MS in the 21st Century Mapping Study to Quantify the Educational Offerings for Patients from Multiple Stakeholders in the Field of Multiple Sclerosis in Europe and Canada

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BACKGROUND

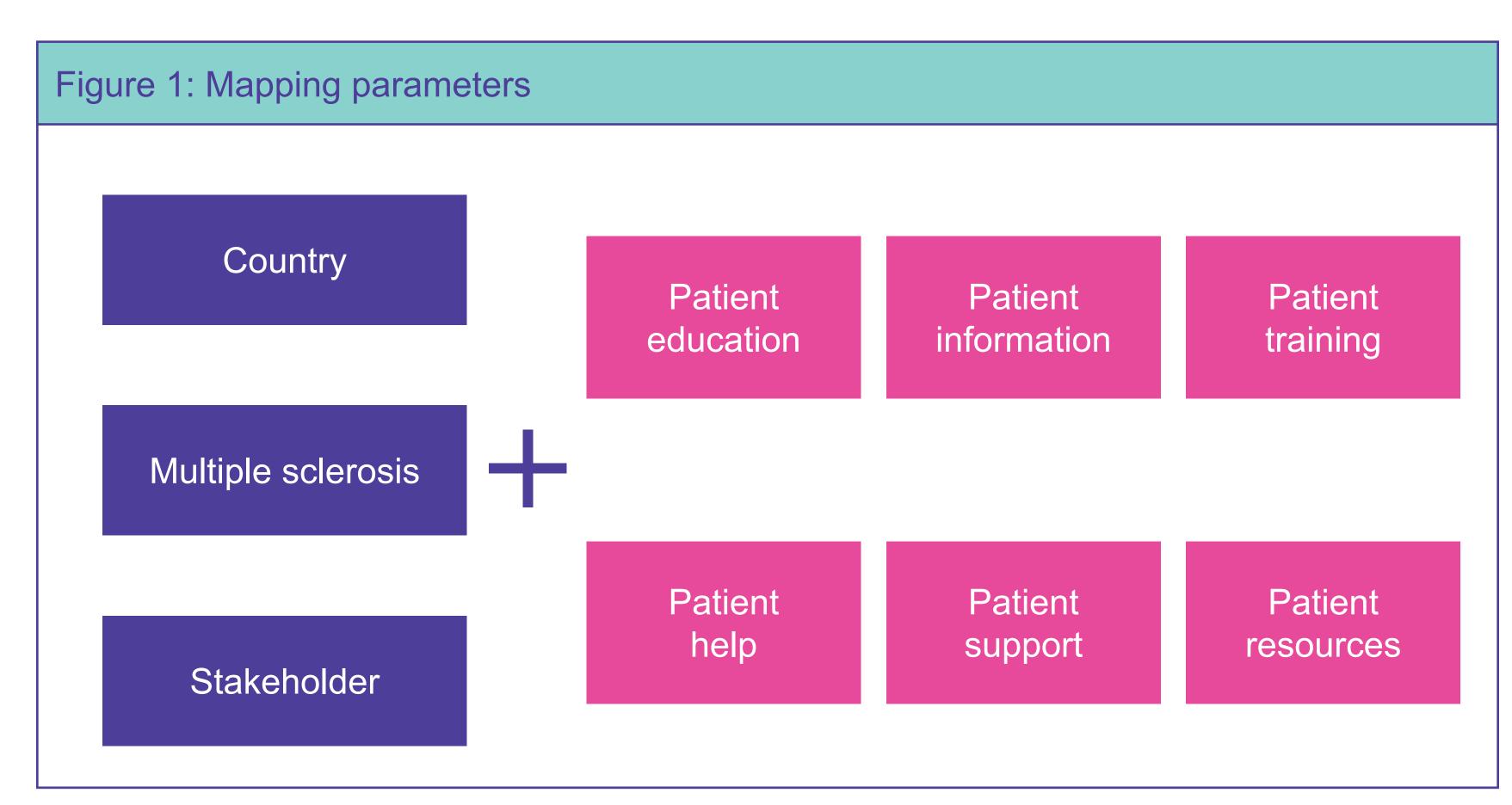
- In 2011, led by a steering group of international multiple sclerosis (MS) specialists, the MS in the 21st Century initiative was formed.
- In 2016, the group took a unique step forward and expanded to include a group of patient representatives to incorporate the patient perspective.
- The group's current focus is to increase collaboration, education and communication between clinicians and people with MS (PwMS).
- To inform the development of educational programmes, the steering group decided to capture the existing educational offerings for PwMS.

