Development of clinical and patient-reported quality metrics for multiple sclerosis: a UK pilot study report

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BACKGROUND

- Improvement programmes and quality standards can improve patient experiences and outcomes.[1]
- However, UK quality standards for people with multiple sclerosis (MS) are suboptimal, ambiguous and restricted to certain patient subgroups and care pathways.[2]
- Data collection (through audit) and application of relevant metrics can provide an important benchmark of current service and identify areas of suboptimal services.
- We have developed and piloted clinical and patient self-reported MS metrics measuring service provision quality to identify areas for improvement.

METHODS

- A Joint Working project was established to bring together a multidisciplinary Working Group of stakeholders including MS clinicians, patient groups and pharmaceutical industry representatives.
- The Working Group developed quality standards, clinician and patient self-reported metrics and standardized data collection forms through an iterative process during workshops and meetings. All materials for the pilot audit were reviewed and refined by the Working Group.
- Draft metrics and associated data collection forms were piloted in four units (St Georges Hospital, London; University Hospitals Birmingham NHS Foundation Trust; Walton Centre NHS Trust, Liverpool; Ayrshire & Arran NHS Trust).
- Responses from completed data collection forms were collated and analyzed by an independent data analyst.

RESULTS

Quality standards, clinical metrics and patient-self reported metrics

- Quality standards and metrics covered: referral, diagnosis, treatment, annual review, general management and education (**Table 1**).

Table 1: Quality standards and associated clinical and patient self-reported metrics

	Quality Standard	Clinical metric	Patient self-reported metric
1	Referral (within secondary care) to a specialist MS team to be sent out within 1 week of suspected or confirmed diagnosis of demyelination	Percentage of people who are referred (within secondary care) to a specialist MS team within 1 week of suspected or confirmed diagnosis of demyelination	N/A
2	Confirmed diagnosis of uncomplicated MS[1] within 4 weeks of receipt of referral to specialist MS team	Percentage of people who have a confirmed diagnosis of uncomplicated MS within 4 weeks of receipt of referral to specialist MS team	N/A
3	A face-to-face follow-up appointment with a specialist MS nurse is offered within 4 weeks of receipt of referral post-diagnosis	(a) Percentage of people with confirmed diagnosis of MS who are offered a face-to-face follow-up appointment with a specialist MS nurse within 4 weeks of receipt of referral (b) Percentage of people with confirmed diagnosis of MS who are offered *and attend* a face-to-face follow-up appointment with a specialist MS nurse within 4 weeks of receipt of referral	N/A
4	People with a confirmed diagnosis of MS and eligible to start DMT are offered to start DMT within 8 weeks of confirmed diagnosis	Percentage of people with a confirmed diagnosis of MS and eligible to start DMT who are offered to start DMT within 8 weeks of confirmed diagnosis	Were you told that you were eligible to start DMT? If yes, were you offered a choice between different DMTs?
5	People with MS have a review at least once every 12 months carried out by an MDT[2]	Percentage of people with MS who have a review at least once every 12 months carried out by an MDT	If you have had a diagnosis of MS for one year or more, in the past 12 months (a) have you seen at least one member of your MS team? (b) have you been asked specifically about any of the following: symptoms; disease activity; lifestyle (e.g. exercise, diet, sleep); social family or employment issues; comorbidities (e.g. smoking, high blood pressure, diabetes); taking part in a clinical trial or research?
6	People with MS have a defined point of contact within the MS service	Percentage of people with MS who have a defined point of contact within the MS service	Do you have a direct phone number or email for a named person within your MS team if you have any questions or concerns? If yes, who is it? Do you know when to contact your MS team?
7	Response to any unscheduled contact by a patient, MDT or GP reporting a patient problem within 3 working days	Percentage of responses conducted within 3 working days of any unscheduled contact by a patient, MDT or GP reporting a patient problem	Have you needed to contact your MS service unexpectedly or outside of your normal scheduled visits to report a problem? If yes, did you receive a response within 3 working days of contact?
8	(a) Response within 3 days of patients reporting symptoms (b) Scheduled clinic visit within 14 days of patients reporting problems	(a) Percentage of patients contacted within 3 days of reporting symptoms (b) Percentage of patients seen in clinic within 14 days of reporting symptoms	In the last 12 months, have you had symptoms you thought may be due to relapse? If you had symptoms, did you report these to the MS team? If you reported symptoms, were you (a) contacted within 3 days? (b) seen in clinic within 14 days? (c) was relapse confirmed after your clinic visit?
9	Every person with MS is offered comprehensive education[3] throughout their disease course	Percentage of people with MS offered comprehensive education throughout their disease course	Do you feel that over the course of your condition, your MS team has kept you well informed of: MS generally; benefits of treatment; monitoring needs; your MS; risks of treatment; lifestyle management?
10	Every MS service should maintain a current database of people with MS	Percentage of MS services maintaining a current database of people with MS	N/A

