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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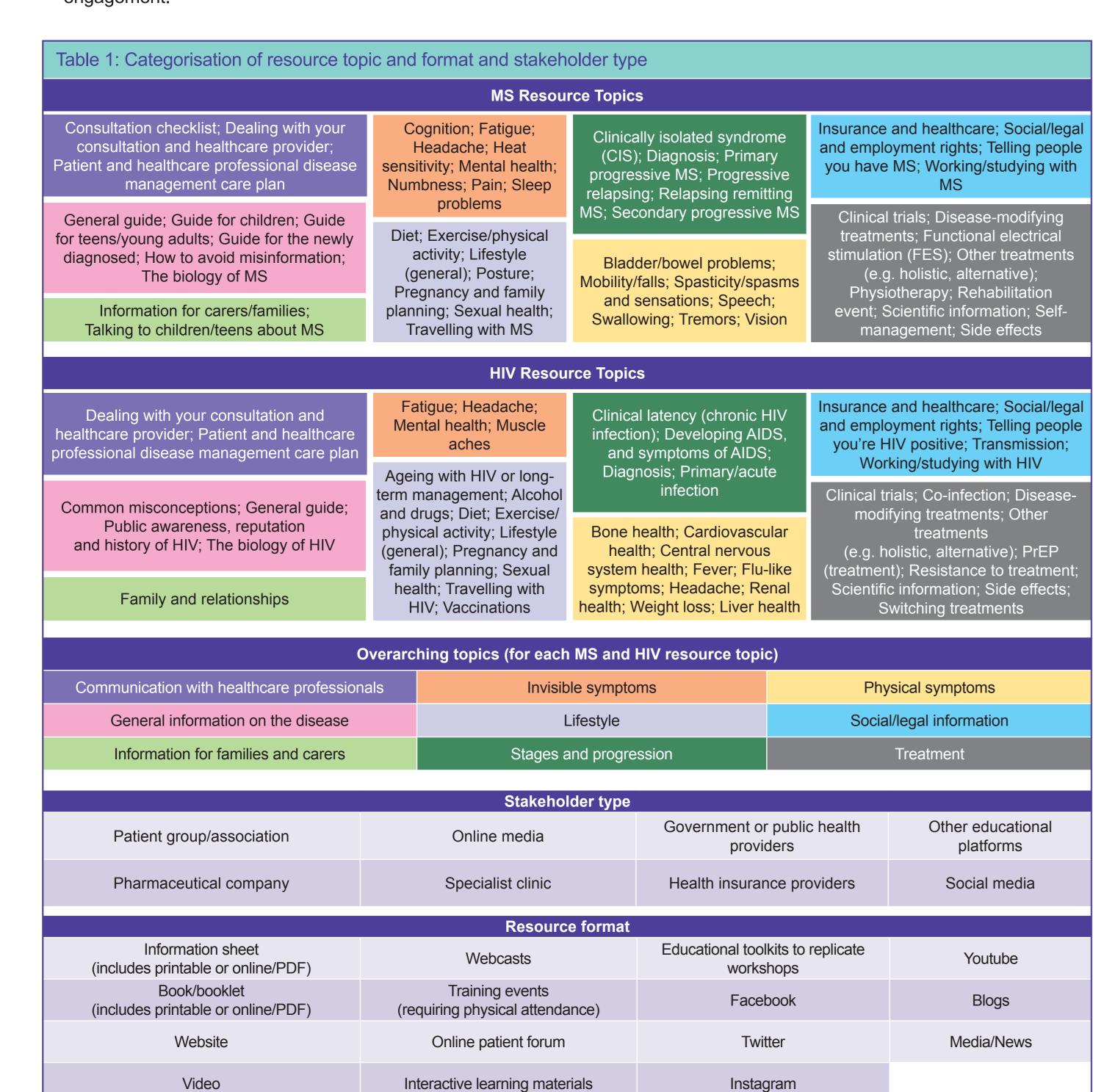
Introduction

- The MS in the 21st Century initiative, formed in 2011, is composed of a Steering Group of international multiple sclerosis (MS) specialists and people with MS (PwMS). The initiative's current focus is to improve education of, and communication between, HCPs and PwMS.
- In 2016, MS in the 21st Century conducted a mapping exercise to capture the existing educational offerings for PwMS in Europe and Canada (Phase 1). This Phase 1 study showed that resources were provided by a broad range of stakeholder types with some topics more represented than others.
- The aim of Phase 1 was to determine whether there was a deficit in the existing educational offerings for MS. In order to provide a measure of relativity, it was necessary to compare the resources available for MS to the educational resources of another comparable chronic condition (Phase 2).
- The Steering Group selected human immunodeficiency virus (HIV) as the comparator disease because both HIV and MS are incurable immunocompromising diseases with similar age demographics. Both diseases require patients to remain on lifelong treatment regimens with side effects that have the potential to greatly impact on quality of life.

