

National Institute for Health and Care Excellence

Stakeholder comments proforma – engagement exercise for quality standard on multiple sclerosis

<p>Please enter the name of your registered stakeholder organisation below. NICE is unable to accept comments from non-registered organisation or individuals. If you wish your comments to be considered please register via the NICE website or contact the registered stakeholder organisation that most closely represents your interests and pass your comments to them.</p>	
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Would you like to express an interest in endorsing this quality standard? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
Separately list each key area for quality improvement that you would want to see covered by this quality standard. EXAMPLE: Pulmonary rehabilitation for	EXAMPLE: There is good evidence that appropriate and effective pulmonary rehabilitation can drive significant improvements in the quality of life and health status of people with COPD. Pulmonary rehabilitation is recommended within NICE	EXAMPLE: The National Audit for COPD found that the number of areas offering pulmonary rehabilitation has increased in the last three years and although many people are offered referral, the quality of pulmonary rehabilitation and its availability is still limited in the UK. Individual programmes differ in the precise exercises used, are of different duration, involve	EXAMPLE: Please see the Royal College of Physicians national COPD audit which highlights findings of data collection for quality indicators relating to pulmonary rehabilitation. http://www.rcplondon.ac.uk/resources/chronic-obstructive-pulmonary-disease-audit

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chronic obstructive pulmonary disease (COPD)	<p>guidance. Rehabilitation should be considered at all stages of disease progression when symptoms and disability are present. The threshold for referral would usually be breathlessness equivalent to MRC dyspnoea grade 3, based on the NICE guideline.</p>	<p>variable amounts of home exercise and have different referral criteria.</p>	
<p>Key area for quality improvement 1</p> <p>Referrals to a consultant neurologist for people suspected of having MS, including urgent referrals.</p>	<p>Access to diagnosis by a consultant neurologist is recommended within NICE guidance.</p> <p>Diagnosis early is essential, to reduce anxiety and ensure people are able to come to terms with a chronic long-term condition. It is also essential so that those people with Clinically Isolated Syndrome or multiple sclerosis who meet prescribing criteria gain access to appropriate disease modifying therapy, which in turn is recognised to have long-term benefits in reducing the rate of relapses and the disability that some relapses bring with them. These criteria are described by the ABN prescribing guidelines and NHS England's clinical</p>	<p>Many people with MS report delays, sometimes significant delays, in being referred to a consultant neurologist who can make a diagnosis of MS. This is an issue not confined to MS: the Neurological Alliance's <i>Invisible Patient</i> report demonstrates that 31% of people with a neurological condition had to visit their GP five times or more before being referred to a consultant neurologist, and nearly 40% had to wait more than 12 months from symptom onset to seeing a consultant neurologist.</p> <p>Early and accurate diagnosis is also humane, since multiple sclerosis is most commonly diagnosed in people of working age between 20-40 years, who will need to make choices and decisions about treatment and management and about life issues such as work, family, financial decisions etc.</p> <p>There are two issues here. The primary one is getting GPs to recognise possible MS or CIS symptoms when they present in the consulting</p>	<p>Neurological Alliance (2015). <i>The invisible patients:revealing the state of neurology services</i>; http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015.pdf</p> <p>Association of British Neurologists. Revised (2009) Guidelines for Prescribing in Multiple Sclerosis. http://www.mstrust.org.uk/competencies/downloads/abn_ms_guidelines_2009_final.pdf</p> <p>NHS England (2014). Clinical Commissioning Policy: Disease Modifying Therapies for Patients with Multiple Sclerosis. http://www.england.nhs.uk/wp-content/uploads/2013/10/d04-p-b.pdf</p>