DMT, disease modifying therapy; N/A, not applicable as unlikely to know timings pre-diagnosis of internal communications among healthcare teams or existence of database; [1]uncomplicated MS, defined by typical clinical and MRI features and presence of oligoclonal bands if CSF tested; [2]MDT, multidisciplinary team: should include as a minimum an MS Nurse Specialist and a neurologist. Additional clarity and specifics of what constitutes an annual review were provided in the data collection forms. [3]Education offered at diagnosis, treatment initiation, disease transition and meant as a broad term including, but not restricted to, patient-tailored courses, leaflets and information resources (on-line and/or printed). Offer to participate in research was also captured.

Patient demographics

- The metrics and data collection forms were piloted (N=117; clinical metrics n=50; patient-self-reported metrics n=67). **Table 2** shows the patient demographics for clinical metrics and patient self-reported metrics, respectively. Note that completion of demographic data was optional for patient self-reported metrics but was completed by all patients.
- For patient self-reported data, the majority of respondents (87%) were white and had relapsing remitting MS (79%) or secondary progressive MS (8%)

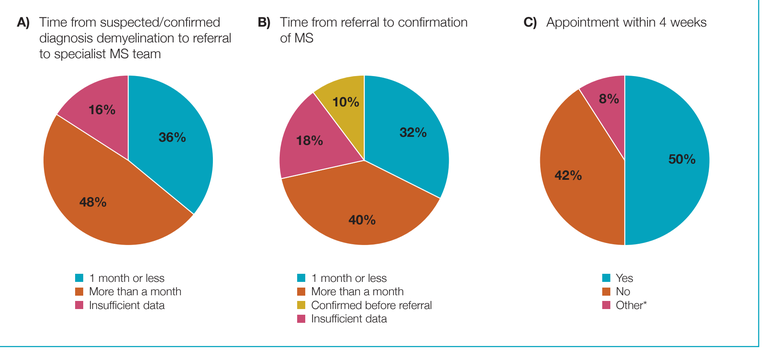
Table 2: Patient demographics for clinical and patient-reported pilots

Recorded from clinical data collection (N=50)			Recorded from patient-reported data collection (N=67)		
Age	< 30 years	14.0%	Age	< 30 years	14.9%
	30–40 years	34.0%		30–40 years	28.4%
	41–50 years	28.0%		41–50 years	23.9%
	51–60 years	22.0%		51–60 years	25.4%
	61–70 years	0.0%		61–70 years	3.0%
	> 70 years	0.0%		> 70 years	3.0%
	Not stated	2.0%		Not stated	1.5%
Gender	Female	66.0%	Gender	Female	75.0%
	Male	32.0%		Male	24.0%
	Not stated	2.0%		Not stated	1.0%
Duration of MS	0–1 years	16.0%	Duration of MS	0–1 years	7.4%
	1–5 years	36.0%		1–5 years	38.8%
	5–10 years	22.0%		5–10 years	23.8%
	> 10 years	18.0%		> 10 years	29.9%
	Not stated	8.0%		Not stated	0.0%

Diagnosis and referral from clinical data collection (N=50)

- Overall 36% of patients were referred (within secondary care) to a specialist MS team within 1 month of suspected or confirmed diagnosis of demyelination (**Figure 1A**); for 40% of patients, time from referral to confirmation of MS was over one month (**Figure 1B**).
- 50% of patients with a confirmed diagnosis of MS were offered a face-to-face appointment with a specialist MS nurse within 4 weeks of receipt of referral (**Figure 1C**). All patients who were offered an appointment attended.