Objectives

- To compare the number, format and topic of patient educational resources, and the stakeholder types from which they arise, in the field of MS to those in HIV.
- To identify areas where the educational offerings for MS may differ, or are lacking when compared with HIV.
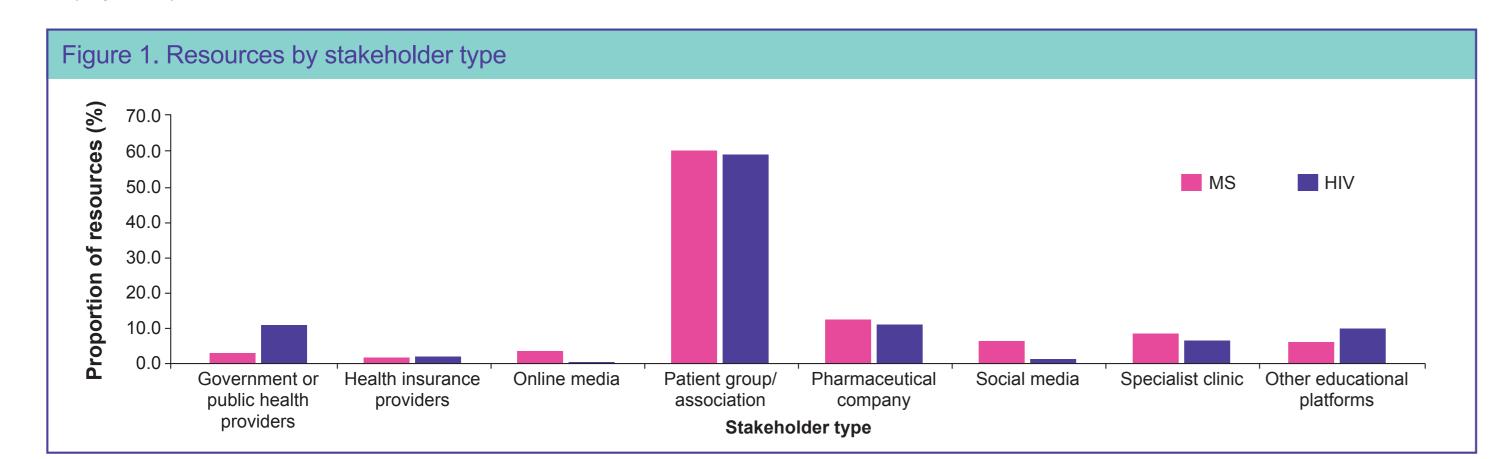
Methods

- Desktop research using country-specific URLs of the Google search engine was designed to obtain results that were as representative as possible of what resources a patient in each country would have access to online. Stakeholders were identified across 20 European countries and Canada by using search terms that were based on a list of stakeholder types, pre-determined by the Steering Group, in combination with the disease name (MS or HIV).
- Stakeholder websites were then explored in full and all relevant pages were recorded as resources in a database and categorised by format, topic, stakeholder type and country (Table 1).
- Resources were categorised into 52 different therapy topics for MS and 46 different therapy topics for HIV. These therapy topics were grouped into 8 overarching topics for analysis (Table 1).
- This research was purely quantitative and at no point were the resources or stakeholders assessed in terms of quality or level of engagement.

Table 1: Categorisation of resource topic and format and stakeholder type

MS Resource Topics			
Consultation checklist; Dealing with your consultation and healthcare provider; Patient and healthcare professional disease management care plan	Cognition; Fatigue; Headache; Heat sensitivity; Mental health; Numbness, Pain; Sleep problems	Clinically isolated syndrome (CIS); Diagnosis; Primary progressive MS; Progressive relapsing; Relapsing remitting MS; Secondary progressive MS	Insurance and healthcare; Social/legal and employment rights; Telling people you have MS; Working/studying with MS
General guide; Guide for children; Guide for teens/young adults; Guide for the newly diagnosed; How to avoid misinformation; The biology of MS	Diet; Exercise/physical activity; Lifestyle (general); Posture; Pregnancy and family planning; Sexual health; Travelling with MS	Bladder/bowel problems; Mobility/falls; Spasticity/spasms and sensations; Speech; Swallowing; Tremors; Vision	Clinical trials; Disease-modifying treatments; Functional electrical stimulation (FES); Other treatments (e.g. holistic, alternative); Physiotherapy; Rehabilitation event; Scientific information; Self-management; Side effects
Information for carers/families; Talking to children/teens about MS			

