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## Background and introduction

- A 2015 report highlighted a wide variation in multiple sclerosis (MS) diagnostic and care services.<sup>1</sup>
- Healthcare quality improvement approaches aim to reduce variation and improve outcomes; action-effect methodology has been used as a systematic framework for visualization and evaluation.<sup>2</sup>

## Objectives

- To encourage widespread implementation of key recommendations from the *Brain health: time matters in multiple sclerosis* report,<sup>1</sup> we set out to develop a quality improvement framework for MS services, to support healthcare professionals (HCPs) in maximizing lifelong brain health in people with MS.

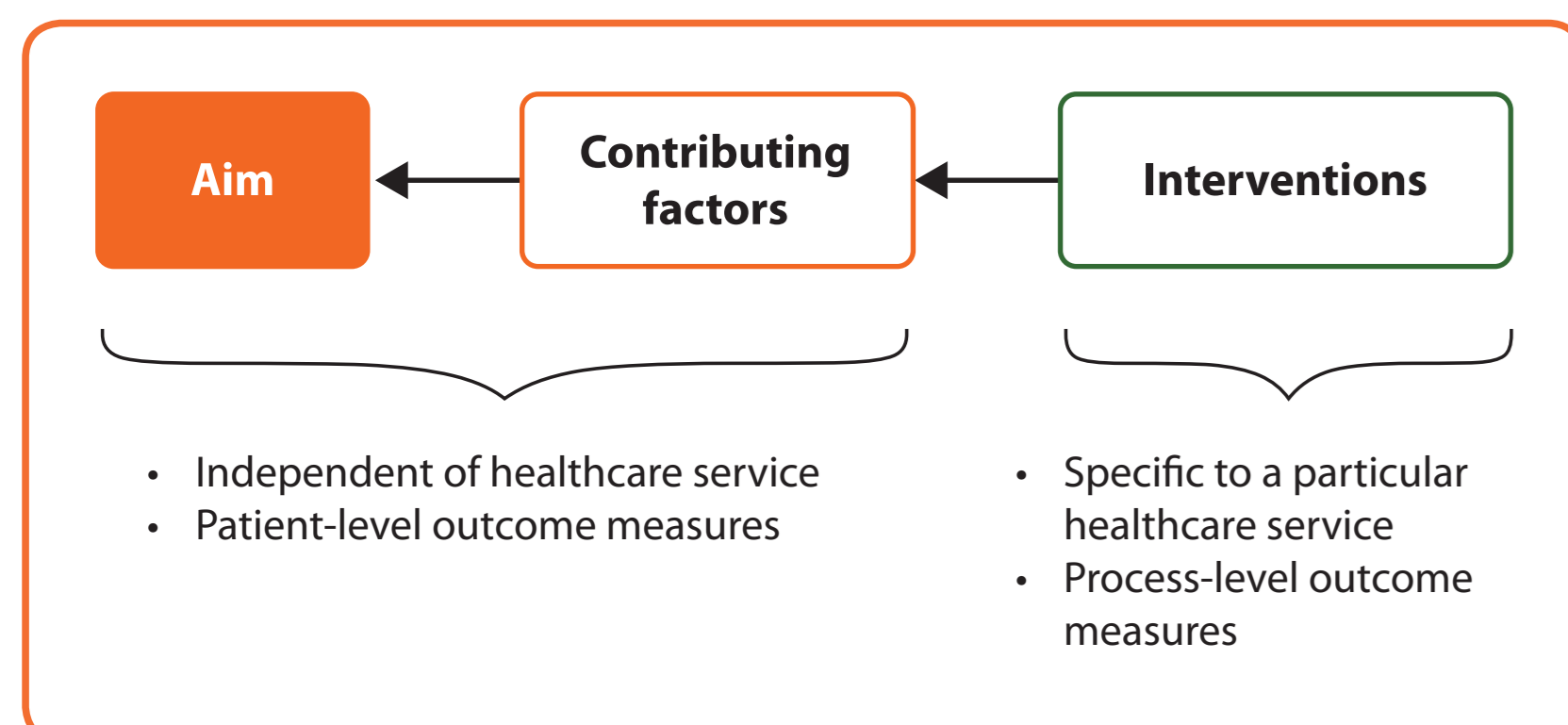
## Methods

### Identifying factors that affect MS service delivery

- An action-effect diagram (AED) of MS services was developed. This methodology (Figure 1) was selected because it:
  - specifies an aim, contributing factors and putative cause-effect relationships
  - highlights where interventions could improve outcomes
  - provides a framework of outcome measures to support evaluation
  - is iterative, allowing continual refinement and local adaptation
  - is visual, to facilitate stakeholder engagement.
- Using the resulting AED, we proposed a quality improvement framework comprising: 1) a framework of factors affecting MS service delivery; and 2) metrics for assessing quality and changes in quality.
- To complement this qualitative approach, a survey was conducted among 9392 delegates at the 2016 European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) congress.
  - The survey asked HCPs which of five factors affecting MS service delivery (see Table 1) they had tried to improve. Respondents could choose more than one answer.

### Developing the quality improvement framework

- To further develop the quality improvement framework, a workshop was held in London in September 2016 involving multidisciplinary HCPs specializing in MS, people with MS, payers and experts in information management, mostly from the UK.
- Participants discussed the factors affecting MS service delivery identified by the AED, and metrics for assessing the quality and changes in quality of MS services.



**Figure 1.** Structure of an action-effect diagram: once the aim is clear, the contributing factors can be identified and potential interventions agreed.

The arrows show putative cause-effect relationships.