Figure 1: Diagnosis and referral from clinical data collection (N=50)



*Includes not known, still awaited and insufficient data provided

Treatment and annual review from clinical data collection (N=50)

- Overall, 35 of 50 patients (70%) were eligible for disease modifying therapy (DMT): 51% of eligible patients began DMT within 8 weeks of prescription.
- For clinical data collection, annual review comprised documented assessment of 8 specific domains: (1) Disease activity (clinical including magnetic resonance imaging if on DMT or clinically indicated); (2) pharmacovigilance (according to therapy being used); (3) lifestyle (e.g. exercise, diet, sleep); (4) comorbidities (e.g. smoking, hypertension, diabetes); (5) symptom check-up (using appropriate tools) (6) advanced/anticipatory care plan (ACP) as appropriate or relevant (7) social, family and employment issues; and (8) outcomes (minimum of Expanded Disability Status Scale; EDSS).
- 74% of patients (37/50) had at least 1 domain assessed in the 12-month period but none had all 8 domains discussed (**Figure 2**). Disease activity and outcomes were assessed and discussed with three-quarters of patients and other domains in over half of patients (excluding ACP which was rarely assessed) (**Figure 3**). Overall, 60% of patients (30/50) had at least 5 domains discussed within the 12-month period (**Figure 2**).

Figure 2: Clinical data on number of domains discussed with patients (N=50)

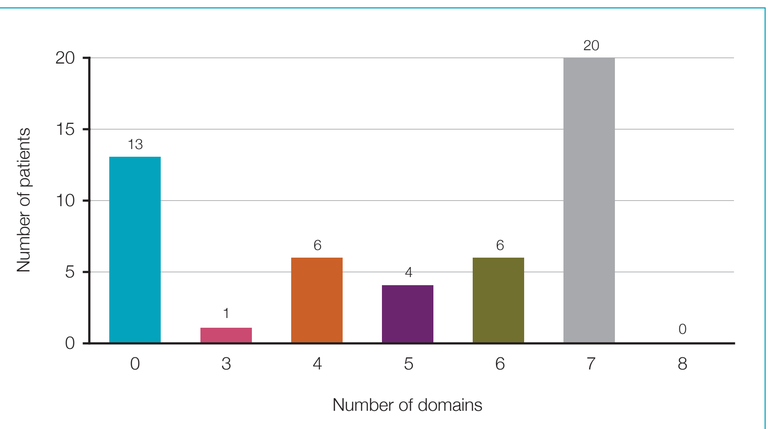
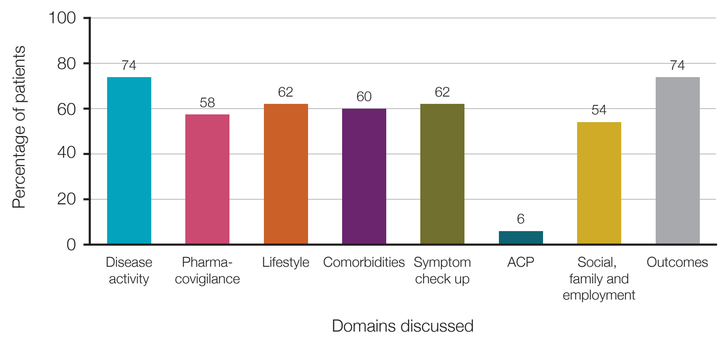


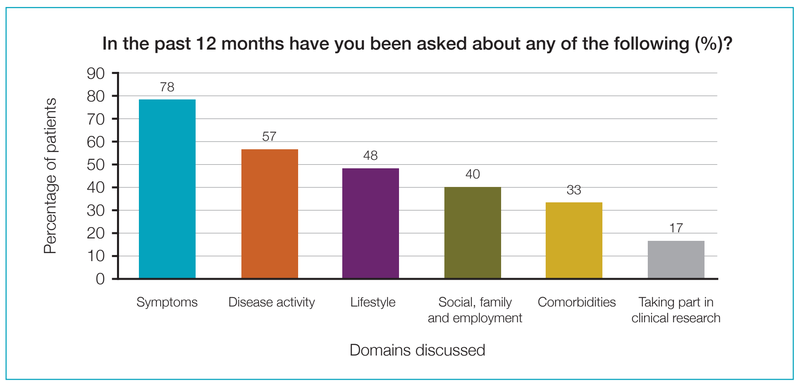
Figure 3: Patients with documented assessment and discussion of domains included in annual review (N=50)



Treatment and annual review from patient-reported data collection (N=67)

- Overall 49 of 67 patients (73%) were told that they were eligible for and could start DMT. Of those eligible, 36 patients (74%) were offered a choice of DMT and 42 patients (86%) felt that they had been involved in making the decision on their DMT treatment.
- Of 67 respondents, 60 (90%) had MS diagnosed for at least 1 year and therefore were eligible for annual review.
- For patient-reported data collection, annual review comprised discussion of 6 specific domains: (1) symptoms; (2) disease activity; (3) lifestyle (e.g. exercise, diet, sleep); (4) social, family and employment issues; (5) comorbidities (e.g. smoking, high blood pressure, diabetes); and (6) taking part in a clinical trial or research. **Figure 4** summarizes patient-reported data on the 6 domains.