HIV Resource Topics			
Dealing with your consultation and healthcare provider; Patient and healthcare professional disease management care plan	Fatigue; Headache; Mental health; Muscle aches	Clinical latency (chronic HIV infection); Developing AIDS, and symptoms of AIDS; Diagnosis; Primary/acute infection	Insurance and healthcare; Social/legal and employment rights; Telling people you're HIV positive; Transmission; Working/studying with HIV
Common misconceptions; General guide; Public awareness, reputation and history of HIV; The biology of HIV	Ageing with HIV or long-term management; Alcohol and drugs; Diet; Exercise/physical activity; Lifestyle (general); Pregnancy and family planning; Sexual health; Travelling with HIV; Vaccinations	Bone health; Cardiovascular health; Central nervous system health; Fever; Flu-like symptoms; Headache; Renal health; Weight loss; Liver health	Clinical trials; Co-infection; Disease-modifying treatments; Other treatments (e.g. holistic, alternative); PrEP (treatment); Resistance to treatment; Scientific information; Side effects; Switching treatments
Family and relationships			

Overarching topics (for each MS and HIV resource topic)		
Communication with healthcare professionals	Invisible symptoms	Physical symptoms
General information on the disease	Lifestyle	Social/legal information
Information for families and carers	Stages and progression	Treatment

Stakeholder type			
Patient group/association	Online media	Government or public health providers	Other educational platforms
Pharmaceutical company	Specialist clinic	Health insurance providers	Social media

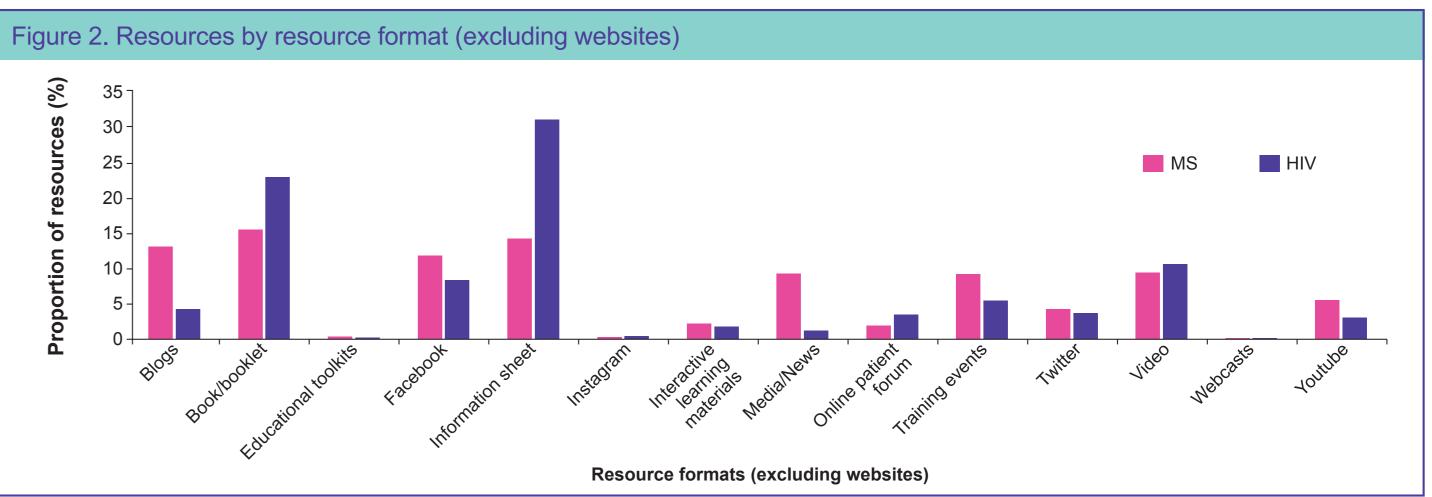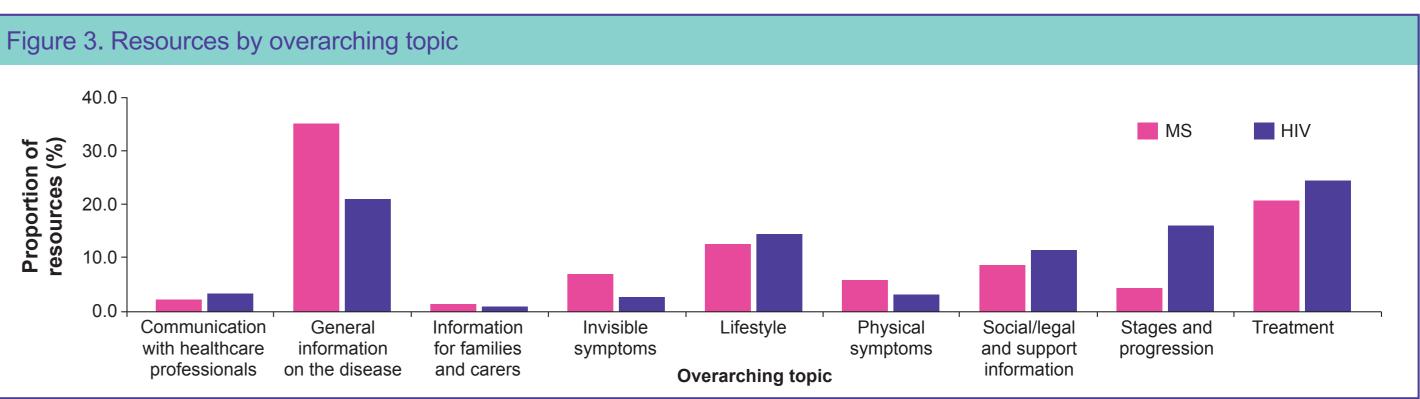| Resource format			
Information sheet (includes printable or online/PDF)	Webcasts	Educational toolkits to replicate workshops	Youtube
Book/booklet (includes printable or online/PDF)	Training events (requiring physical attendance)	Facebook	Blogs
Website	Online patient forum	Twitter	Media/News
Video	Interactive learning materials	Instagram	

