Health related quality of life aspects not captured by EQ-5D-5L: Results from the IMPRESS (International Multiple Sclerosis) study

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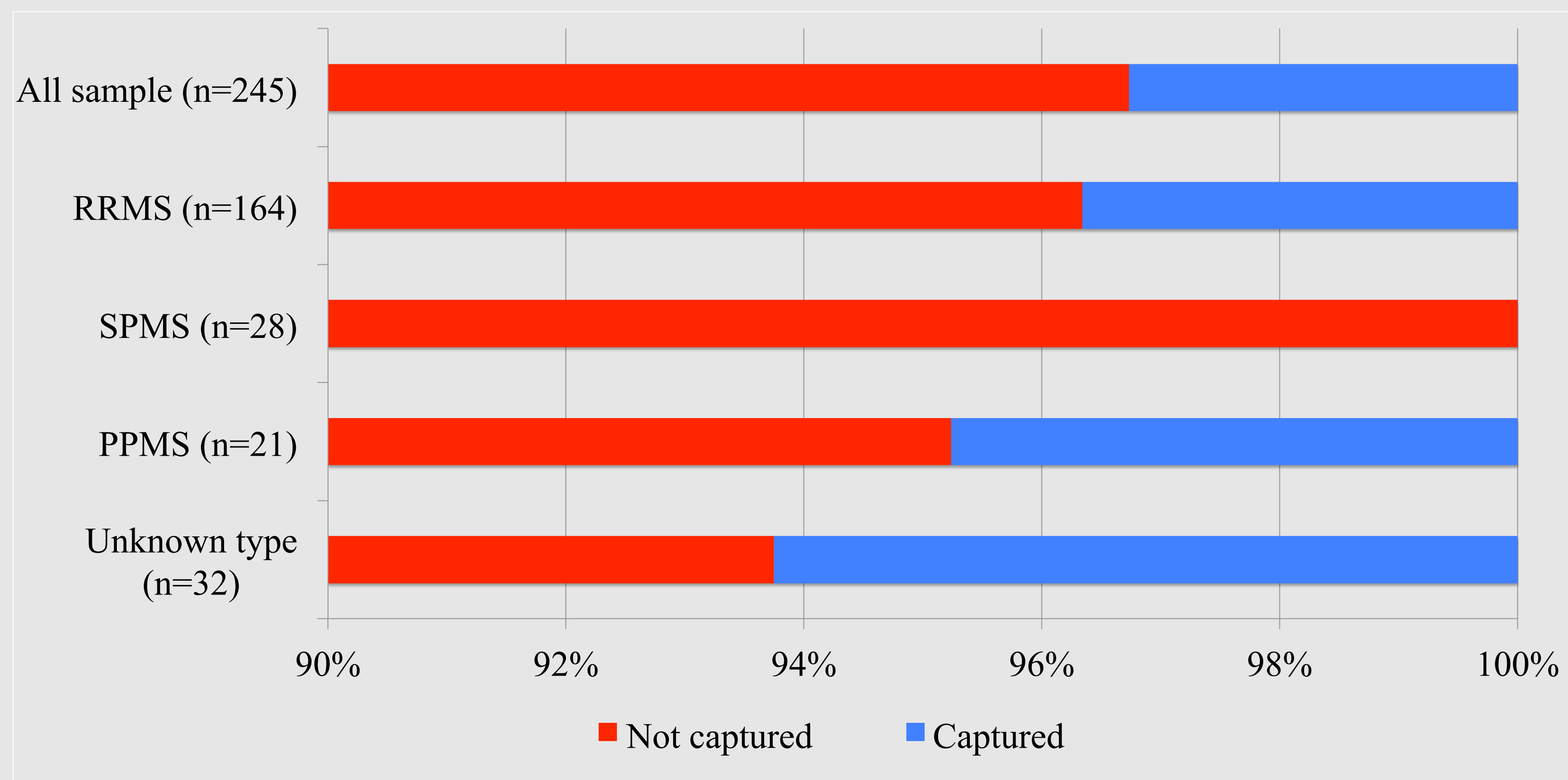1. Medical Technology Research Group, LSE Health, London School of Economics

Background & Objectives

Multiple Sclerosis (MS) is the second most common cause of neurological disability and highest per capita costs among all other neurological disorders [1]. By imposing pre-defined domains on Health Related Quality of Life (HRQoL) measurement EQ-5D-5L is believed to lack dimensions of HRQL that may be impacted by chronic diseases such as MS, including dexterity, social functioning and vitality and therefore, raises questions as to the extent to which it represents the pragmatic Quality of Life (QoL) of patients [2-4] which is shaped by a unique combination of different important aspects for each individual.