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	commissioning policy on disease modifying drug therapy.	<p>room, and making suitable referrals quickly. Therefore a key area for quality improvement and a metric will be the number of times someone had to present to their GP before getting referred to a consultant neurologist.</p> <p>A separate but related issue is that most people with MS benefit from being diagnosed by a neurologist with a special interest in MS. This is for a number of reasons, but a primary the MS specialist neurologist is more likely to recognise</p>	
<p>Key area for quality improvement 2</p> <p>Everyone to be offered information and support at diagnosis and on a regular basis thereafter, even if it has been declined previously.</p> <p>"The consultant neurologist should ensure that people with MS and with their agreement their family members or carers are offered oral and written</p>	<p>Information provision at diagnosis has been shown to be vital – and often lacking - by MS Trust research and by a recent Cochrane review. It is vital to enable the individual to adjust to the new diagnosis, and then to subsequent challenges as they arise in the course of this lifelong condition.</p> <p>The MS Trust study identified the need for information to aid adjustment to the diagnosis and to come from a trusted source, but also that it needs to be supported with expert input from specialists.</p>	<p>There is no metric for measuring whether people with MS are provided with written information at diagnosis or at later stages of their condition, and this seems to be dependent on the individual health professionals involved.</p> <p>Anecdotally, the MS Trust continues to hear stories from individuals who were not offered information at diagnosis or who were offered information but no support in how to interpret and manage that information at times of key decision making, eg choosing a disease modifying therapy.</p> <p>The Guideline recommends that the neurologist is offering written information at diagnosis, which we believe should be quality assured information such as the MS Trust's <i>Making sense of MS</i>.</p>	<p>MS Trust research: The information needs of the newly diagnosed. Way Ahead 2012;16(4):6-7 http://www.mstrust.org.uk/professionals/information/wayahead/articles/16042012_03.jsp</p> <p>Köpke S, Solari A, Khan F, Heesen C, Giordano A. Information provision for people with multiple sclerosis. Cochrane Database Syst Rev. 2014 Apr 21;4.</p> <p>Solari A¹.Effective communication at the point of multiple sclerosis diagnosis. Multiple Sclerosis. 2014 Apr;20(4):397-402.</p>

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<p>information at the time of diagnosis". "Review information, support and social care needs regularly. Continue to offer information and support to people with MS even if this has been declined previously."</p>	<p>A Cochrane review of information provision for people with multiple sclerosis found that the emotional burden on people with MS at diagnosis was high, and emphasised the need for careful monitoring and management of mood symptoms (chiefly anxiety). Information provision improved patients' knowledge of their condition, the achievement of 'informed choice', and satisfaction with the diagnosis communication.</p> <p>The House of Care model identifies that engaged, informed individuals and carers are more able to deal with the issues that living with a long-term condition throws at them.</p> <p>This is a finding replicated by new research into Patient Activation, where involving people actively in managing their health is more likely to reduce health inequalities and deliver improved outcomes, better quality care and lower costs</p>	<p>There is no recommendation in the Guidance about who should be offering information and support beyond diagnosis, but it makes sense that this should be the MS specialist nurse if available, or other health professional with specialist expertise in MS. A key consideration at this point is the inequitable provision of MS specialist nurses across England, with unsustainable caseloads in some areas.</p> <p>We are also concerned that people with MS who were diagnosed some time ago may not be known to services, and a key area for quality improvement is identifying these individuals so that information and support is available to them.</p>	<p>Hibbard J, Gilbert H.(2014) Supporting people to manage their health:an introduction to patient activation. London: King's Fund. http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health</p> <p>Coulter A, Roberts S, Dixon A. (2013) Delivering better services for people with long-term conditions: building the House of Care. London: King's Fund. http://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions</p> <p>Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480</p>

