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# Using IMPrESS to guide policy change in Multiple Sclerosis

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on behalf of the IMPrESS team (P. Kanavos, principal investigator)

# Background

- Multiple-sclerosis (MS) is the most common cause of disability among central-nervous-system (CNS) diseases.
- It can cause impairment in various areas of an **individual's life** and their **caregivers'/family**, and **society...**
  - Diagnosis is most prevalent in young adults and impacts the rest of their lives, and of their family/friends, and thus society
  - MS can impact on family roles, employment, health-related-quality-of-life (HRQoL) and daily functioning
- ... That translate into **enormous social/economic burden** and **decreased HRQoL**.

# What is missing?

- International evidence to capture
  - The full picture of the multiple domains of MS on patients/caregivers as well as their HRQoL and experience of care
- Experience of patients /caregivers/clinicians
  - Early diagnosis
  - When shifting to early diagnosis and treatment with new (oral) disease modifying drugs
- Identification of the criteria driving value assessments in MS medicines by analysing the health technology assessment (HTA) decisions

# IMPrESS Objectives

Online surveys with PWMS, their caregivers and clinicians as well as secondary data from the literature and health-technology-assessment (HTA)

- To estimate the socioeconomic burden and health related QOL in individuals with MS.
- To explore the impact that a paradigm shift in the management of MS
  - could have on health outcomes and resource utilisation.
- To compare individual with MS and clinician experiences of MS-management
  - to identify whether their views on MS-management are aligned
  - to explore the factors which influence these views.
- To identify the criteria driving value assessments in MS medicines by analysing the health technology assessment (HTA) decisions.

**The focus of the presentation is on PWMS and carer data from the IMPrESS surveys**

# The IMPrESS

The screenshot shows the LSE Health and Social Care website. The top navigation bar includes links for Main, Staff & students, Library, Departments & institutes, Research centres, and Apps. Below this is a search bar and a secondary navigation bar with links for Home, About us, Research, Who's who, Outputs, Impacts, Events, Teaching, and Blog. The main content area features a sidebar with a menu and a main article titled "Towards better outcomes in multiple sclerosis by addressing policy change: The International MultiPIE Sclerosis Study - IMPrESS". The article text discusses research led by Prof Kanavos on the impact of MS on health and wellbeing, and lists authors: Panos Kanavos, Michela Tinelli, Olena Efthymiadou, Erica Visintin, Federico Grimaocia, and Jean Mossman. A "Read the report" link is provided. Social sharing icons for Facebook, Twitter, and LinkedIn are visible at the bottom of the article.

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## Towards better outcomes in multiple sclerosis by addressing policy change: The International MultiPIE Sclerosis Study - IMPrESS

New research led by Prof Kanavos studied the significant impact of MS on the health and wellbeing of both people with the disease, and their caregivers, along with its broader socio-economic impact. Results confirmed that there is an urgent need to achieve better outcomes for people with MS and the evidence suggests that this is possible if policy makers address three key issues: Improve the quality of care and health outcomes for every person with MS; Generate further robust evidence to inform decision making; Increase the responsiveness of health care systems to new evidence on MS.

Authors: Panos Kanavos (the principal investigator), Michela Tinelli, Olena Efthymiadou, Erica Visintin, Federico Grimaocia and Jean Mossman

Read the [report](#).

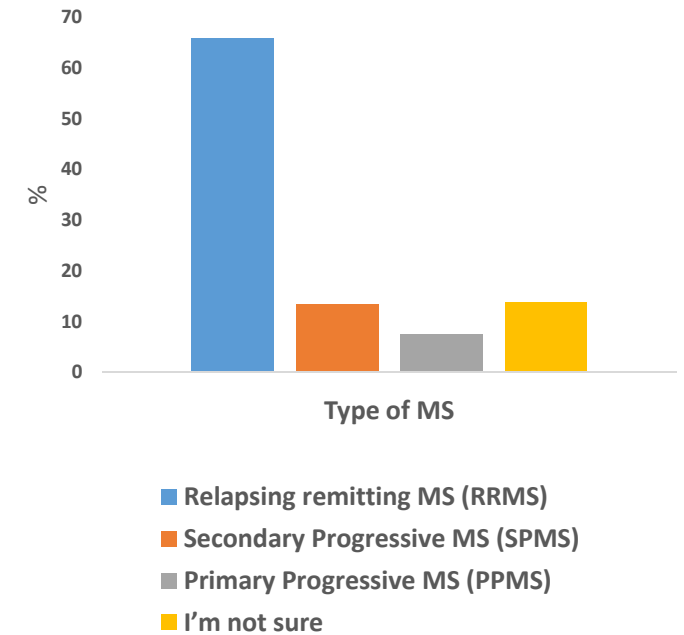
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This presentation reports on the final data (data collection closed December 2016)

