

A mapping study to compare the educational offerings for patients in the fields of multiple sclerosis and HIV in Europe and Canada

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Background: The MS in the 21st Century initiative, formed in 2011 and led by a Steering Group (SG) of international multiple sclerosis (MS) specialists and patient advocates, focusses on developing programmes to improve the education of and communication between healthcare professionals (HCPs) and people with MS (PwMS). In 2016, the SG conducted a mapping exercise to capture the existing educational offerings for PwMS in Europe and Canada, which indicated patient resources varied by topic, format and country.

Objective: Phase 2 was designed to compare the number and type of patient resources in the field of MS to similar offerings for patients in the field of HIV, which the SG identified as a comparator chronic disease.

Method: The Phase 1 methodology was repeated for Phase 2. Research was conducted across multiple stakeholders including patient associations, pharmaceutical companies and public healthcare/government services. Resources were categorised by topic and format including, websites, information sheets and social media.

Results: 673 stakeholders were mapped in 21 countries resulting in the identification of 6,249 resources for HIV; compared to 5,342 resources identified in Phase 1 for MS. Resource formats identified were similar for both diseases: websites were the most common for both; HIV (77.5%), MS (72.8%). The most frequently identified topics for both HIV and MS included general disease information (treatment information, general guides and lifestyle advice), accounting for 60.8% and 68.9% of resources, respectively. More resources dealt with effective patient–HCP communication for HIV (3.7%) compared to MS (2.5%). The origin of the patient information was similar for both: the majority of resources were provided by patient associations/advocacy groups (HIV 59.1% and MS 60.2%).

Conclusion: There is a large offering of patient educational resources for HIV in Europe and Canada and when compared with the field of MS, suggests PwMS may be underserved.

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