

# Piloting the MS Self-Reported Assessment Tool for People with Multiple Sclerosis



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On behalf of the Therapists in MS (TiMS) Group.

## Background

MS is a lifelong disease. The myriad of symptoms that people experience are complex and change over time, requiring individual assessment and management. In light of this, the NICE MS Guideline (2014) recommends that all people with MS should have a comprehensive annual review of their health and care by professionals with expertise in MS.

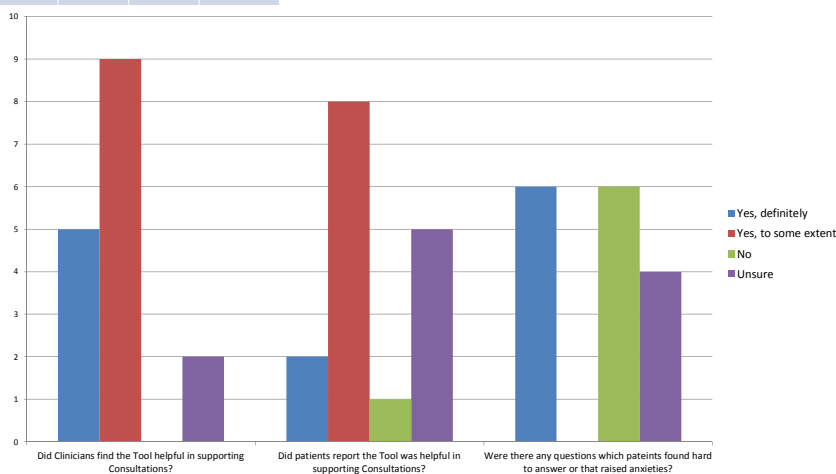
The MS Self-Reported Annual Review Assessment Tool (AR) was developed to assist in the implementation of this guidance. Its intention is for the person with MS to be central to the process by enabling them to identify and prioritise their symptoms and care management. We aimed to pilot this tool to gain an understanding of its use in different settings and whether it is a useful adjunct to practice.

I have difficulty with.....	Yes -this is a long-standing problem for me	Yes - this is new to me within the last 6 months	Sometimes - but it comes and goes	No/Not applicable	These are the main 3 points I would like to discuss (Please number with 1 being most important)
my sight (even if I'm wearing glasses)					
my breathing (possibly including chest infections)					using my hands
my speech/reading/writing					my balance & walking (including having (or nearly) tripped or fallen)
swallowing (I may cough/choke when I am eating or drinking) or with managing my saliva (e.g. dribbling)					getting around inside my home (even though I may use equipment/walking aids)
my weight (gaining or losing weight)					getting around outside my home (including difficulties walking on uneven ground or slopes)
pain					getting about in the community (driving or using public transport)
spasms, muscle stiffness					my mood - I often feel sad, anxious or depressed
shaky or jerky movements					changes in my personality/ behaviour
fatigue or tiredness which is impacting on my work/home life					my relationship due to my MS
my bladder (possibly including infections)					sex/intimacy due to my MS
my bowels (possibly including constipation)					sleeping
daily activities such as washing, dressing, cooking and shopping (even though I may use equipment to help me)					remembering things/ planning/ concentrating
					motivating myself to do things (including things suggested by professionals)
					participating in social activities/ hobbies
					my work (or I would like to work)
					benefits and/or my finances
					my current accommodation
					understanding about MS and what it means for me.
					my medication

Figure 1: The Annual Review Assessment Tool

## Methods

Sixteen sites from across the UK were provided with the tool, a guidance template for registering its use within their workplace, and advice to implement it in the way that suited their service. Following this, participants were requested to complete an online survey questionnaire.



## Results

52 professionals (physiotherapists, occupational therapists, nurses, psychologists) across 16 sites (9 Hospitals, 2 MS Centres, 5 Community) trialled the tool over a 6-week timeframe with 173 patients (range 7 - 20). Seven services posted the tool to patients to complete prior to their appointment (mode 2-3 weeks). In 14 sites the professionals felt the tool was useful in supporting their consultation; 10 sites reported that patients valued the tool. 43% (n=6/14) reported difficulty with some questions, such as future care plans.

## Conclusions:

- Developing an AR tool that all clinicians agree on is difficult, particularly given the variety of MS types, disability levels and clinical settings in which it is used.
- This pilot demonstrated that the AR tool was generally feasible to implement, with most services considering it a useful adjunct to practice.
- Gaining the patient perspective is an important next step in furthering our understanding of the value of this tool.

## Feedback:



## References:

NICE (2014) Multiple Sclerosis in Adults: Management. NICE Guidelines [CG186] Available at <http://www.nice.org.uk/guidance/cg186>