Figure 4: Patient-reported data on 6 domains comprising annual review (N=60)



- In addition, the majority (80%) of patients eligible for annual review felt that they had enough time to discuss their MS and any concerns they had with their MS team.

Contact and management from patient-reported data collection (N=67)

- 88% of patients had a direct phone number or email for a named person within their MS team to contact with any questions or concerns. Most commonly this was either an MS nurse only (69%) or less commonly an MS nurse and a therapist (8%) or MS nurse and consultant (7%). The majority (82%) of patients knew when to contact their MS team
- 52% of patients had needed to contact their MS service unexpectedly or outside of their normal scheduled visits to report a problem; of these, 77% received a response within 3 working days of contact.
- Overall 37% of patients had experienced symptoms they thought may be due to relapse; of these, 76% reported their symptoms to the MS team.
  - 79% of patients reporting symptoms were contacted by the MS team within 3 working days and 37% were seen in clinic within 14 days of reporting.

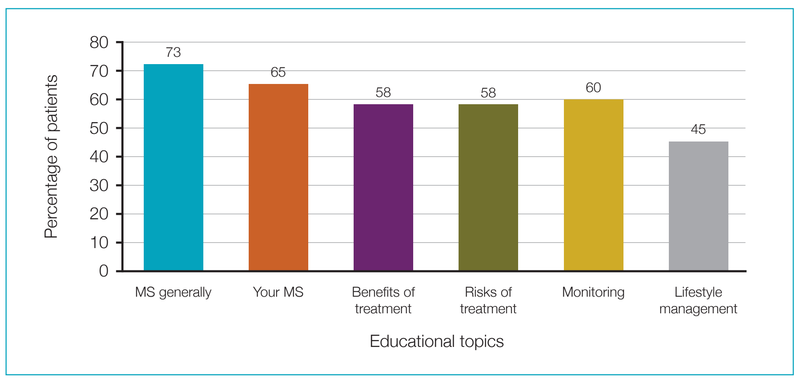
Patient education, clinical trial opportunities and MS service from clinical data collection (n=44 and n=50)

- Clinical responses (44 responses) indicated that 64% of patients were offered formal ongoing education (not restricted to during routine consultation) at different times or stages of their disease course but only 12% of patients had taken part in a research study (50 responses).
- Around one-third (38%) of responding units reported having a single integrated database for MS patients.

Patient education from patient-reported data collection (N=67)

- The majority of patients (78%) felt that their MS team had kept them well informed over the whole course of their condition though 15% felt that they had not (7% not stated). Education considered the following 6 topics: (1) MS generally; (2) their MS specifically; (3) benefits of treatment; (4) risks of treatment; (5) monitoring needed as part of treatment; and (6) lifestyle management. **Figure 5** summarizes patient-reported data on the 6 topics.

Figure 5: Educational topics patients on which patients were kept informed



CONCLUSIONS

- We have developed and piloted clinical and patient-reported metrics and associated data collection forms for evaluation of the quality of MS services, covering: referral, diagnosis, treatment, annual review, general management and education.
  - Our pilot data indicate that improvements are required in timely referral and diagnosis of people with MS and commencement of DMT.
    - However, the overall caseload of MS units may be older than our cohort, which may affect data availability (e.g. diagnosis data may be difficult to obtain for patients diagnosed a long time ago).
  - Although the majority of people with MS have an MDT annual review (where annual review is defined as documented assessment and discussion of 5 or more domains), more effort is required to discuss lifestyle, social factors, comorbidities and opportunities to participate in research
  - Three-quarters of patients received timely response following unscheduled contact however only around one-third (37%) were seen in clinic within 2 weeks, indicating an area for improvement.
  - More effort should also be made to educate people with MS on the benefits/risks of treatment and lifestyle management.
  - Just over one-third (38%) of units had an integrated MS database. If MS units wish to show quality, more effort should be undertaken to document all aspects of care and a minimal dataset for MS needs to be routinely collected and analyzed.
- In conclusion, the MS metrics/data forms were feasible to administer in routine clinical settings and simple to interpret and provide a valuable benchmark that allows areas for service improvement to be identified and specific goals to be set to monitor and measure service delivery.

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