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

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BACKGROUND

• Improvement programmes and quality standards can improve patient experiences and outcomes.
• In the UK, national quality standards for MS are suboptimal, ambiguous and restricted to certain patient subgroups and care pathways.
• Data collection and analysis of relevant metrics can provide an important benchmark of current service and identify areas for improvement.
• 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 Group was established to bring together a multidisciplinary Working Group of stakeholders including MS nurses, doctors, 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. The forms were piloted 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 and Ayrshire & Arran NHS Trust).
• Responses from completed data collection forms were collated and analysed by an independent data analyst.

RESULTS

Quality standards, clinical metrics and patient self-reported metrics

<table>
<thead>
<tr>
<th>Quality standard</th>
<th>Clinical metric</th>
<th>Patient self-reported metric</th>
<th>Patient self-reported metric</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Follow initial visits to a named nurse within 1 month of diagnosis</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>2</td>
<td>Confirmed diagnosis of uncomplicated MS within 1 week of receipt of referral to MS service</td>
<td>Percentage of people who have a confirmed diagnosis of MS within 1 week of receipt of referral to MS service</td>
<td>N/A</td>
</tr>
<tr>
<td>3</td>
<td>A face-to-face follow-up appointment with a MS nurse is offered within 2 weeks of confirmed diagnosis</td>
<td>Number of people who have an appointment with a MS nurse within 2 weeks of confirming diagnosis</td>
<td>N/A</td>
</tr>
<tr>
<td>4</td>
<td>People with MS have access to a face-to-face follow-up appointment with a MS nurse within 12 months of confirmed diagnosis</td>
<td>Percentage of people with MS who have an appointment with a MS nurse within 12 months of confirmed diagnosis</td>
<td>N/A</td>
</tr>
<tr>
<td>5</td>
<td>People with MS have a named nurse for 12 months continuing to MS service</td>
<td>Number of people with MS who have a named nurse for 12 months continuing to MS service</td>
<td>N/A</td>
</tr>
<tr>
<td>6</td>
<td>People with MS have access to a named person within 12 months of confirmed diagnosis</td>
<td>Percentage of people with MS who have a named person within 12 months of confirmed diagnosis</td>
<td>N/A</td>
</tr>
<tr>
<td>7</td>
<td>People with MS have access to at least one face-to-face appointment within 6 months</td>
<td>Percentage of people with MS who have at least one face-to-face appointment within 6 months</td>
<td>N/A</td>
</tr>
<tr>
<td>8</td>
<td>People with MS have access to at least one face-to-face appointment within 12 months</td>
<td>Percentage of people with MS who have at least one face-to-face appointment within 12 months</td>
<td>N/A</td>
</tr>
<tr>
<td>9</td>
<td>People with MS have access to at least one face-to-face appointment within 2 years</td>
<td>Percentage of people with MS who have at least one face-to-face appointment within 2 years</td>
<td>N/A</td>
</tr>
<tr>
<td>10</td>
<td>People with MS have access to at least one telephone appointment within 6 weeks</td>
<td>Percentage of people with MS who have at least one telephone appointment within 6 weeks</td>
<td>N/A</td>
</tr>
</tbody>
</table>

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

Overall, 88% of patients who were referred (within secondary care) to a specialist MS team within 1 month of a confirmed diagnosis of MS were offered a face-to-face appointment with a specialist with a MS nurse within 4 weeks of receipt of referral (Figure 1A). All patients who were offered an appointment attended.

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

Overall, 36% of patients were offered (within secondary care) to a specialist MS team within 1 month of a suspected or confirmed diagnosis of demyelination (Figure 1A) for 45% of patients, time from referral to confirmation of MS was over one month (Figure 1B).

Of the 50% of patients with a confirmed diagnosis of MS, 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 the MS nurse only (86%) across all the units or MS nurse and a neurologist (9% or MS nurse and consultant) (7%).

In conclusion, the MS metrics/data forms were feasible to administer in routine clinical settings.

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

Clinical responses (44 responses) showed that 64% of patients were offered formal ongoing education (not restricted to routine consultation) at different times or stages of their disease course but only 1% of patients had taken part in a research study (20% response).

Conduct and manage clinical and patient self-reported data collection (N=87)

The majority of patients (70%) felt that their MS team had kept them well informed over the whole course of their condition although 15% felt that they had not (7% rated not at all). Education was considered the following topic: 70% (80% their MS specifically) (60% benefits of treatment) (40% of patients taking part in a clinical trial or research)?

Patient education from patient-reported data collection (N=87)

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Table 1: Patient demographics for clinical and patient-reported data collection

In conclusion, the 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.

CONCLUSIONS

• We have developed and piloted clinical and patient-reported metrics and associated data collection forms to evaluate the quality of clinical services, covering care pathways, diagnostic, treatment, annual review, general management and education. Our pilot data indicate that improvements are required in 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 analysis (e.g. diagnosis delay data may be difficult to obtain for patients diagnosed during pregnancy).
• The majority of patients with MS have an annual review (80% refers to defined assessment and discussion of 6 or more domains), more effort is required to discuss lifestyle, social factors, comorbidities and manage to patients’ preferences.
• Three-quarters of patients received timely response following unscheduled contact (87%), which is reported to be related to local factors and services, including data on contact service.
• Many of the patients had not had an integrated MS database. MS units wish to show quality, more effort should be undertaken to document all aspects of care and obtain patient feedback.
• In conclusion, the MS metrics/data forms were feasible to administer in routine clinical settings. Consideration of people to improve and gain feedback in metrics that areas for service improvement to be identified and specific goals to be set to monitor and measure services.

ACKNOWLEDGEMENTS

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REFERENCES

2. Italian Societies for Health and Care Research (SIR), Multiple Sclerosis Society (Battisti) (18 January 2019).