

Systematic mapping of global family-orientated educational offerings for people with multiple sclerosis and members of their support networks

Authors: Alice Laroni^{1,2}, Heidi Thompson³, Pieter van Galen⁴, and Gavin Giovannoni⁵
on behalf of the MS in the 21st Century initiative, and Nektaria Alexandri⁶

¹University of Genoa, Italy; ²IRCCS Ospedale Policlinico San Martino, Genoa, Italy; ³Craigavon Hospital, Northern Ireland; ⁴MS in the 21st Century steering group member, Belgium; ⁵Blizard Institute of Neurology, and Barts and The London School of Medicine and Dentistry, UK; ⁶Global Medical Affairs, Neurology & Immunology, Merck KGaA, Germany

Background

- The MS in the 21st Century initiative, formed in 2011, is a steering group of international multiple sclerosis (MS) specialists and people with MS (PwMS). The initiative's focus is to improve the education of, and communication between, healthcare professionals (HCPs) and PwMS, with a view to ultimately supporting more effective shared decision-making and improving patient engagement and outcomes.
- In 2019, to inform the development of future educational programmes and resources, a systematic mapping exercise was conducted to identify family-orientated online resources for PwMS or members of their support network, to allow for the identification of unmet educational needs.

Objective

- To report, for the first time, findings of a global mapping exercise to identify the availability and distribution of online educational resources tailored towards, or providing guidance on interacting with, the families, carers and support persons of PwMS.

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 for the resources that PwMS, or members of their support network, in each country would discover while searching for information on topics around families and family planning in MS.
- Eleven keyword terms were developed to reflect the types of information a PwMS might search for (Table 1).

Table 1: Mapping search terms

Search terms	
Guides for teenagers	
Guides for children	
Guides for young adults	
Information for carers / helpers	
Talking to children about MS	
Information for families	
Family planning	
Pregnancy	
Sexual health	
Talking to teenagers about MS	
Telling people that you have MS	

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	

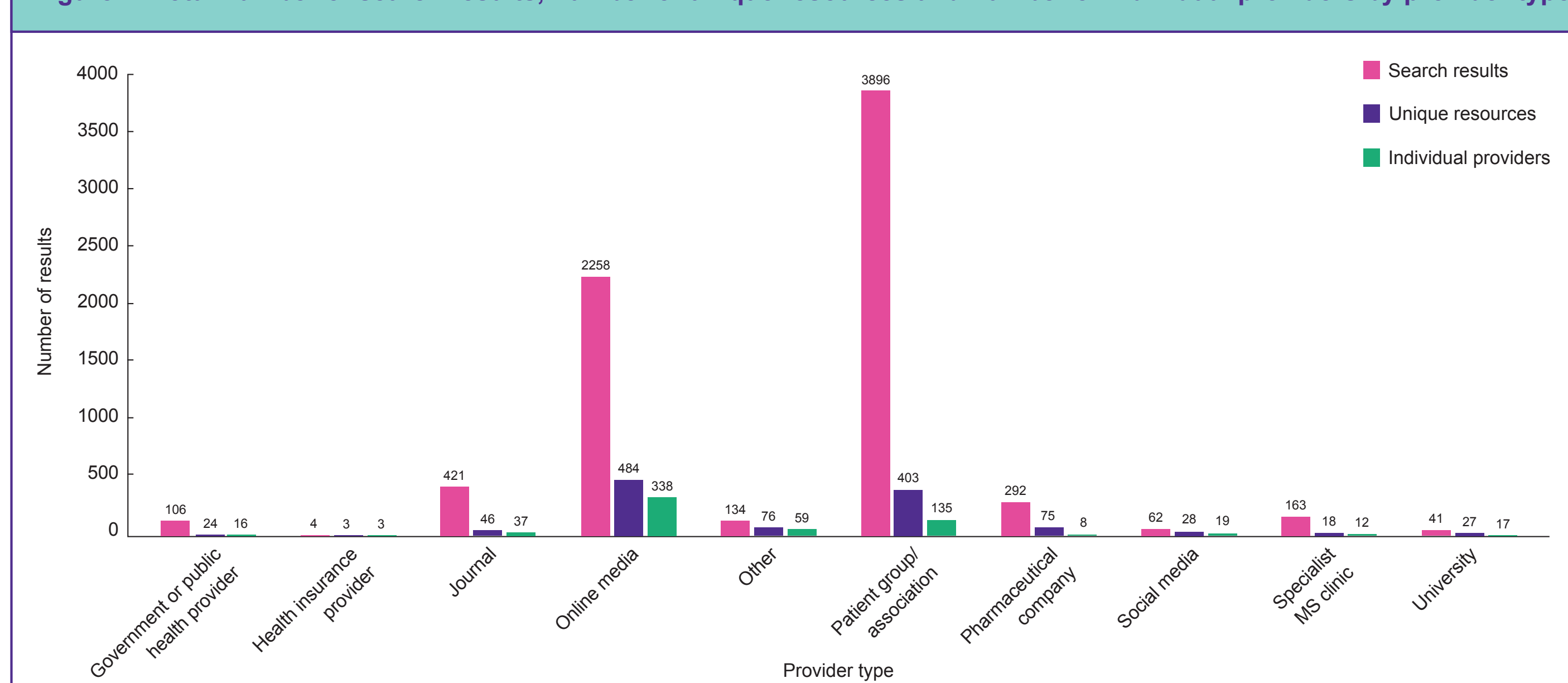
Languages	
Arabic, Chinese (Traditional), Czech, Danish, Dutch, Egyptian, English, Filipino, Finnish, French, German, Greek, Hebrew, Hindi, Hungarian, Indonesian, Irish, Italian, Japanese, Korean, Malay, Norwegian, Polish, Portuguese, Romanian, Russian, Spanish, Swedish, Thai, Turkish, Urdu, Vietnamese	

