Poster number IS05

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.

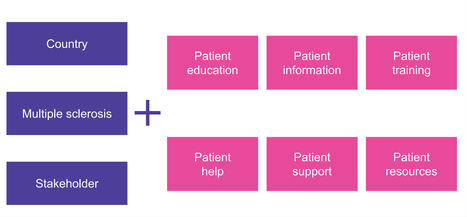
OBJECTIVE

- 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).

Figure 1: Mapping parameters



- 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).

Table 1: Classification of resource therapy topics, overarching themes and format

Therapy topics		
General guide to MS	Diet	Functional electrical stimulation (FES)
Guide for the newly diagnosed	Exercises/physical activity	Other treatments
Guide for children	Posture	Specific MS guides
Guide for teens/young adults	Pregnancy/family planning with MS	Rehabilitation event
Mobility/falls	Travelling with MS	Patient support
Bladder/bowel problems	Primary progressive MS	Information/support for carers and family
Spasticity/spasms	Secondary progressive MS	Talking to children/teens about MS
Cognition	Relapsing remitting MS	Legal/employment rights, working/studying with MS
Fatigue	Clinically isolated syndrome (CIS)	Dealing with your consultation
Mood/depression	Physiotherapy	Patient and healthcare professional (HCP) disease management care plan
Pain/sleep problems	Self-management	Other sources of information/support
Sexual health and MS	Disease-modifying treatments	Consultation checklists
General lifestyle advice	Scientific information	How to avoid misinformation

Overarching themes				
General guides	Invisible symptoms	MS stages	Information for families	Communication and interaction with HCPs
Physical symptoms	Lifestyle	Treatment	Social/legal information	How to avoid misinformation

Resource format			
Information sheet	DVD/videos	Training events (physical attendance)	Educational toolkits to replicate workshops
Leaflet/poster/postcard	Webcasts	Online communities and forums	Website/online content
Booklet	Slide decks	Interactive resources	Digital tools (e.g apps)
Book	Workshops	Online eLearning modules	Other

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).

Figure 2: Combined distribution of available online resources by country

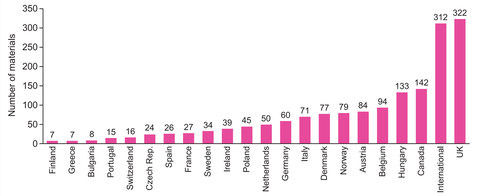
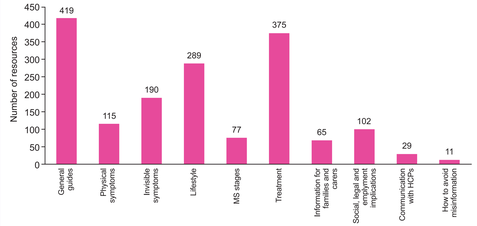


Figure 3: Online resources categorised by theme



- Less frequently identified (6% of all materials) were materials which dealt with effective communication with HCPs and MS stages (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 (Figure 4).
- 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.

Figure 4: Online resources, for pharmaceutical companies only, categorised by theme

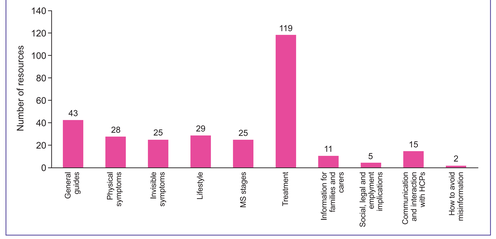


Figure 5: Lowest reported resource themes by stakeholder

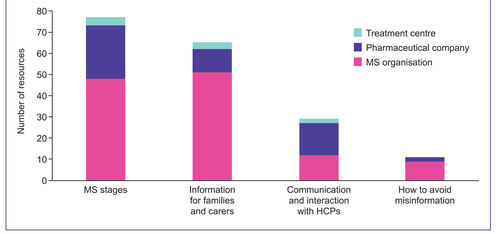
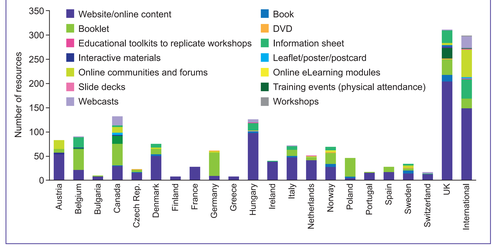


Figure 6: Format of resources produced by stakeholders by country



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.

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