

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

Short title for conference app (max 45 characters): **Mapping family-orientated online MS resources**

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## **Background:**

The MS in the 21<sup>st</sup> Century initiative is composed of a steering group of international healthcare professionals (HCPs) and people with MS (PwMS). The group's focus is to improve the education of, and communication between, HCPs and PwMS, with a view to ultimately supporting more effective shared decision-making and improving patient engagement and outcomes.

## **Objective:**

To report 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:**

Eleven keyword terms were developed searched in 50 different countries using country-specific Google URLs. For each country, all searches were performed both in English and any official national languages. Front-page results only were recorded and then categorised by provider, language, format, topic and aim.

## **Results:**

Of the 11,110 possible search results returned, only 66.4% (7,378) were deemed relevant to families of PwMS. These results comprised 1,189 individual educational resources, with the most common appearing 155 times. On average, each resource appeared 6.2 times (median of 2). Resources came from 747 different providers with on average 9.8 results per provider. The three most identified providers were National MS Society (US) (518), MS Trust (UK) (497), and WebMD (430), the top 10 providers made up 38.8% of all search results. Of the individual educational resources identified, 41.3% were on the topic of 'pregnancy and family planning' with the next most common topic being 'general information on MS for families' (22.5%).

## **Conclusion:**

This mapping has shown 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.

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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 Canbex 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 21<sup>st</sup> Century steering group members**

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