Results

- A total of 373 stakeholders were mapped for HIV, resulting in the identification of 6,249 resources; compared to 5,342 resources from 673 stakeholders identified for MS. The median number of resources per stakeholder was 6 for HIV compared with 2 for MS.
- For both HIV (59.1%, n=3696) and MS (60.2%, n=3217) the majority of resources came from patient associations/advocacy groups (Figure 1).
- Government or public health providers were a greater source of resources for HIV (10.7%, n=668) than MS (2.8%, n=152) (Figure 1).

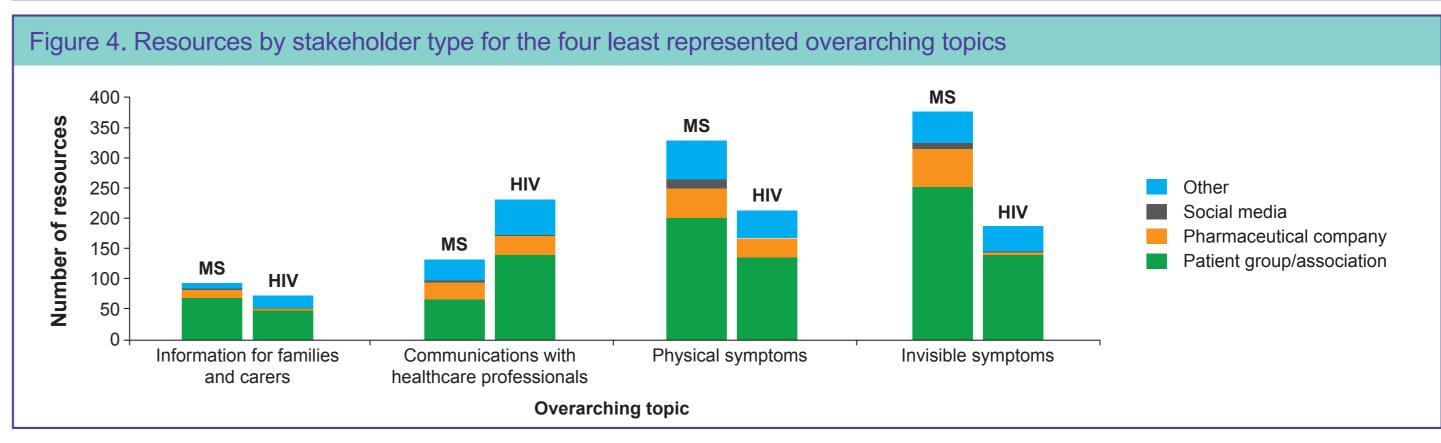Figure 1. Resources by stakeholder type

- Websites were the most common resource format for both HIV (77.5%, n=4845) and MS (72.8%, n=3887). Additional analysis of resource formats has excluded websites in order to better visualise fine scale differences between the other formats.
- A higher proportion of resources for MS came from social media stakeholders than for HIV (6.2%, n=329 and 1.3%, n=80, respectively) (Figure 1). The same trend was found across multiple social media formats including Facebook (11.8%, n=172 MS; 8.4%, n=118 HIV), YouTube (5.6%, n=82 MS; 3.1%, n=44 HIV), Twitter (4.3%, n=63 MS; 3.8%, n=53 HIV) and blogs (13.1%, n=190 MS; 4.3%, n=60 HIV) (Figure 2).