OBJECTIVE

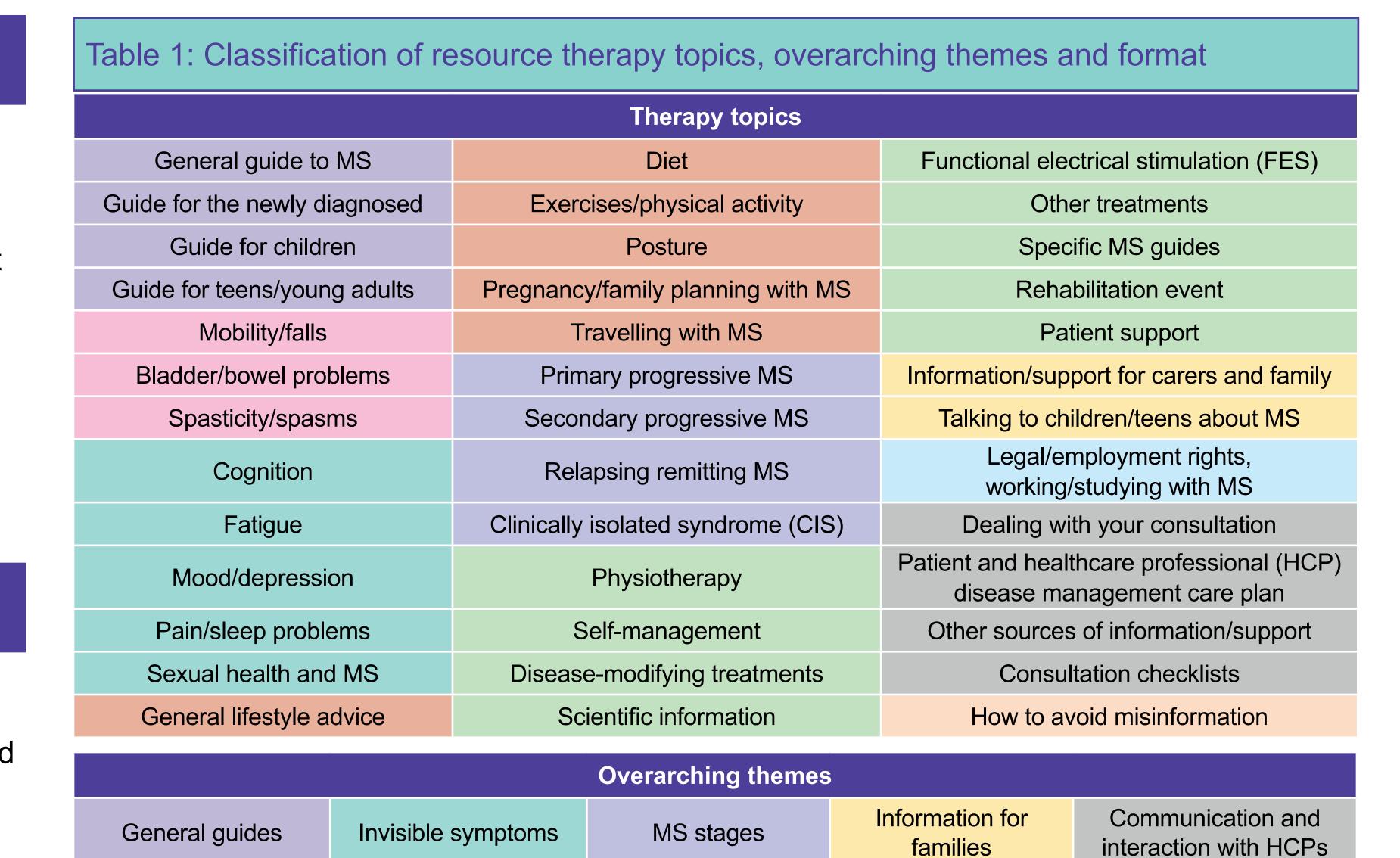
- The mapping exercise aimed to better understand the diversity and number of patient educational materials available for PwMS across Europe and Canada provided by a broad range of stakeholders involved in the care and education of PwMS.
- This research model will be applied to other global regions.