- 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, 1,111 searches were performed, across 50 countries, using 32 languages (Table 1).

Results

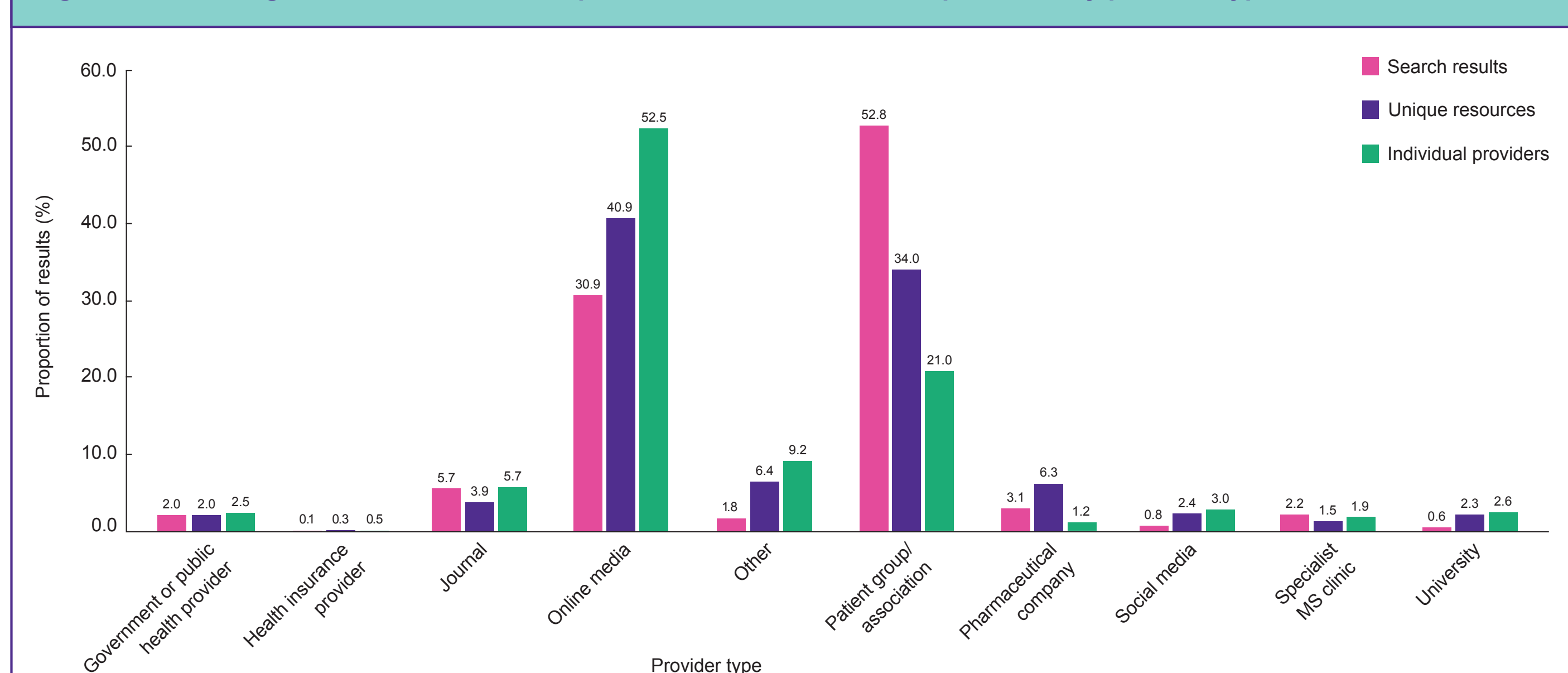
- This research, as detailed in the methodology, returned 11,110 results, of which, 7,377 were relevant to MS.
- This comprised 1,184 unique resources, with the most common appearing 156 times (13.2% of all search results returned).
- Resources came from 648 individual providers and the average number of search results per provider was 9.5 and the average number of unique resources per provider was 1.9.
- The most commonly found resource providers were 'patient groups/associations' and 'online media', 3,896 (52.8%) and 2,258 (30.6%) respectively (Figure 1).

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



- It is interesting to note the small number of resources from 'pharmaceutical companies', 'government or public health providers' and 'specialist MS clinics' (292, 106 and 163, respectively). 'Social media' resources were particularly scarce with just 62 search results while 'journals' ranked a little higher, with 421 resources found (Figure 1).
- 'Patient group/association' accounted for 21.0% of individual providers yet produced 34.0% of the unique resources and 52.8% of search results (Figure 2).

Figure 2: Percentage of search results, unique resources and individual providers by provider type