❖ This study aimed to assess the extent to which MS patients consider that EQ-5D, a generic HRQoL measurement tool, captures the dimensions that are important to their wellbeing.

Methods

- A web-survey (Qualtrics ®) of non-institutionalised individuals with MS.
- 14 patient associations (at national or supra-national level) were invited to cascade the surveys to their network of patients.
- Survey collected data on i) Demographics, ii)type of MS (i.e. Relapsing Remitting MS – RRMS, Primary Progressive MS – PPMS, Secondary Progressive MS – SPMS, iii)QoL (EuroQoL 5-domain; EQ-5D-5L) and EQ-5D-5L VAS, iv) Other, non EQ-5D domains which impacted greatly on their wellbeing and respondents thought were not captured by the EQ-5D and v) aspects that changed over the course of patients' illness
- Microsoft® Excel 2010 was used to generate descriptive statistics

Figure 1. Proportion of patients across all sample and types of MS reporting aspects not captured by the EQ-5D-5L

Figure 2. Proportion of patients across all sample and types of MS reporting that important QoL aspects changed over the course of their illness
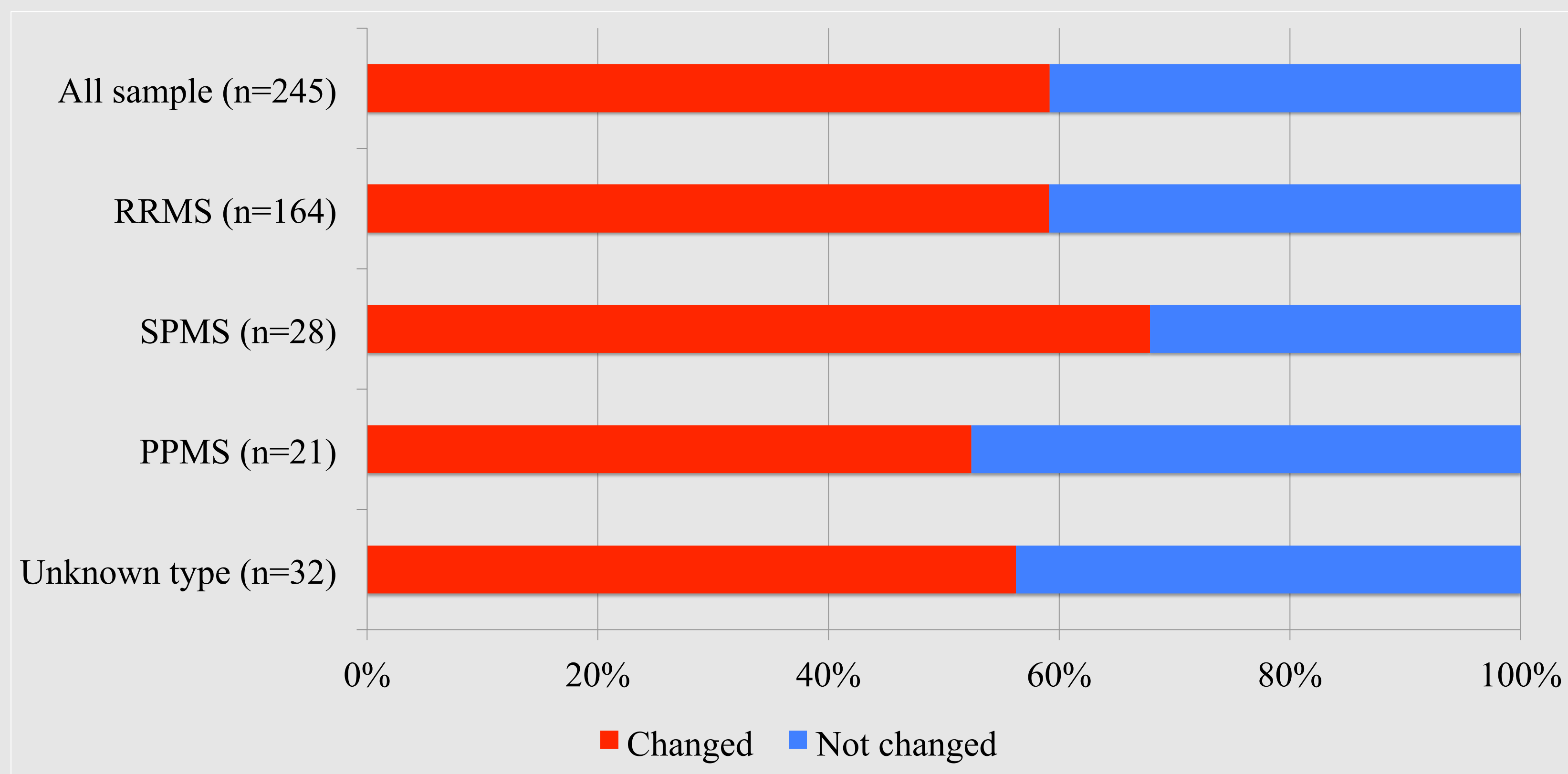
Results