METHODS

 Educational resources in Europe and Canada were recorded using pre-defined mapping parameters (Figure 1).



- Desk research and telephone interviews were conducted to investigate resources from stakeholders including: patient associations and advocacy groups, pharmaceutical companies, educational institutions and providers, healthcare/government services and MS centres/clinics.
- After reviewing the initial data collected, additional topics and material formats were added to the original parameters, resulting in 39 different therapy topics and 16 resource formats (Table 1).
- To allow for cross-analysis between parameter categories (stakeholder, country, format, etc), the 39 therapy topics were combined into 10 overarching themes (Table 1).



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Resource format						
Information sheet	DVD/videos	Training	events (physical attenda	ance)	Educational toolkits to replicate workshops	
Leaflet/poster/postcard	Webcasts	Online communities and forums Wel		Websi	te/online content	
Booklet	Slide decks	Interactive resources		Digital tools (e.g apps)		
Book	Workshops	Online el earning modul			Other	

Social/legal

How to avoid

RESULTS

Resource review

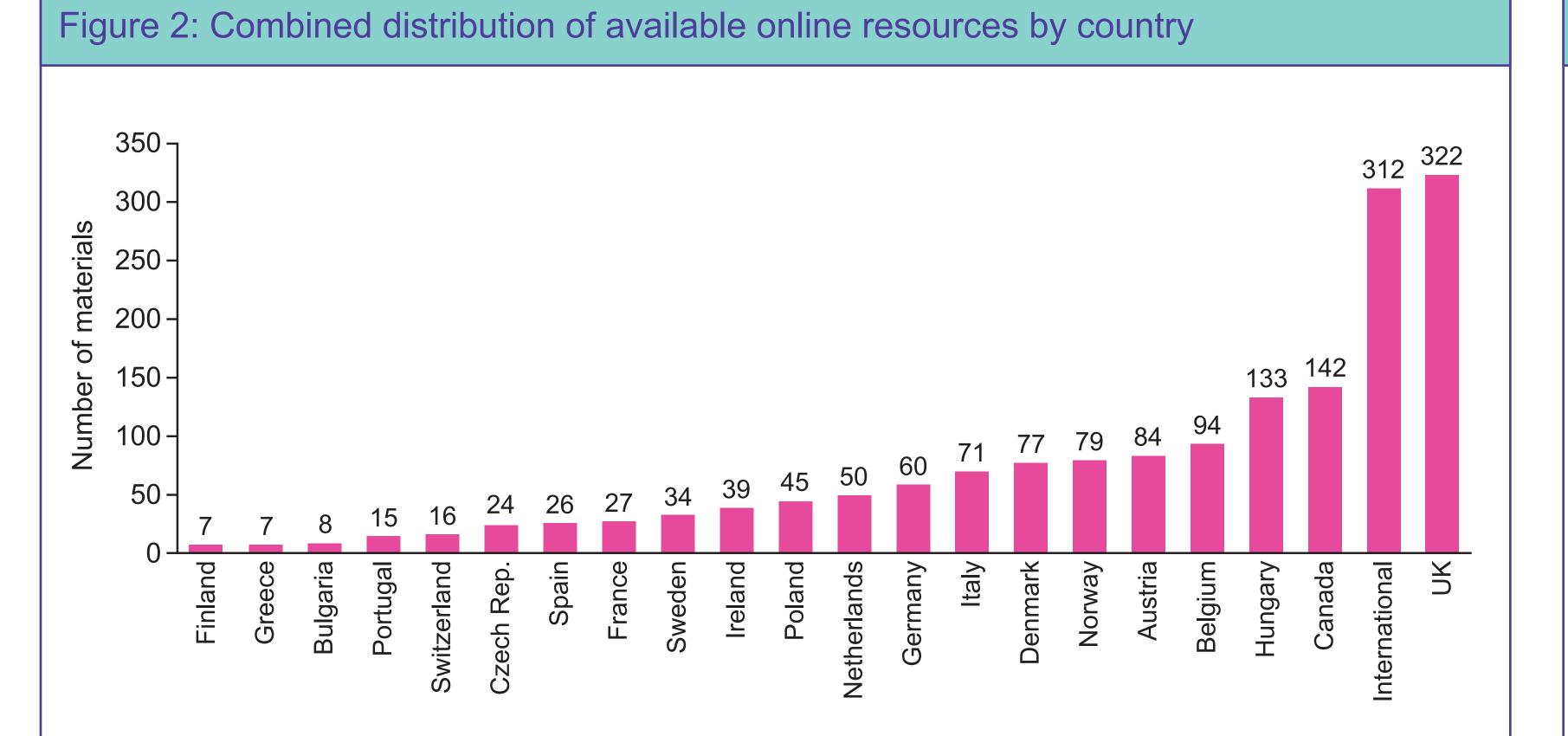
- From the 21 countries mapped, 1,857 different educational resources were identified across all stakeholders, which included websites and online information, leaflets, and patient videos. Excluding social media resources, a total of 1,672 materials were further analyzed.
- The group also considered:
- How the resources were distributed across country and stakeholder
- How the resources were categorised by therapy topic and overall theme
- How the resources were disseminated to PwMS

