

# Do MS services need to refocus on the needs of people with advanced MS?

*Findings from MS Forward View and commencement of a pilot programme to establish the Advanced MS Champion role.*

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## MS Forward View

**Aim:** The range and complexity of Disease Modifying Drugs (DMDs) for people with relapsing MS have increased significantly, placing a greater burden on MS services. MS Forward View<sup>a</sup> aimed to identify the priority actions needed for the UK MS sector to deliver efficient, effective and equitable services for everyone with MS.

### Methodology:

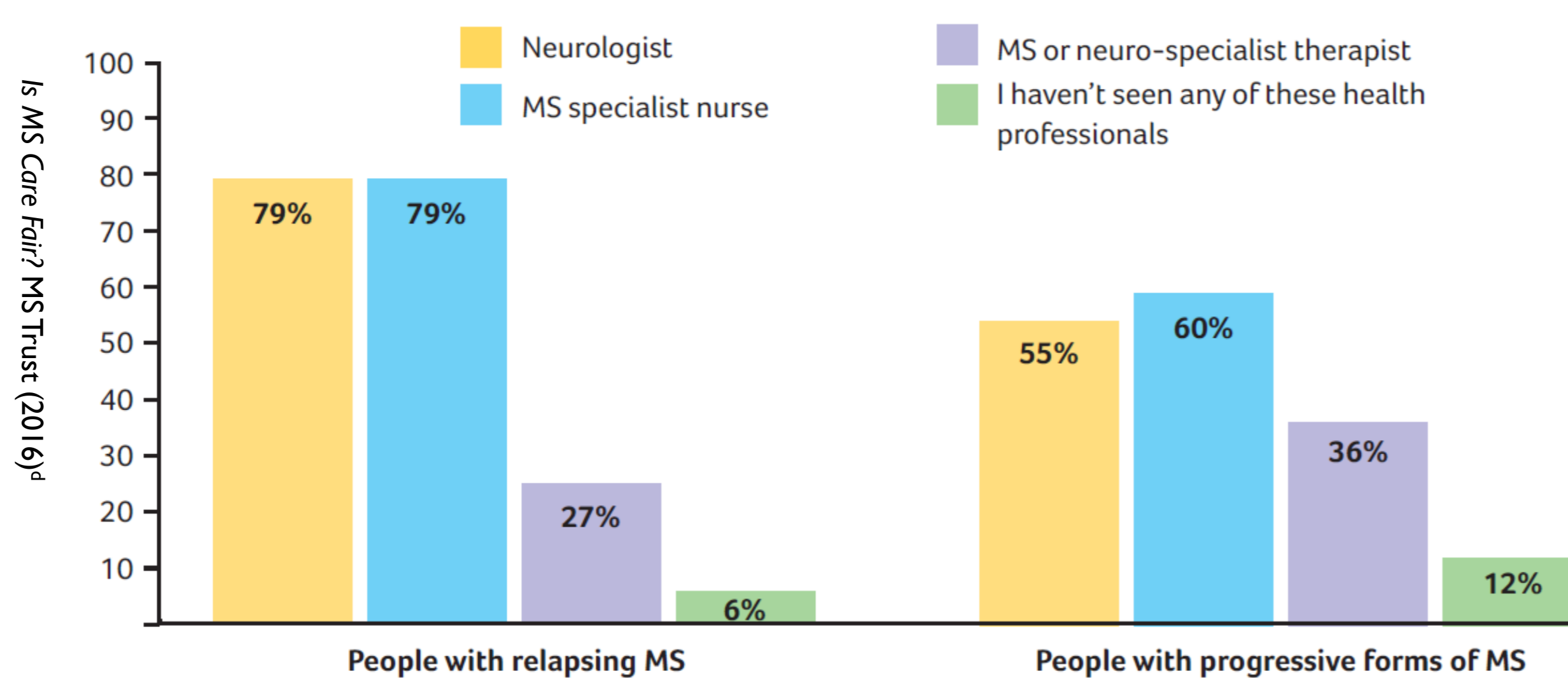
The MS Trust assembled an expert advisory group consisting of health professionals and representatives from the voluntary sector, professional organisations and pharmaceutical companies. A Lay Forum of people with MS and carers was established to share insights from lived experience. We used narratives from across the MS sector as well as more formal methodologies including:

- Surveys of people living with MS and health professionals
- Functional mapping of the DMD pathway
- Workshops and interviews focused on care for people with Advanced MS using a graphic facilitator

### Results:

The increasing choice around DMDs for people with relapsing MS, whilst welcome, has impacted significantly upon the capacity within MS nurse services to provide holistic, proactive care to people not on DMDs. People living with Advanced MS, who often have complex needs and find physical access to services most difficult, are most likely to lose touch with specialist services.

**Q: During the past year, have you had a face-to-face consultation with any of the following about your MS?**



## What is 'advanced MS'?

**Advanced MS** describes the **scale of burden** MS has on an individual, rather than the type of MS<sup>c</sup>. Someone with 'advanced MS' has:

- Multiple, concurrent symptoms
- Dependence on others for some or all care/support needs
- Significant impairment of function

## Advanced MS Champions Pilot Programme<sup>e</sup>

In 2017, the MS Trust announced the launch of the **Advanced MS Champions** Pilot, a three year programme to establish six leads for advanced MS across the UK. The posts will be funded using a pump-prime funding model for 15 months, and services will be supported by the MS Trust to develop and improve care for people with advanced MS and their families. The aim of the pilot is to demonstrate the value of this model with the ultimate goal of facilitating widespread implementation of the Advanced MS Champion role and making sure no one has to face MS alone.

## Evaluating the Pilot

Evaluation will be tailored to individual sites, but key areas of data collection will include qualitative and quantitative methods:

- Service-users' views, including carers
- Patient reported outcome measures
- Impact on use of unscheduled care including emergency hospital admissions
- Activity and capacity of whole service
- Case histories

This approach will ensure we can demonstrate the impact of the role across the three domains of impact on service capacity, patient outcomes, and financial viability.

### References

- Croft et al (2016). MS Forward View: A consensus for the future of MS Services. ([mstrust.org.uk/ms-forward-view](http://mstrust.org.uk/ms-forward-view)).
- Mynors et al (2016). Improving the efficiency of DMD provision. ([mstrust.org.uk/dmd-services](http://mstrust.org.uk/dmd-services)).
- Roberts et al (2016). Improving services for people with Advanced MS. ([mstrust.org.uk/improving-services-people-advanced-ms](http://mstrust.org.uk/improving-services-people-advanced-ms)).
- Is MS Care Fair? (2016). ([mstrust.org.uk/ms-care-fair](http://mstrust.org.uk/ms-care-fair)).
- [mstrust.org.uk/advanced-ms-champions](http://mstrust.org.uk/advanced-ms-champions)