- More resources for HIV than MS came in the format of downloadable information sheets (31.1%, n=436 HIV; 14.3%, n=208 MS) and booklets (22.9%, n=322 HIV; 15.5%, n=226 MS) (Figure 2).
- The most frequent overarching resource topic for MS was general information (35.1%, n=1876) followed by treatment (21.0%, n=1120). For HIV, the most frequent topic was treatment (24.8%, n=1547) followed by general information (21.3%, n=1330) (Figure 3).
- The four least represented topics across the two fields were information for families and carers (1.8%, n=94 MS; 1.2%, n=73 HIV), communication with healthcare professionals (2.5%, n=131 MS; 3.7%, n=232 HIV), physical symptoms (6.1%, n=328 MS; 3.4%, n=214 HIV), and invisible symptoms (7.0%, n=375 MS; 3.0%, n=188 HIV) (Figures 3 and 4).

Figure 2. Resources by resource format (excluding websites)

Figure 3. Resources by overarching topic

Figure 4. Resources by stakeholder type for the four least represented overarching topics

- There were more resources for HIV compared with MS for a number of the overarching topics, most notably: disease stages and progression (17.2%, n=1073 HIV; 4.7%, n=253 MS), lifestyle (14.7%, n=918 HIV; 12.8%, n=686 MS), social/legal information (11.6%, n=725 HIV; 9.0%, n=479 MS), and effective patient-HCP communication (3.7%, n=232 HIV; 2.5%, n=131 MS) (Figure 3).
- A higher proportion of resources for MS covered invisible symptoms, including mental health issues (7.0%, n=375) compared with HIV (3.0%, n=188) (Figure 3). A higher proportion of these resources for MS came from pharmaceutical companies (16.5%, n=62 compared to 2.1%, n=4 for HIV) (Figure 4).
- Within the overarching theme of treatment, there were more MS resources on 'other treatments', including holistic and alternative therapies (11.4%, n=128) than in HIV (5.2%, n=81). There were many more resources covering the side-effects of HIV treatments (14.2%, n=219) than MS treatments (1.2%, n=13) (Figure not shown).

Discussion

- The inferences that can be drawn from the data are limited due to the purely quantitative nature of the study. No assumptions were made about the quality of, or engagement with, the resources and only direct comparisons between the relative proportions of resources available have been conducted.
- A lack of public awareness around MS may be one factor in explaining why a larger proportion of its resources come from social media sources than for HIV. PwMS may feel more comfortable talking about their disease openly in public without fear of any existing stigma and might also feel that it is their responsibility to raise the level of public awareness, making them more vocal sources of information than in HIV.
- In addition, MS symptoms can affect PwMS's ability to spend large amounts of time outside the home, potentially resulting in a greater reliance on the internet for social interactions.
- A high level of public awareness about HIV since the 1980's might have translated into a larger amount of high quality printable resources from centralised organisations (government or public health providers) and less emphasis on grassroots awareness relative to MS. This could also explain the larger number of resources per stakeholder seen in HIV as opposed to the more diffuse educational landscape for MS.
- The MS educational landscape offers fewer resources on social/legal information, which covers topics such as employment rights, compared to HIV. This is a potential gap in the educational landscape of MS, considering that MS symptoms can have a significant impact on PwMS in the workplace.
- Considering the traditional marginalisation of such issues, the higher number of resources covering the invisible compared to physical symptoms of MS (including mental health issues) is a positive discovery.
- The higher number of alternative treatment resources in MS potentially represents a greater amount of misinformation about the disease. This may be due to the more diffuse educational landscape compared to HIV.

Conclusions

- These Phase 2 data showed that the educational resources for both MS and HIV come from a number of different sources and cover a wide variety of topics. While there were many similarities between the educational offerings of the two diseases, there were also many differences.
- It is clear that patients are turning, more frequently, to the internet for information about their health[1]. Therefore, it is essential to ensure that the resources they are accessing online are relevant and accurate and that their HCPs are able to guide them to these resources.
- This study may be expanded on by surveying PwMS about how they access and interact with online resources.

References

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Acknowledgements and disclosures

MS in the 21st Century Steering Group members