# Responses

Patients with MS - Responses received from 1152 individuals, completed used for analysis 856 (21 countries)

Carers - Responses received from 265 individuals, completed used for analysis 144 (21 countries)



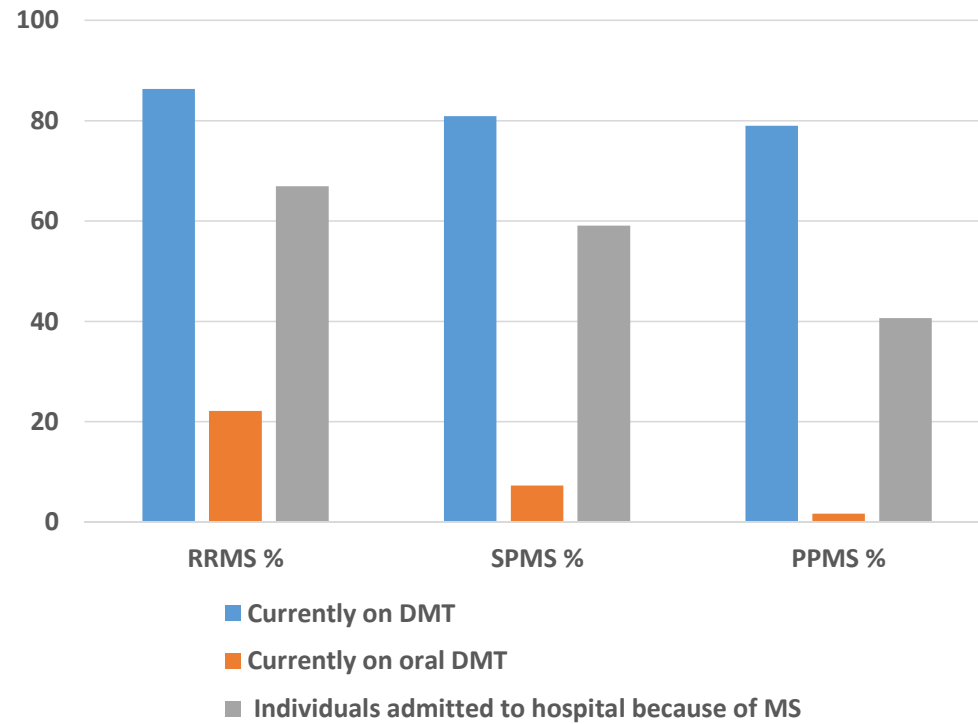
The majority of responses:



BMJ

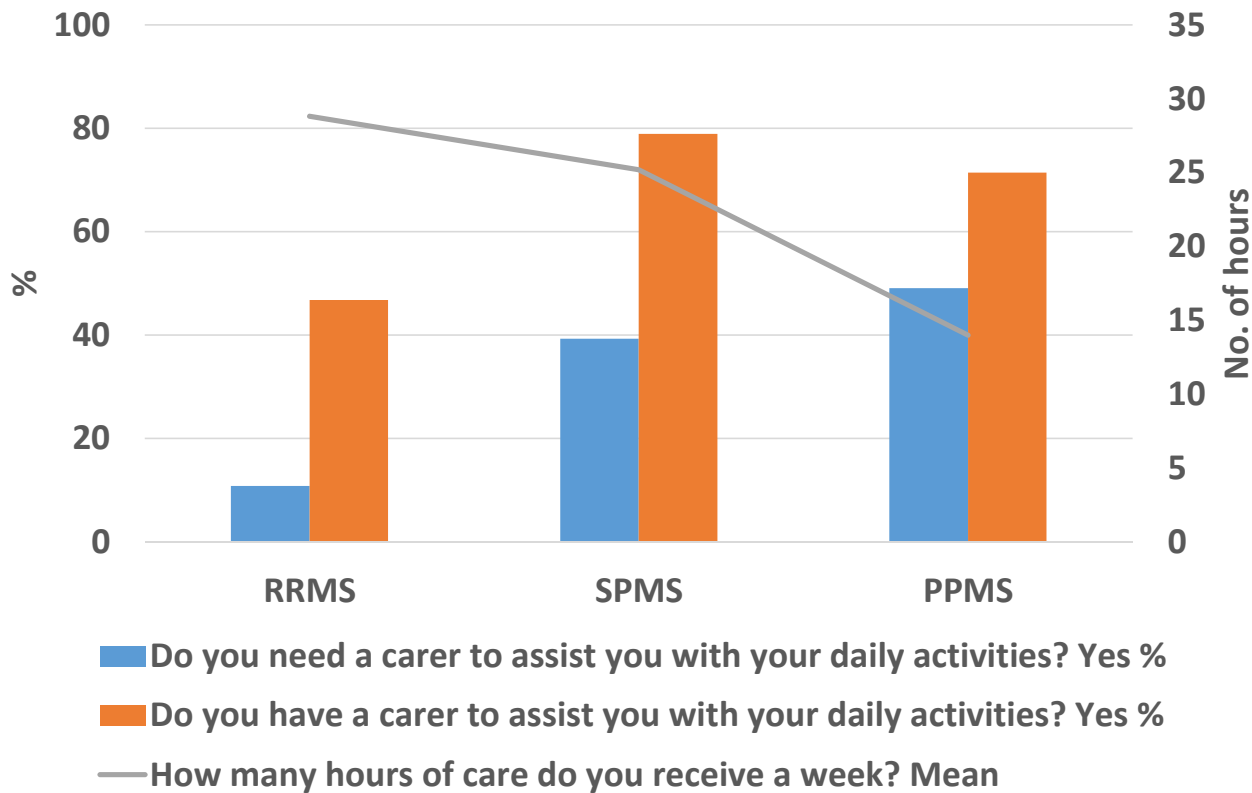
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# PWMS - Access to medicines and hospitalisation



Patients treated earlier\* showed a trend towards: being on oral DMT; reporting less admissions to hospital