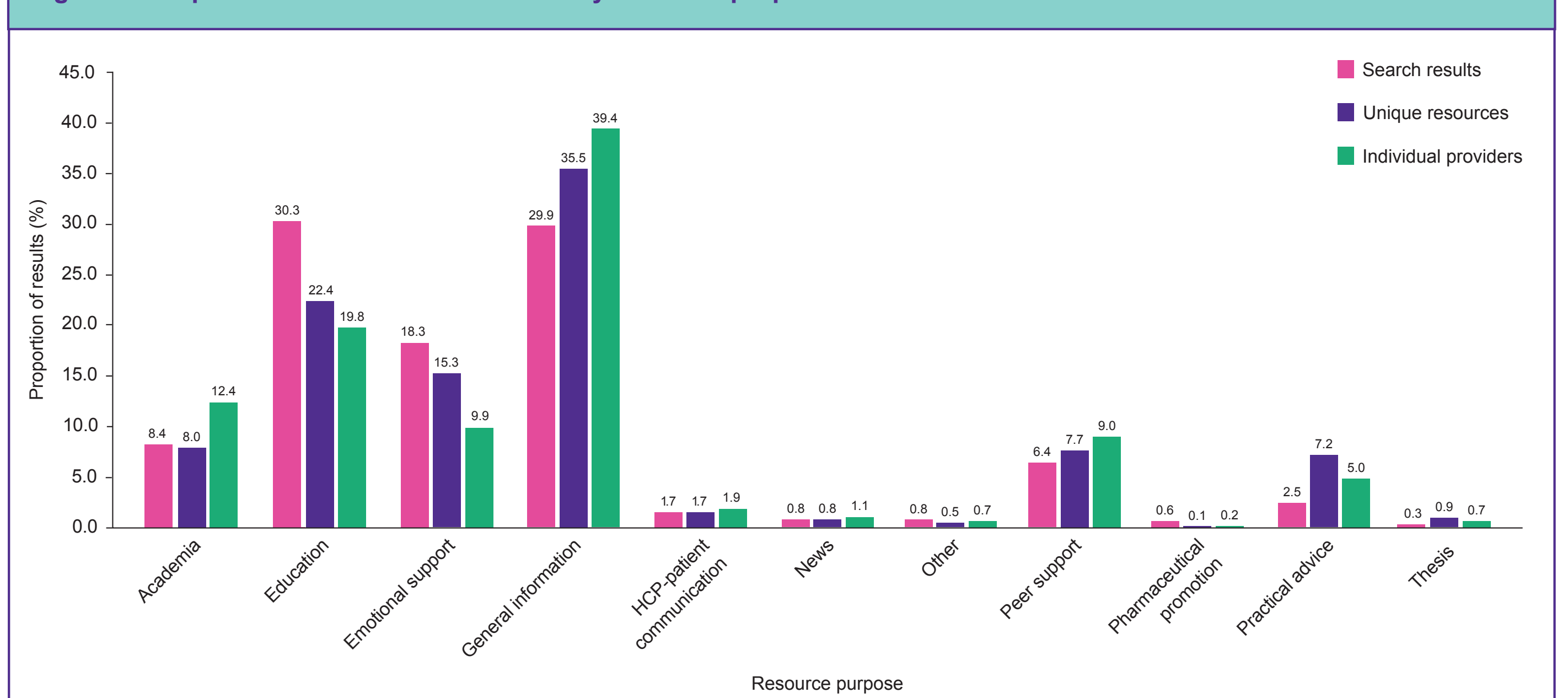
- Conversely, 'online media' accounted for 52.5% of individual providers, yet produced only 40.9% of unique resources, which were found 30.9% of the time during searches (Figure 2).
- 'Pharmaceutical company' providers only accounted for 3.1% of the search results despite producing 6.3% of the unique resources (Figure 2).
- Eleven resource providers were ranked in the top 20 for both the number of unique resources and the number of times their resources appeared in search results. Of these, nine providers were 'patient group/association', one was an 'online media' provider and the other one was a 'pharmaceutical company' (Figure 3).
- Interestingly, there were six providers which featured in the top 10 lists for both metrics, all of whom were, patient groups/associations: National MS Society US, MSIF, MS Society of Canada, MS Society UK, The Multiple Sclerosis Foundation (MS Focus) and MS Trust UK (Figure 3).
- The top 20 providers accounted for 52.9% (n=3,902) of the search results found and 25.6% (n=303) of total unique resources found (Data not shown).

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



- When interpreting the intended purpose of the unique resources, the top 3 intentions identified 'general information', 'education', and 'emotional support' (35.5% n=420, 22.4% n=265, 15.3% n=181, respectively).
- However, in terms of search results 'education' was the most common resource purpose (30.3% n=2,237) followed by 'general information' and 'emotional support' (29.9% n=2,206 and 18.3% n=1,352, respectively) (Figure 4).
- The number of search results and unique resources intended to support 'patient-HCP communication' was very low 1.7% n=122 and 1.7% n=20, respectively (Figure 4).