- 246 responses from France (n=97), USA (n=70), Romania (n=44), UK (n=25) and Germany (n=10).
- Average EQ-5D-5L index and VAS scores were 0.60 (±0.12) and 63 (±4.7) respectively and Health State Utility Values (HSUVs) ranged from 0.77 in Germany to 0.49 in France, and from 0.63 for RRMS, 0.51 for SPMS and 0.21 for PPMS patients.

❖ **Important wellbeing aspects not captured by EQ-5D-5L**
- Evaluation of the EQ-5D-5L tool showed that **97% (n=237)** of all patients who responded to the question; "which aspects of their illness had a big impact on their health, that were not captured by the EQ-5D-5L", consider this instrument insufficient in capturing all of the important wellbeing aspects that added a significant burden to their HRQoL and this percentage fluctuated between types of MS amounting up to nearly **100% for SPMS,** 95% for PPMS and just above 96% for RRMS patients (Figure 1).
- Such aspects mainly included **fatigue (79% of respondents)**, **balance & dizziness (62%)**, tingling & numbness (61%) and bladder problems (55%) (Figure 3). Less commonly reported aspects included vision (41%), bowel problems (31%), sexual discomfort (30%) and Maintenance of relationships (24%).
- Fatigue was the most commonly reported aspect not captured by EQ-5D-5L across all disease types. Other items not captured by EQ-5-5L fluctuated between the different types of MS (Figure 4).

❖ **Important wellbeing aspects that changed over the course of patients' illness**
- **57% (n=145)** of all patients who responded consider that the aspects of their illness that have a big impact on their health have changed over the course of their disease and this percentage fluctuated between types of MS (Figure 2).
- **Mobility** and **Usual activities** were the most common EQ-5D-5L items that changed over the course of patients' illness (51% and 43% respectively), whereas **Fatigue** and **Balance/Dizziness** were the most common non- EQ-5D-5L items (48% and 45% respectively) (Figure 5).
- Other less commonly reported aspects that changed included Vision (27%) and Bowel (f22%) problems, along with sexual dysfunction (23%) and maintenance of relationships/social life (19%) (Figure 5).