## Disclosures

J Hobart has received consulting fees, honoraria, support to attend meetings or research support from Acorda, Asubio, Bayer Schering, Biogen Idec, F. Hoffmann-La Roche, Genzyme, Merck Serono, Novartis, Oxford PharmaGenesis and Teva. M Alexander has nothing to disclose. A Bowen has nothing to disclose. H Butzkueven has received consulting fees from Biogen, Genzyme, Merck, Novartis and Oxford PharmaGenesis; and grant/research support from Genzyme, Merck and Novartis. G Giovannoni has received consulting fees from AbbVie, Bayer HealthCare, Biogen, Canbex Therapeutics, Five Prime Therapeutics, GlaxoSmithKline, GW Pharma, Merck, Merck Serono, Novartis, Oxford PharmaGenesis, Protein Discovery Laboratories, Roche, Sanofi Genzyme, Synthon, Teva Neuroscience and UCB; and grant/research support from Bayer HealthCare, Biogen, Merck, Merck Serono, Novartis and Sanofi Genzyme. T Kenny has received consulting fees from AbbVie, Dune Business Consulting, Lilly, Matrix Policy Solutions, Quality Improvement Clinic, Shire and Spoonful of Sugar. G Kobelt has received consulting fees from Almirall, Bayer, Biogen, Merck Serono, Novartis, Sanofi Genzyme, Teva and Oxford PharmaGenesis. T Ziemssen has received personal compensation for participating on advisory boards, trial steering committees and data and safety monitoring committees, as well as for scientific talks and project support, from Bayer HealthCare, Biogen Idec, Elan, Genzyme, Merck Serono, Novartis, Roche, Sanofi-Aventis, Synthon and Teva.

Support for MS Brain Health activities and materials has been provided by Oxford PharmaGenesis, Oxford, UK, funded by grants from AbbVie, Actelion Pharmaceuticals and Sanofi Genzyme and by educational grants from Biogen, F. Hoffmann-La Roche, Merck KGaA and Novartis, all of whom had no influence on the content.

Presented at the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum, 23–25 February 2017, Orlando, FL, USA

Major contributing factor	Outcome measure
1 Early referral	Time from initial appointment with a primary care physician to referral
2 Early diagnosis	Time from referral to initial assessment by an MS HCP Time from initial assessment by an MS HCP to MRI scan
3 A brain-healthy lifestyle	Holistic regular <sup>a</sup> review, conducted by an MS HCP who encourages a brain-healthy lifestyle
4 Early treatment with a DMT	Time from diagnosis to initial DMT prescription
5 Ongoing appropriate treatment with a DMT	Eligible people with MS who are taking a DMT Eligible people with MS who are taking a 'more effective DMT' <sup>b</sup> Regular <sup>a</sup> use of MRI to monitor disease activity