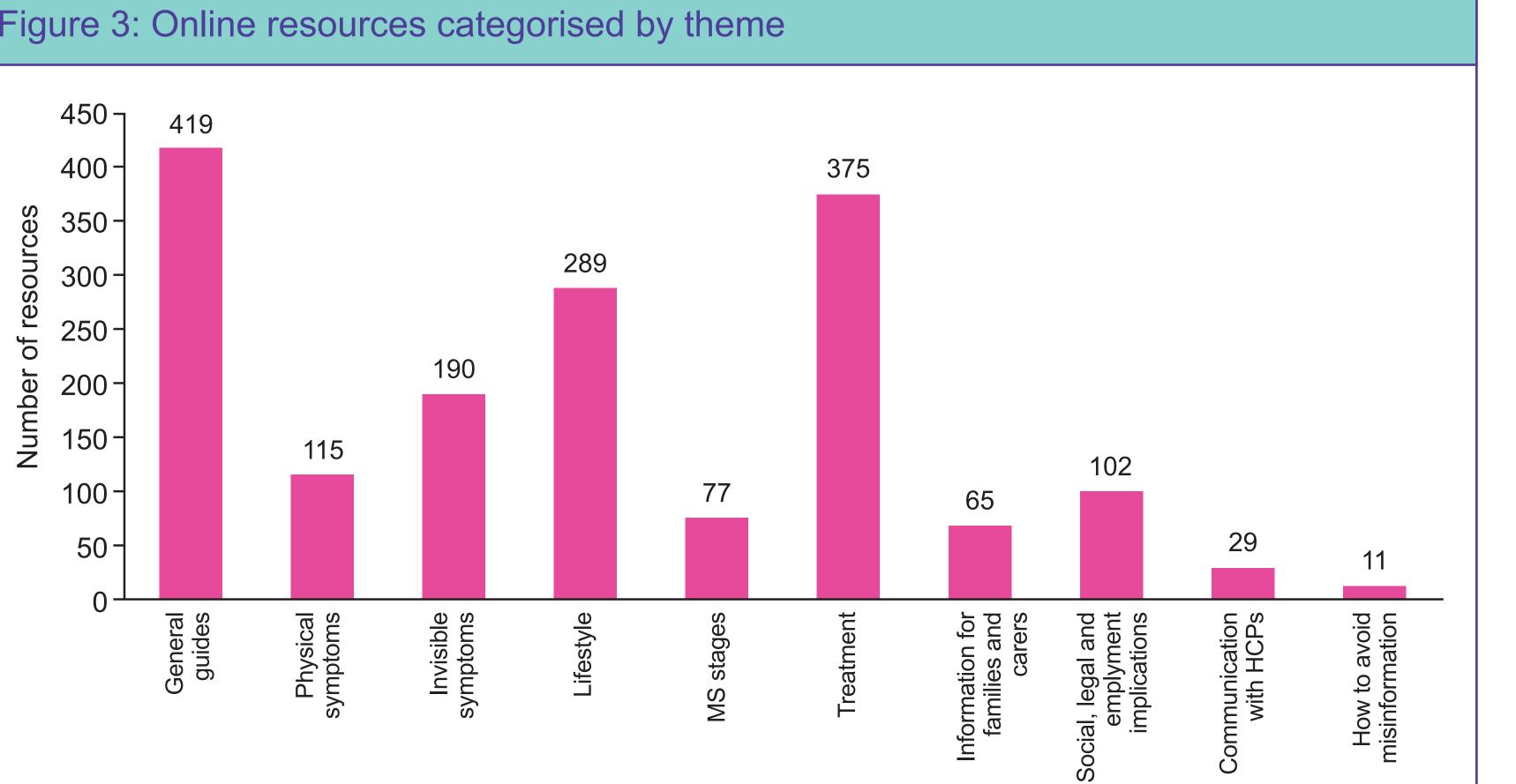
Resource distribution across country and stakeholder