Figure 3. Most commonly reposted QoL aspects across all sample, which according to the respondents were not captured by the EQ-5D-5L
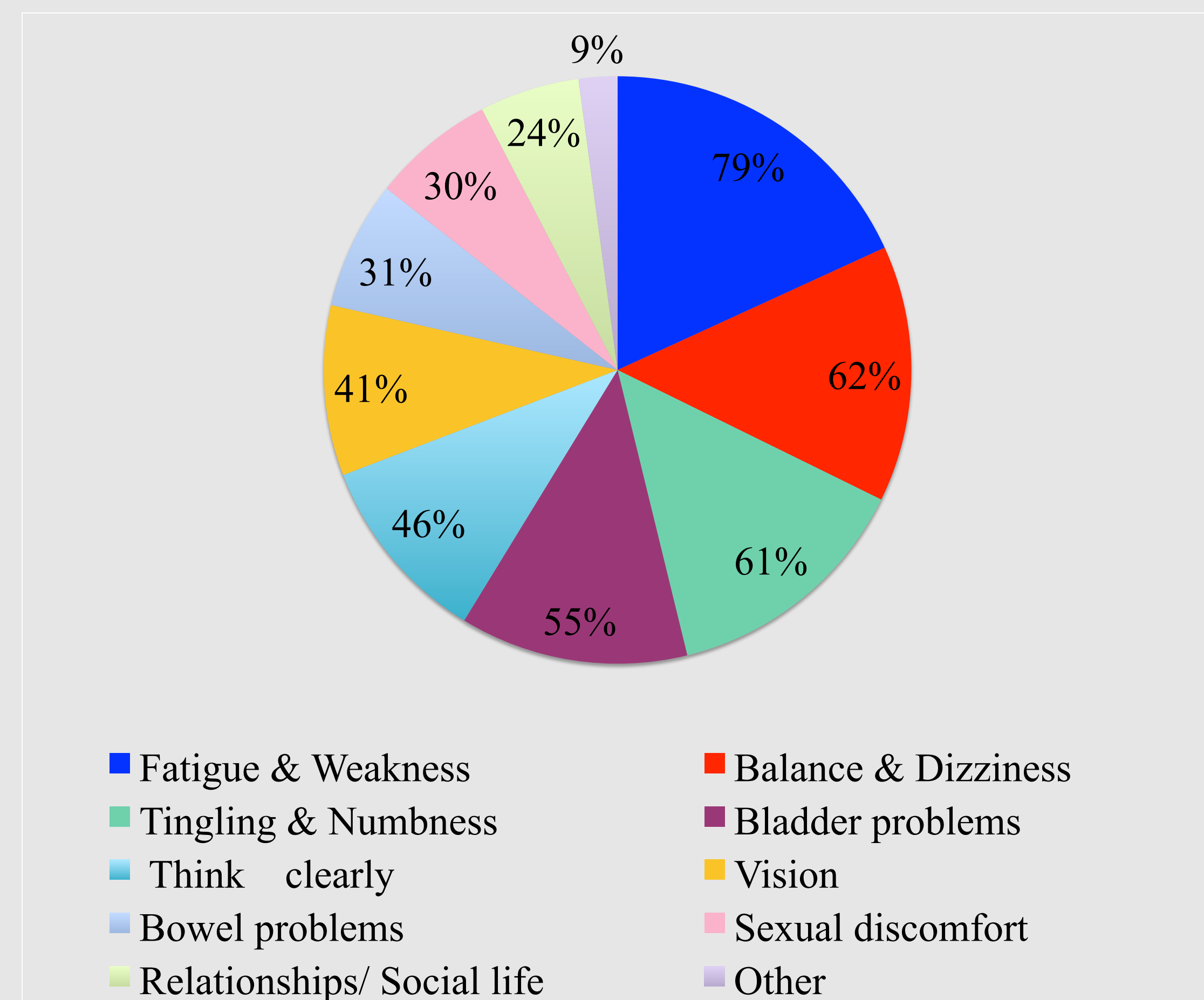
Figure 4. Most commonly reposted QoL aspects across types of MS, which were not captured by the EQ-5D-5L
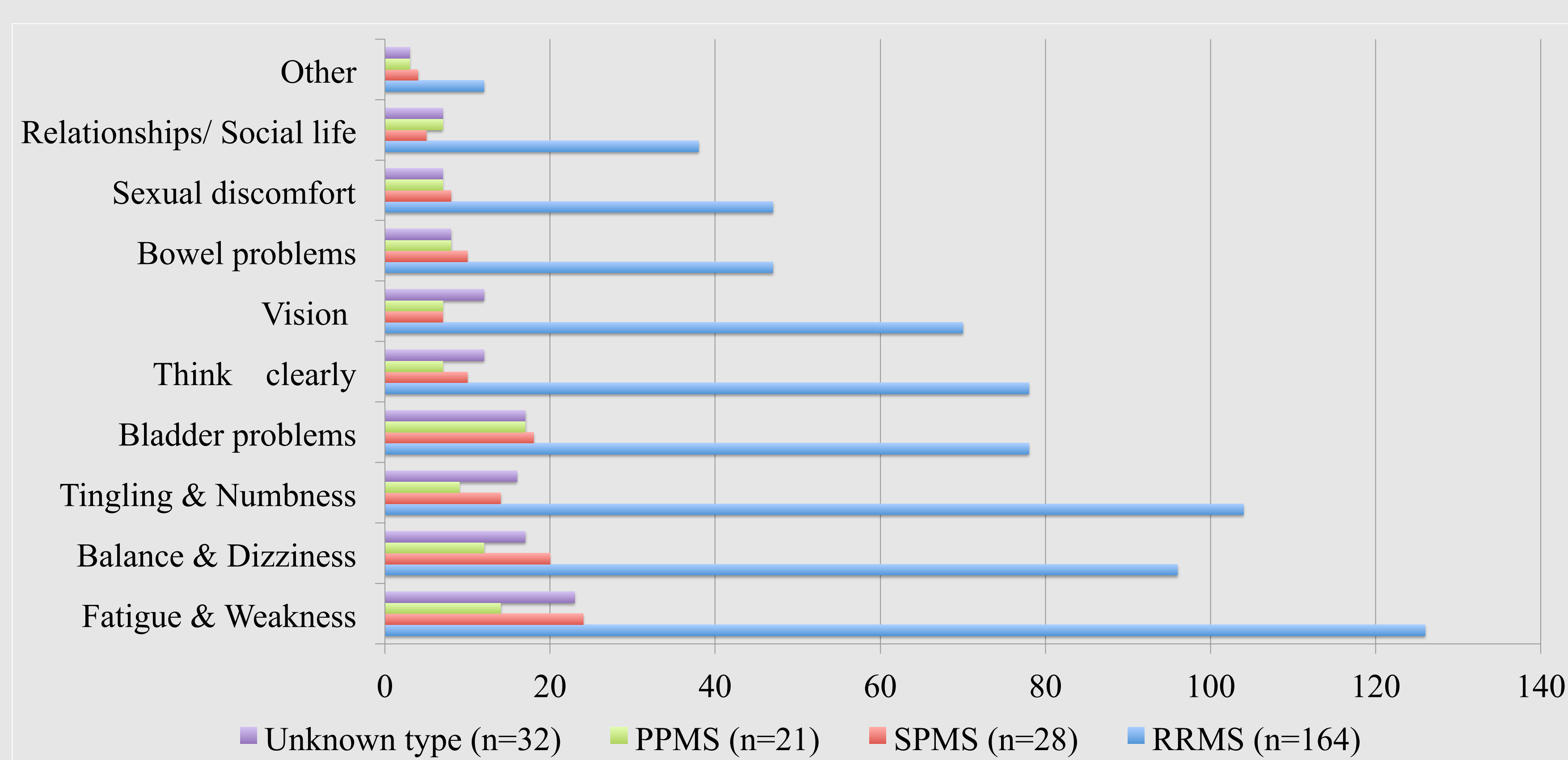
Figure 5.. Most common EQ-5D-5L and non-EQ-5D-5L aspects of patients' illness that had a big impact on their health and that changed over the course of their disease