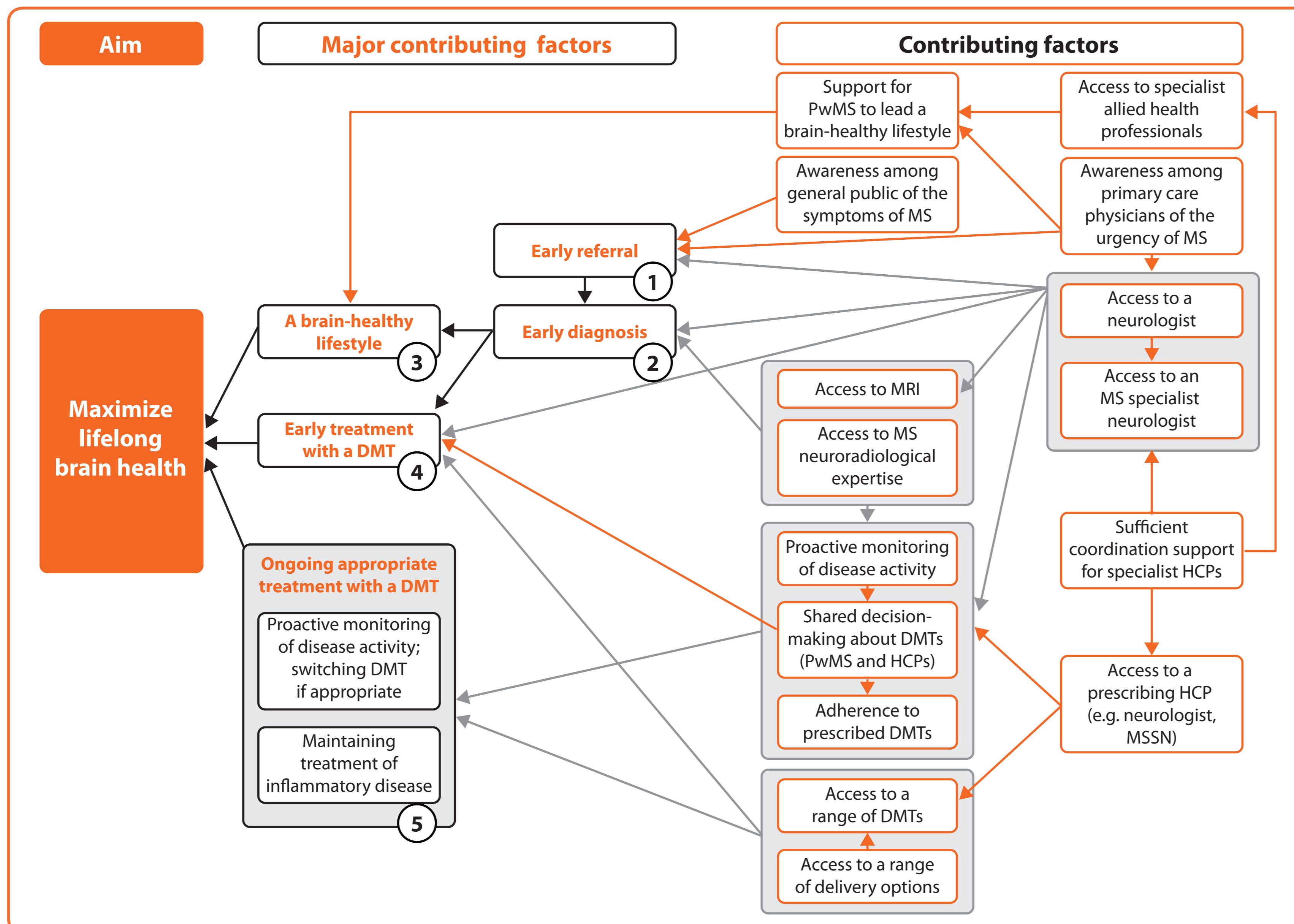
**Table 1.** Proposed outcome measures to assess the major contributing factors shown in Figure 2.