- Of the 1,672 materials mapped, the highest single-country total was from the UK (322) (Figure 2).
- Country of origin was recorded for online information to determine where resources were being distributed from. Five regions distributed 59% of all resources for PwMS.
- Materials were produced primarily by patient associations (50%), while pharmaceutical companies (14%) and treatment clinics (12%) also contributed a variety of materials.

Resource overall theme

- Topics of the online materials varied but were grouped into 10 overarching themes.
- The most common materials identified were general guides, lifestyle advice and treatment information, which accounted for 65% of materials (Figure 3).



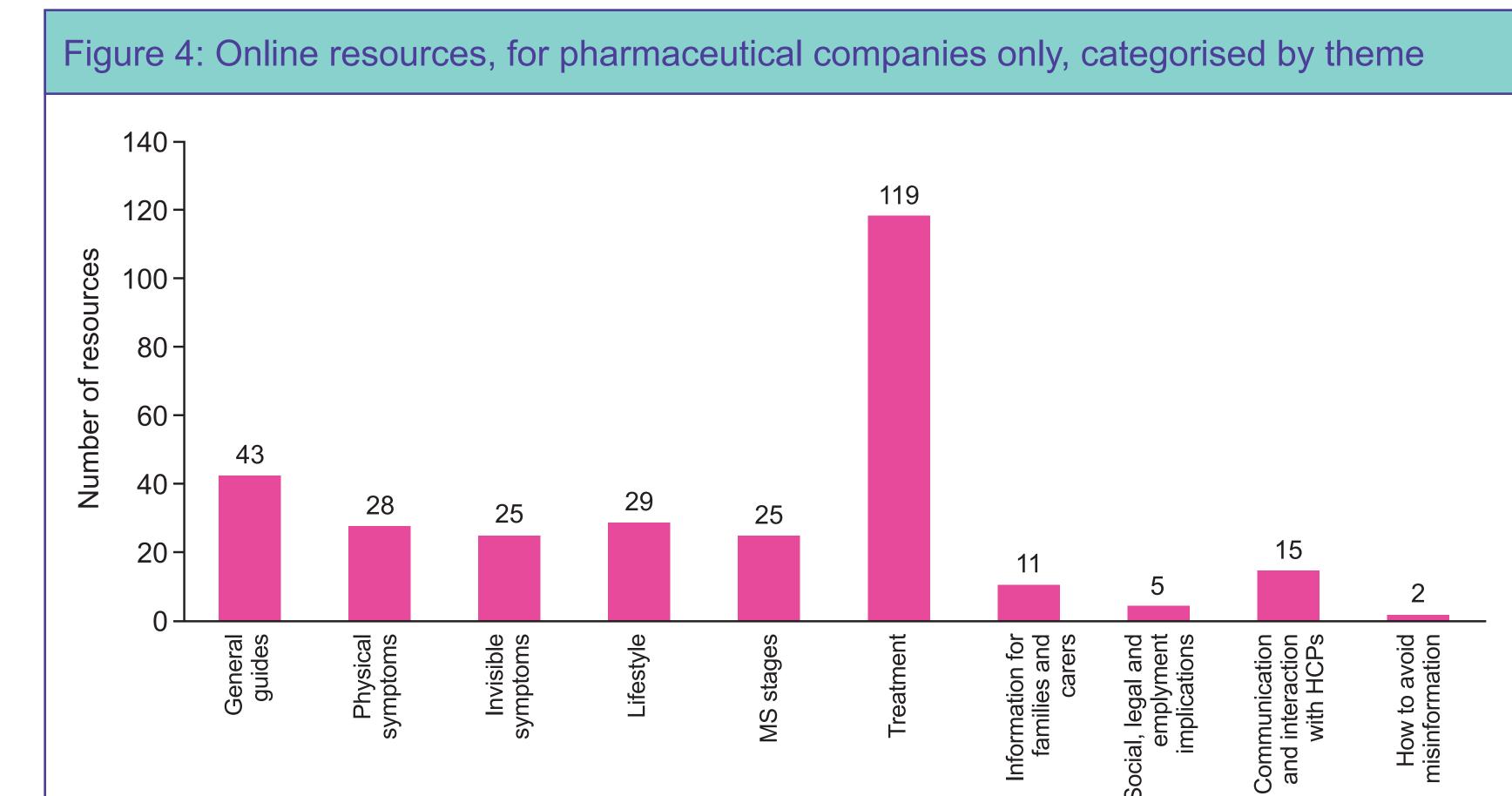


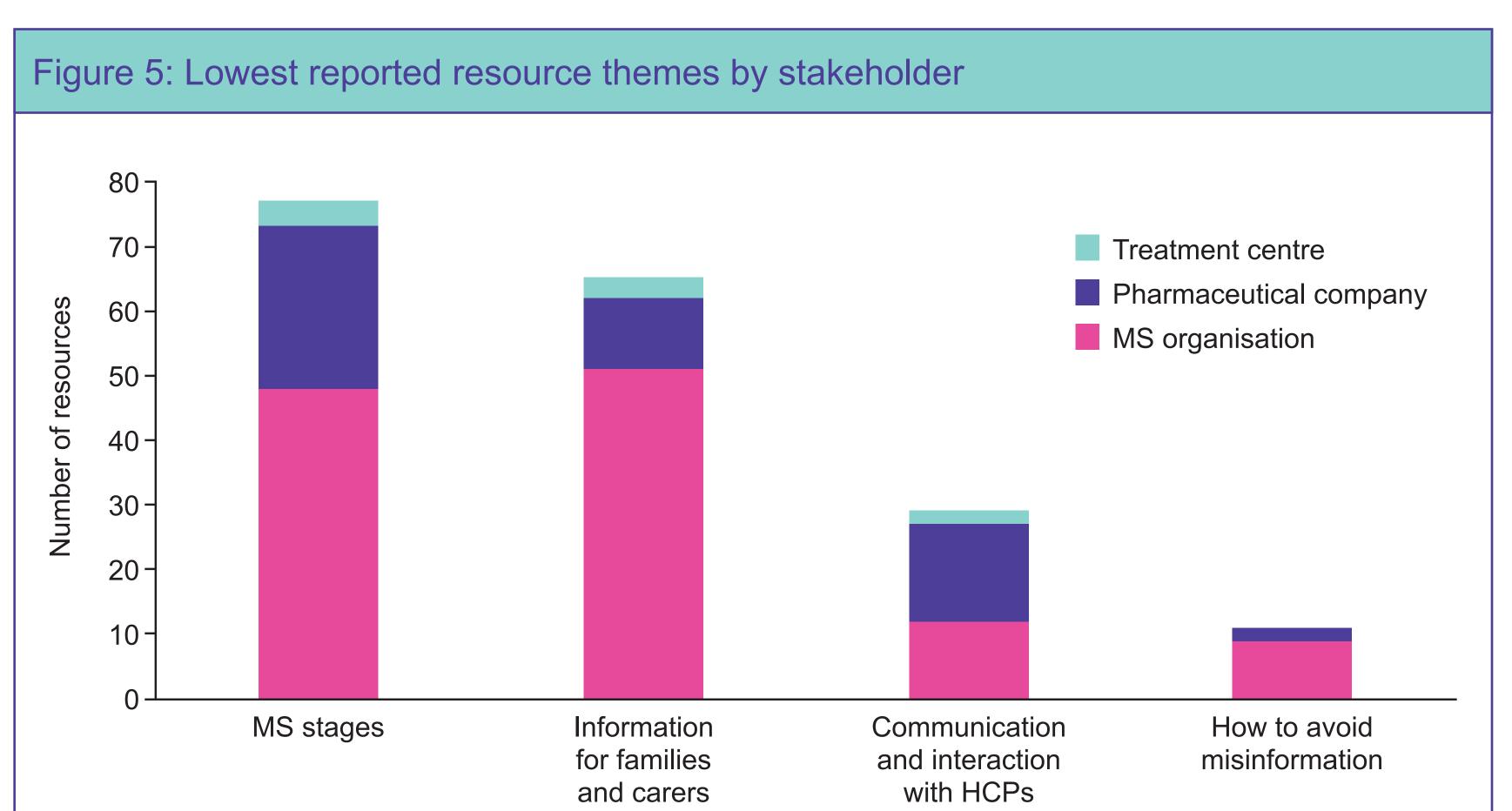


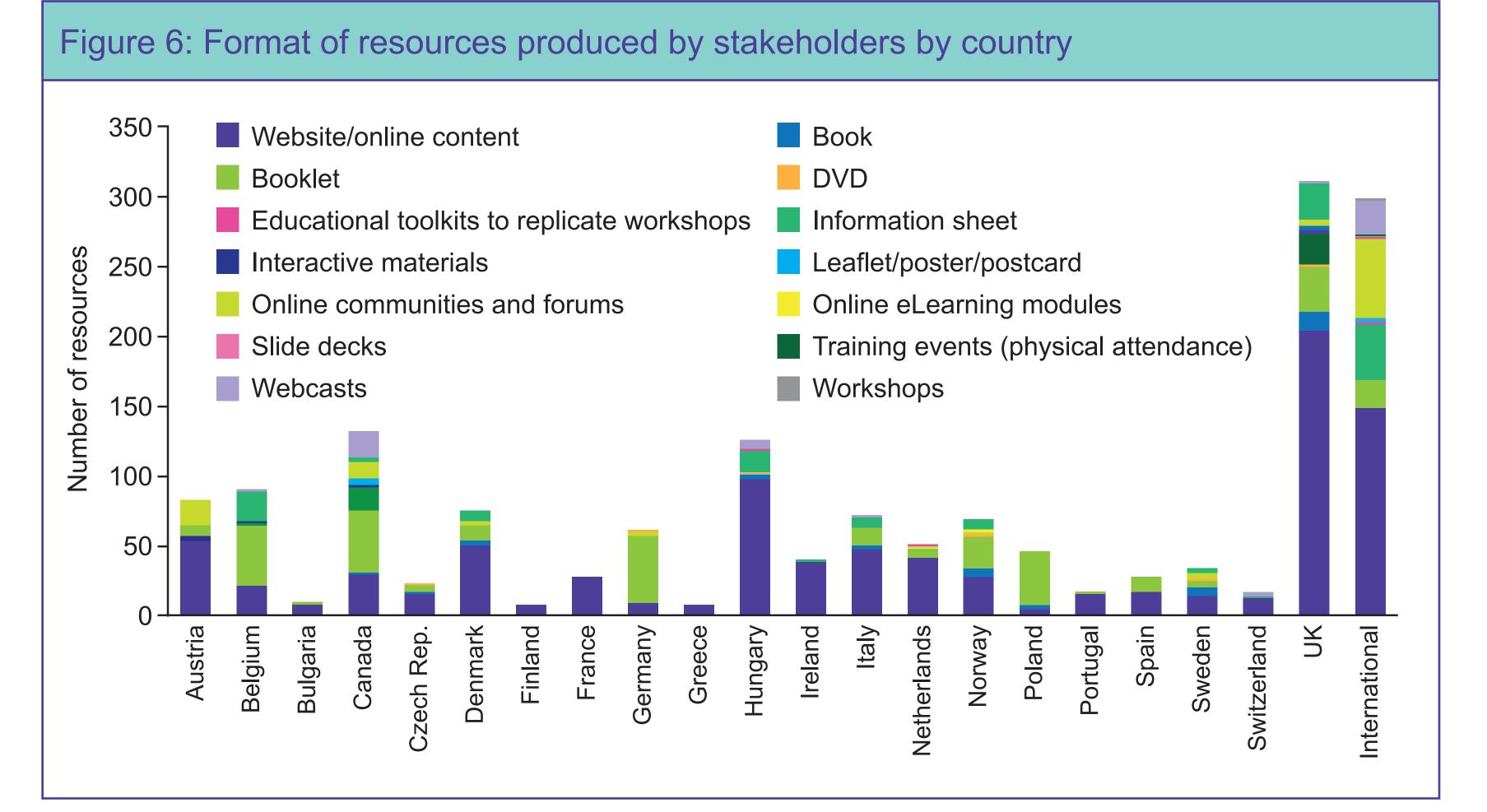
- The majority of resources offered by pharmaceutical companies were treatment-based. Only 5% of all resources focused on improving communication and interaction with HCPs
- For the least frequent themes, resources were analysed according to stakeholder.
- It was found that MS organisations produced the majority of resources focused on effective patient-physician communication, how to avoid misinformation, and MS stages (Figure 5).