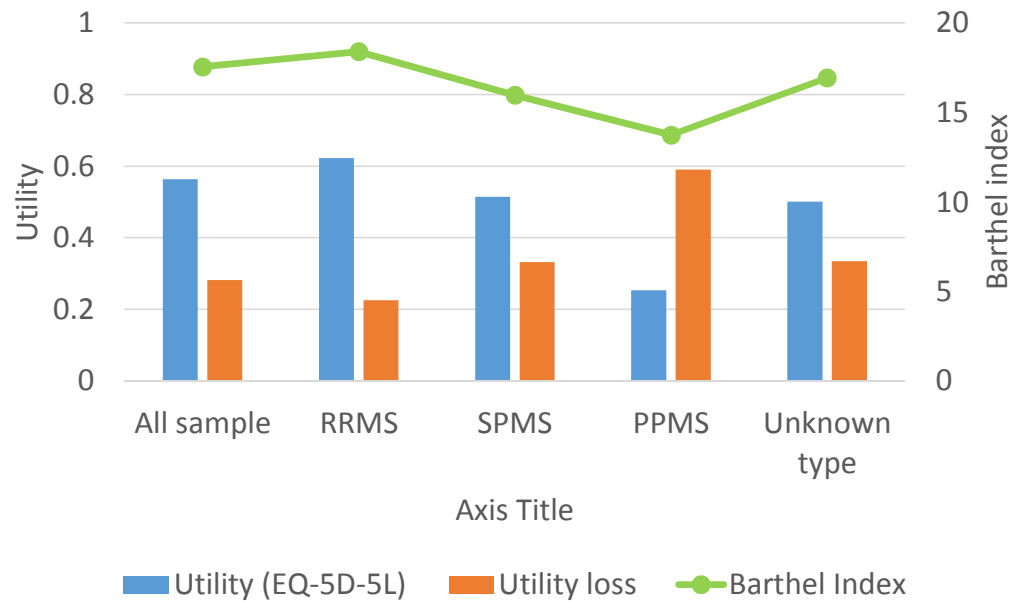
# PWMS - Access to informal care



Patients treated earlier\* showed no change in access to informal care

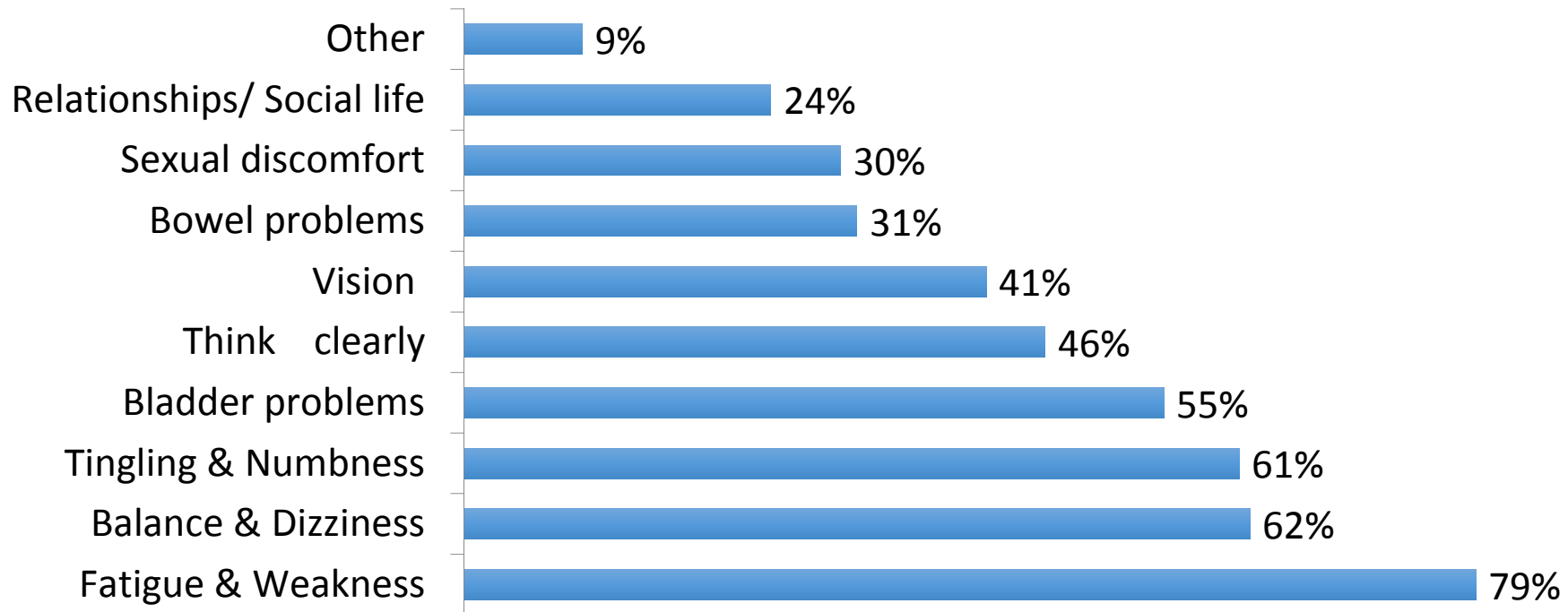


# PWMS - Quality of life



Patients treated earlier in the course of the disease showed a trend towards: higher EQ5D utility score

## PWMS - Most commonly QoL aspects, not captured by the EQ-5D



# PWMS - Experience of MS

- 80% had experience of MS treatment with DMTs from the start of their treatment;
- 38% were currently receiving DMTs
- 30% of whom receiving DMTs were currently on oral
- The preferred source of information for PWMS were the internet (79% MS-specific sites) and clinicians 64%
- 67% wanted to be actively involved in the process

## Caregiver - costs, quality of life, and how they feel (compared with PWMS)

	Carers	Individuals with MS
<b>Total annual indirect costs, mean (sd) *</b>	<b>€31,653</b> (33,475)	<b>€16,318</b> (4910)
<b>EQ5D utility , mean (sd)</b>	<b>0.73</b> (0.20)	<b>0.59</b> (0.28)
<b>How they feel/level of disability</b>	The majority of the caregivers felt no or mild burden because of their status as caregiver (Zarit score=5.98)	The majority of PWMS reported low levels of disability (Barthel index=16.95)

\*subsets of countries: UK, France, Germany, USA

## Future management of people with MS: achieving better outcomes for PWMS

- Improve the quality of care and health outcomes for every person with MS: Diagnosis, treatment and management goals should be set to provide the best health outcome for every person with MS
- (Further) robust evidence should be generated and used in order to make appropriate decisions about care management MS strategies
- Increase responsiveness of health care systems to new evidence on MS, and guidelines would avoid inappropriate variations in eligibility for DMT initiation across local settings and strengthen diagnosis, treatment and monitoring.

## What policy change is needed if patients are to get treatment personalised to their needs

- Starting treatment early at the point of clinical diagnosis
- Sharing information with the PWMS and supporting PWMS via their preferred source of information
- Considering personal experiences of MS-management and engagement in their care

# Acknowledgments

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