Figure 4: Proportion of resources identified by intended purpose



Discussion

- Searches revealed many resources and providers repeated in the results. Some resources were present in results from every country searched. This highlights a saturation of repeated information online, which may prevent PwMS from accessing tailored local resources that provide a broader range of information.
- 'Patient groups/associations' comprised one fifth of the individual providers but over half the search results found during the mapping exercise. This indicates that these groups are very successful at targeting PwMS as well as their families, carers and support persons, highlighting their importance in the online landscape of PwMS support.
- Conversely, resources produced by 'online media' (comprised mostly of news and generic health websites) accounted for half the individual providers, these resources only represented one third of the search results. This indicates that while online media providers make up the majority of information sources on the internet, other MS specific providers are more successful at disseminating information to PwMS.
- It is interesting to note also, the small proportion of search result content from 'pharmaceutical companies', 'government or public health providers' and 'specialist MS clinics'. This potentially highlights a gap in the online landscape, due to the role of these providers in producing official sources of information on the availability and diversity of treatment and care options for PwMS in a specific region.
- 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 optimisation on the impact of individual resources.
- Data presented here shows similar trends to that from a similar mapping exercise on the topic of disease progression. This exercise also highlighted the presence and importance of 'patient group/associations' at producing targeted and relevant resources for PwMS, notably when compared to the 'scattergun' approach of 'online media'. Conversely, for information on the topic of disease progression 'pharmaceutical companies' were shown to outperform other provider types, and one quarter were present in the top 8 rankings for unique resources and search results.

Conclusions

- These global data highlight the diversity in the availability of educational resources related to the support networks of PwMS accessible online at a global level. It is noteworthy that only two-thirds of front-page search results in this mapping were relevant to MS, potentially indicating a lack of available information for families and of these, and a large proportion were repeated resources from a small fraction of the individual providers.
- It is interesting to note the large proportion of unique information for PwMS produced from 'patient group/association' providers, thus highlighting their importance on providing relevant information on families and family planning.
- While this poster has taken an initial overarching look at these data, this mapping methodology provides many more opportunities for further data analysis, particularly in terms of resource content as well as distribution both geographically and by language.
- The lack of information to support patient-HCP communication with the families, carers, and support persons of PwMS is of particular importance to MS in the 21st Century given the objectives of the initiative and should be further investigated to determine the potential benefits of additional resources in this area.

Acknowledgments and disclosures

The MS in the 21st Century initiative is financially supported by Merck KGaA, Darmstadt, Germany. Secretariat support and editorial input is provided by Cello Health Communications. Medical writing assistance was provided by Cello Health Communications (Owen Webb and Cassie Mackenzie) and funded by Merck KGaA, Darmstadt, Germany.

Alice Laroni has received personal compensation from Novartis, Sanofi Genzyme, Biogen, Merck, Roche, and TEVA for public speaking and advisory boards. Heidi Thompson has received honoraria for advisory board participation and travel grants from Merck & Biogen.

Pieter van Galen receives consultant fees and honoraria from Merck KGaA, has received honoraria as a moderator from Biogen, and has been a patient advisor for Novartis and Roche.

Gavin Giovannoni is a steering committee member for AbbVie (daclizumab trials) and Biogen Idec (BG12 and daclizumab trials), and has received honoraria for speaking from Canex Therapeutics. He is a clinical advisor regarding the development of VSN16. He has received consultancy fees for advisory board meetings for GW Pharmaceuticals, and for speaking at the launch of Sativex in Norway.

Nektaria Alexandri is an employee of Merck KGaA.

MS in the 21st Century Steering Group members

Brigit Bauer, Trishna Bharadia, Alexey Boyko, Elisabeth Celius, Maria Paz Giambastiani, Gavin Giovannoni, Jeremy Hobart, Elisabeth Kasilingam, Jürg Kesselring, Dawn Langdon, Alice Laroni, Sarah A Morrow, Jocelyne Nouvet-Gire, Celia Oreja-Guevara, Majja Pontaga, Stanca Potra, Peter Rieckmann, Sven Schippling, Jane Shanahan, Marja-Liisa Sumelähti, Heidi Thompson, Pieter van Galen, Patrick Vermersch, Mitzi Williams, and David Yeandle.

