. This suggests that these providers are very successful at targeting their specific audiences, as opposed to the more 'scattergun' approach taken by 'online media' providers.
- The high number of times 'journal' provider resources appeared in search results is interesting as these resources are not typically intended for, and may not meet the needs of, PwMS. This shows the variety that exists in search results in terms of information intended for different audiences.
- Overall, it was noted that the number of unique resources and the number of providers did not directly affect the number of times resources appeared in search results. This may point to the high influence of factors such as search engine optimization on the impact of individual resources.

Conclusions

- These global data highlight the importance of different providers for PwMS education online; with providers' resources varying significantly in both frequency and impact.
- These data also highlight the potential limitations of restricting information searching to Google with high numbers of repeated resources from non-MS-specific providers potentially at the expense of more tailored information sources.
- While this poster has taken an initial overarching look at these data this mapping methodology provides many more opportunities for futher data analysis, particularly in terms of resource content as well as distribution both geographically and by language.
- The relative absence of resources intended to support patient-HCP communication on the topic of disease progression is of particular importance to MS in the 21st Century given the objectives of the initiative and should be further investigated to determine the benefit of additional resources in this area.

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