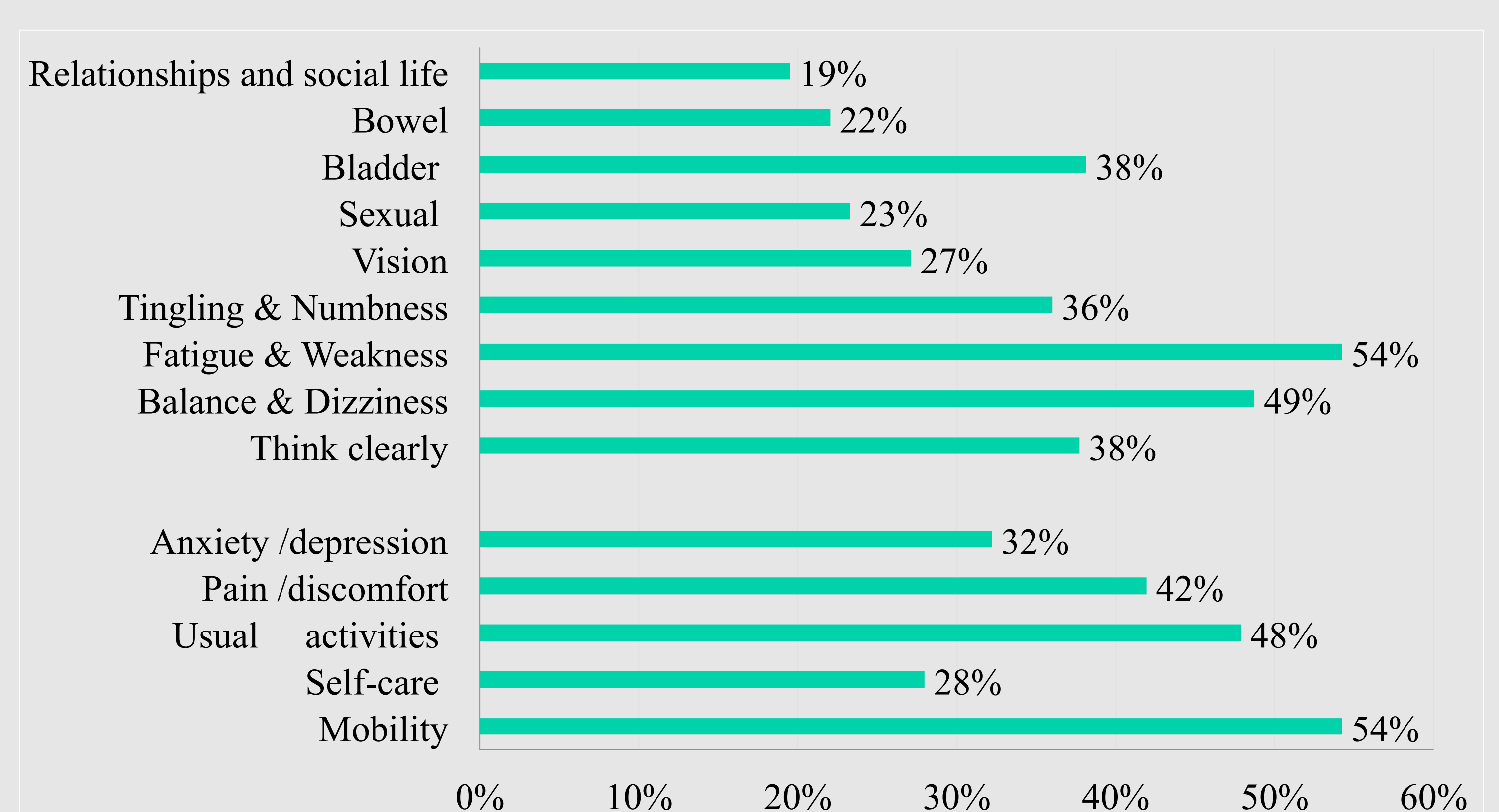
Conclusions & Future directions

Our analysis highlights that utilisation of the EQ-5D-5L in HRQoL measurement might fail to capture key QoL attributes in MS patient populations. However, as our study has limitations (i.e. the use of a web-survey resulted in data unable to be verified by the author and raised issues related to the patients' understanding of the EQ-5D domains and their severity levels) our results should be interpreted with caution.

❖ Further mapping of MS patients' utilities against EQ-5D-5L and other generic HRQoL tools is required in order to ensuret that these instruments capture all QoL aspects important to MS patients.

References

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This research consists part of **"The International MultiPlE Sclerosis Study (IMPrESS)"** which is available online at: http://www.lse.ac.uk/LSEHealthAndSocialCare/research/LSEHealth/MTRG/IMPRESS-Report-March-2016.pdf

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