<sup>a</sup>Specific targets would be set by healthcare services. <sup>b</sup>Definition is dependent on local treatment guidelines and licensing. DMT, disease-modifying therapy; HCP, healthcare professional; MRI, magnetic resonance imaging.

## Results

- Our AED provided a framework of five contributing factors and associated outcome measures for quality improvement in MS services (Table 1; Figure 2).
- At the workshop, the framework was discussed and expanded, such that a total of 24 potential outcome measures were identified (Table 2).
- These outcome measures could help support HCPs in maximizing lifelong brain health in people with MS.

- Of the 72 HCPs who completed the survey (Figure 3), 94.4% reported that they had tried to improve at least one of the five contributing factors to MS services that were listed.
  - 'Early treatment with a disease-modifying therapy (DMT)' was the factor most frequently targeted for improvement (66.7%), and 'early referral' was least commonly targeted (44.4%).
- Of 51 respondents who reported their country of origin, the majority were from Europe (34/51, 66.7%), and of those, most were from the UK (15/34, 44.1%).



**Figure 2.** Action-effect diagram for quality improvement in MS services; these factors are independent of healthcare service and geography.

Circled numbers refer to the outcome measures listed in Table 1.

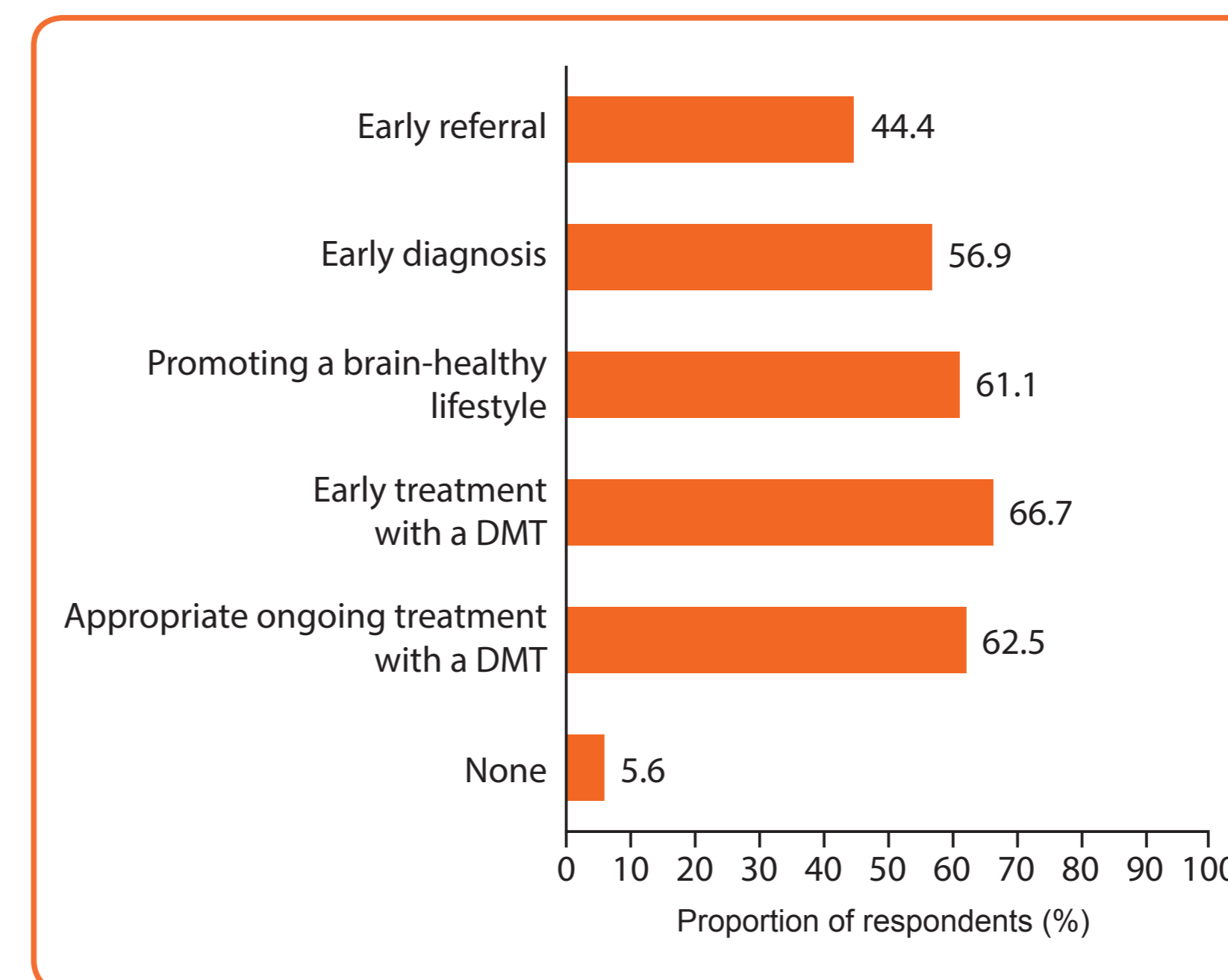
Arrows show putative cause-effect relationships.