Resource dissemination

- Websites and online content were the most common formats, followed by booklets/leaflets (Figure 6).
- When looking at resource format breakdown by country, website content was most common for the UK and Italy whereas booklets and leaflets were more common for Germany.







CONCLUSIONS

- This research demonstrated that there is a large offering of educational materials for PwMS but the type and number of materials varies between countries.
- Most materials were accessed through patient associations, although pharmaceutical companies also contributed.
- There was a good offering of general information about MS for PwMS, but information on specific topics, including education around communication with healthcare providers, was lacking across all countries mapped.
- There is a lack of guidance for specific stages of disease, particularly disease progression and later stages of MS.
- Few articles focused on patient and HCP perspectives, with no articles identified on joint educational programmes focused on improving interaction in a consultation setting.
- This study analysed resources in a snapshot of time and resource quality was not assessed. It may also be possible that smaller organisations, without an online presence, may not have been captured.
- These findings reinforce MS in the 21st Century's survey data that more educational resources are needed. The group will use this information to tailor materials and programmes to address the identified needs and to create tools to increase the quality of interaction between physicians and patients.

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MS IN THE 21ST CENTURY MEMBERS

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DISCLOSURES

Peter Rieckmann receives honoraria for lectures from: Almirall, Apple Healthcare, Baxter, Bayer, Biogen Idec, Boehringer-Ingelheim, Cerner, Daiichi Sankyo, Genpharm, Genzyme, Medtronic, Merck Serono, Novartis, Pfizer, Roche, Sanofi-Aventis, Siemens AG and Teva. He receives research grants from: Bayer, EMD Serono, Novartis, Teva, MS Society of Canada, Canadian Institute of Health Research, Hertie Foundation, Oberfranken-Stiftung and German Neurology Foundation. He is on an advisory board or steering committee for: Abbvie, Bayer, Biogen Idec, Novartis, Merck Serono, Teva, German Multiple Sclerosis Society and Canada Drug Review. Elisabetta Verdun Di Cantogno is an employee of Merck KGaA.