NICE multiple sclerosis quality standard

Tarek A-Z. K. Gaber FRCP, Mary Brown MRCP

NICE quality standards should be viewed as a valuable resource to help guide those planning and delivering care to provide high-quality services for patients.

In 2010, NICE published the first, of currently 120 strong, quality standards (QS). NICE states that the main aim of these QS is to ‘define the high priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement’.

The QS are a reflection of the recent move by NICE to expand its remit to include more tools to support not only clinical but also public health and social care services provision. This move made it necessary to provide more concise recommendations to guide commissioners and provider organisations, and help them to recognise the priorities for their services and benchmark its quality against a minimum set of standards.

The range of published QS is vast with many ambitious documents dealing with common and complex conditions such as dementia and stroke to a more focused QS with a narrower remit such as atrial fibrillation.

The multiple sclerosis (MS) QS was published in January 2016.1 The 39-page document contains six quality statements that cover a patient’s journey from diagnosis to long-term management. No statements are made about the later stages of the condition. A large number of references to other NICE guidelines are included, making the document a much more substantive piece of work than its relatively short text suggests.

Diagnosis and early management

The first two quality statements aim at ensuring that patients are offered adequate information about the condition, first by the diagnosing neurologist (QS 1), and second by another member of the team (usually an MS nurse specialist) soon afterwards (QS 2). A follow-up appointment (within 6 weeks of diagnosis) is important as it gives a patient the opportunity, after adjusting to the diagnosis, to ask questions and get information suited to their individual circumstances. It is preferable for a clinician in that second appointment to be the person involved in the long-term management of the patient. The appointment can lay the basis of such a long-term, trusting relationship between patient and clinician (neurologist/MS nurse specialist).

Long-term management

Quality statement 3 is probably the most crucial and also the most challenging for commissioners and providers. It emphasises the importance of having a single point of contact for a patient with a particular person or team that can access a network of services that are able to meet a patient’s needs. As this person is often an MS nurse specialist, the quality statement lays a huge responsibility on the nurse’s shoulders.

In many cases it is difficult to establish whether a particular complaint (eg pain) is related to MS or not with a risk of delayed diagnosis of an unrelated condition.2 Another risk is increasing burden on the multi-disciplinary team (MDT) because of the high number of referrals for input such as physiotherapy, as it is not reasonable to expect MS nurse specialists to appraise the need for each potential therapy/treatment option. One strategy to tackle this problem is to integrate the MS nurse specialist within the MDT team, with him/her spending sessions within the regional neuroscience department and other sessions in the community, building a stronger relationship with the MDT team and also providing opportunities to discuss complex cases with other clinicians and professionals. Dedicated input from a rehabilitation medicine specialist should also support the MS nurse dealing with complex cases.

Quality statement 4 recommends support for MS patients to remain active despite problems with immobility or fatigue. It is important to emphasise the importance of this support being provided by a health care professional with experience in MS (eg physiotherapist). Fatigue, in particular, is an extremely common and complex problem in MS and a generic advice from a non-specialist can lead to worsening of symptoms. Access to advice and support to maintain activity should also be available in the long term as a patient’s clinical condition/psychosocial context change.

Compliance with quality statement 3 (single point of contact) should facilitate implementation of quality statement 5, setting a period of 14 days as the maximum time to provide treatment for MS relapses. Even the most experienced neurologist can struggle with differentiating between genuine and pseudo relapses.5 There is a risk that such pressure to comply with such a relatively short period may lead to inappropriate management in complex or atypical cases as some services may
Table 1. Recommended steps to help ensure compliance with MS QS

<table>
<thead>
<tr>
<th>QS</th>
<th>Quality statement</th>
<th>Recommended action</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Detailed information on diagnosis provided by neurologist</td>
<td>– Review neurologists’ job plans and clinic templates and ensure that adequate time is available for patients with new diagnosis of MS (and preferably all other conditions)</td>
</tr>
<tr>
<td>2</td>
<td>Face-to-face contact in less than 6 weeks with a neurologist / MS nurse</td>
<td>– Adequate capacity for emergency clinic slots for neurologist / MS nurses. Ability of MS nurses to do domiciliary visits if needed – Ensure all regional neuroscience departments are aware of the person responsible (eg MS nurse specialist) for a particular catchment area – It is the responsibility of the neurologist making the diagnosis to ensure timely reporting of the diagnosis to the MS nurse specialist</td>
</tr>
<tr>
<td>3</td>
<td>Single point of contact</td>
<td>– Easy access to MS nurse (eg answerphone) with prompt response (eg within 48 hours) to patient contact – Integrating MS nurse specialist within MDT team – Support of a rehabilitation medicine specialist available to MS nurse</td>
</tr>
<tr>
<td>4</td>
<td>Support for MS patients with mobility problems or fatigue</td>
<td>– A timely access to assessment and advice from a physiotherapist with experience with MS should be available not only on diagnosis but throughout the patient’s journey especially when changes in the clinical condition or psychosocial circumstances</td>
</tr>
<tr>
<td>5</td>
<td>Management of relapses within 14 days</td>
<td>– Ensure that the MS nurse specialist has the time/capacity to promptly see patients with potential relapse and can access the advice of a neurologist in a timely manner</td>
</tr>
<tr>
<td>6</td>
<td>Annual reviews for all patients</td>
<td>– Establish a register for all MS patients under the service – Ensure adequate capacity in neurology, MS nurse specialist clinics</td>
</tr>
</tbody>
</table>

be forced to rely on a less robust method of assessment such as phone consultations.

The sixth and final QS recommends an annual review for every MS patient. This QS should be a huge incentive for service providers to establish a register or a database of MS patients. This can be a complex and time-consuming exercise, however, huge benefits such as facilitating research, audits and ensuring that no patient falls through the net could be achieved.\(^6\)

The clinical needs of MS patients vary greatly with some patients having stable disease with unchanging needs for decades, whilst others have rapidly changing clinical/psychosocial issues requiring more regular appraisal of needs. Personally, I feel that such a blanket requirement for annual reviews may carry the risk of rendering a service less efficient with some patients having unnecessary annual reviews whilst others, with complex and rapidly changing clinical needs, struggle to access support because of lack of capacity in the service.

Conclusion
As the Health and Social Care Act 2012\(^7\) states that the care system should consider NICE quality standards in planning and delivering services, commissioners and providers of health and social care should refer to the library of NICE quality standards in general and the MS QS in particular when designing high-quality services for MS patients.

The concise nature of the quality statements and the explicit proposal of clear measurements for compliance make this document a valuable and easy-to-use tool to improve MS services. Neurologists and MS specialists should welcome the strict time frames set by QS 1, 2, 5 and 6 and should negotiate with their neuroscience departments to ensure that their job plans and clinic templates have the capacity to meet these QS. Table 1 suggests a few practical steps that can help service providers to meet the six QS.

Dr Gaber is a Consultant in Neurological Rehabilitation at Wrightington Wigan and Leigh NHS Foundation Trust, Wigan, Dr Brown is a specialty trainee in rehabilitation medicine, North West deanery.

Declaration of interests
No conflicts of interest were declared.

References