DMT, disease-modifying therapy; HCP, healthcare professional; MRI, magnetic resonance imaging; MSSN, MS specialist nurse; PwMS, people with MS.

Objective	Outcome measure
To promote and support early referral and self-referral	Date of first symptoms Date of first reporting of symptoms to an HCP
To promote appropriate assessment and early diagnosis	Date of diagnosis Time to seeing an MS specialist neurologist
To promote and support a brain-healthy lifestyle	Measure of the level of knowledge of PwMS Annual comprehensive assessment
To treat early, with a DMT where appropriate	Time to treatment Proportion of eligible PwMS taking a DMT
To monitor disease activity and switch DMT if appropriate	Annual comprehensive assessment Number of PwMS switching DMTs Number of PwMS being monitored using MRI on a regular basis PRO: Were you offered the opportunity of an appropriate discussion about switching when [a specific criterion is met]?
To maintain treatment with a DMT for as long as the PwMS would be at risk of inflammatory disease activity if they were not receiving treatment	PRO: Why did you stop taking a DMT?
To ensure that PwMS are 'empowered' and at the heart of their decision-making, treatment, care and support	Measure of activation of PwMS, e.g. on a scale of x–y how much do you contribute to [a given criterion]? Do PwMS have email addresses on record? PRO: Have you received a care plan? PRO: Were your information needs met? PRO: Do you know your last MRI result and what it means in comparison to the previous one? First visit: time to discuss implications of diagnosis, information about education and support given
To minimize the impact of MS	Proportion of PwMS diagnosed with depression Proportion of PwMS in work Proportion of PwMS with cognition test result Proportion of PwMS seeing allied HCPs Admissions data on UTIs and chest infections

**Table 2.** Refined outcome measures agreed by multidisciplinary HCPs, PwMS, payers and experts in information management in a workshop held on 13 September 2016.

DMT, disease-modifying therapy; HCP, healthcare professional; MRI, magnetic resonance imaging; PRO, patient-reported outcome; PwMS, people with MS; UTI, urinary tract infection.



**Figure 3.** Factors affecting MS services and the proportion of HCP survey-respondents at ECTRIMS 2016 that had tried to improve them. Respondents could choose more than one factor.

DMT, disease-modifying therapy; ECTRIMS, European Committee for Treatment and Research in Multiple Sclerosis; HCP, healthcare professional.

## Conclusions

- An AED can provide a systematic framework for quality improvement in MS diagnostic and care services.
- Some HCPs are actively trying to improve MS services. However, the responders from ECTRIMS are unlikely to be representative of MS HCPs globally; the majority were from the UK, where the meeting was held. More detailed work and a systematic approach are needed to identify the key barriers to effective service delivery.
- The framework of factors affecting MS service delivery and the metrics described here could provide the basis for a quality improvement tool that could be used by clinicians and people with MS to improve MS care.
- Any 'generic' quality improvement tool that results from such a process would need to be tailored to local systems and requirements.

## References

- Giovannoni G *et al.* *Mult Scler Relat Disord* 2016;9:55–48.
- Reed JE *et al.* *BMJ Qual Saf* 2014;23:1040–8.



To read *Brain health: time matters in multiple sclerosis*, visit [www.msbrainhealth.org](http://www.msbrainhealth.org)