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<p>Key area for quality improvement 3</p> <p>Care for people with MS using a coordinated multidisciplinary team approach.</p> <p>“Care for people with MS using a coordinated multidisciplinary approach. Involve professionals who can best meet the needs of the person with MS and who have expertise in managing MS, including consultant neurologists, neurologist, MS nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care</p>	<p>Access to the multidisciplinary team for people with MS is recommended within NICE guidance.</p> <p>Multidisciplinary input is known to be vital to deal with the complex and inter-related symptoms of MS and other neurological conditions, especially those that are not susceptible to medical intervention alone, such as mobility and dexterity problems, spasticity, pain, cognitive symptoms and speech and swallowing symptoms.</p> <p>For people with MS, access to MS specialists, as part of a wider multidisciplinary team, means having support to feel in control of the many symptoms of MS. It means being prepared for potential problems or changes and knowing how to prevent crises. It means being able to receive the expert support to recover from set-backs and to adapt to new circumstances.</p> <p>Access to MS specialists in neuro-rehabilitation is becoming</p>	<p>But access to specialists who can provide that care is limited.</p> <p>Research undertaken by the Association of British Neurologists indicates that the UK has around less than a third of the European average of consultant neurologists per head of the population. In 2011, there were 285 UK consultant neurologists, or approximately 1:115,000 of the UK population.</p> <p>MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable.</p> <p>The small descriptive study into NHS provision of physiotherapy led by Markwick found “that the majority of the free text comments on MS services were negative (55%). Physiotherapy provision was rated the most negative of NHS services (38%), with the primary complaints being lack of information about services and excessive waiting times for appointments. This study has revealed that NHS physiotherapy provision is not meeting the needs of PwMS.”</p> <p>While there is less detailed information about the other members of the multidisciplinary team, a recent report by the MND Association has found that there are not currently enough speech and</p>	<p>Association of British Neurologists, Royal College of Physicians (2011). Local adult neurology services for the next decade. Report of a working party. https://www.rcplondon.ac.uk/publications/local-adult-neurology-services-next-decade</p> <p>Mynors G, Bowen A. MS specialist nursing in the UK 2014: the case for equitable provision. MS Trust: Letchworth Garden City. http://www.mstrust.org.uk/shop/product.jsp?prodid=480</p> <p>Markwick R¹, Singleton C, Conduit J. The perceptions of people with multiple sclerosis about the NHS provision of physiotherapy services. Disability Rehabilitation 2014;36(2):131-5</p> <p>All-Party Parliamentary Group on MND. <i>Condemned to silence: inquiry into access to communication support for people with MND</i>. London: 2014.</p> <p>Neurological Alliance. Navigating neurology services: helping strategic clinical networks to be a success story. London: NA. 2013.</p>

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<p>and continence specialists; GPs.”</p>	<p>more difficult but is key to maintaining and promoting function in people with mild to significant disability, particularly in common MS symptoms such as spasticity, pain, mobility, cognition, dexterity, speech and swallowing and other issues. Input from a range of therapists and other specialists is essential to ensure a coordinated approach to these symptoms which may be interrelated; for example, untreated spasticity can cause pain, mobility problems, sleep disorders and infections.</p> <p>MS specialists are also vital in aiding health promotion, such helping people with MS to stay active, eat healthily and prevent secondary complications of MS such as pressure ulcers, urinary tract infections. MS specialists aid the individual to make choices about care and treatment that suit each person's unique circumstances.</p> <p>Much of this is recognised in the NICE Guideline's recommendations around</p>	<p>language therapists to meet the needs of people with MND, a considerably smaller population than that of people with MS.</p> <p>Access to neuro-specialists working in rehabilitation is key to ensuring optimal outcomes for people with MS and other neurological conditions. Improving access to neuro-specialist therapists working in community settings has long been an aim of the National Clinical Director for Neurosciences, David Bateman – for example, in the Neurological Alliance's <i>Navigating neurology services</i> report - but so far with limited success, and despite NHS England's work to improve rehabilitation services, for example through its Rehabilitation Delivery Board.</p> <p>Work in progress by the MS Trust indicates that specialist neuro-therapist teams, particularly in community settings, are under pressure to take on more general caseloads. As a result skills are being lost and services are finding caseloads less and less manageable.</p> <p>We are also aware that continence services are not always available and that neuro-psychologist and dietitian services are very rare. While some people with MS may benefit from general psychology services, in some areas even initiatives such as IAPT (Improving Access to Psychological Therapies) are not available to individuals presenting with an MS diagnosis.</p>	

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	symptom management, particularly	<p>Overall, we would suggest a metric for quality improvement that measures the number of MS teams which involve or have access to the whole range of healthcare professionals outlined in the Guideline, including measurement of how many of these services are specialist.</p> <p>As part of that metric, we might like to see the range of services on offer, eg patient education in the form of 'getting to grips' and symptom management courses; and symptom specific management such as cognitive assessments; fatigue management courses; exercise classes.</p>	
<p>Key area for quality improvement 4</p> <p>"Offer the person with MS an appropriate single point of contact to coordinate care and help them access services"</p>	<p>An appropriate single point of contact for people with MS has been recognised as important in NICE Guidance. The House of Care model for long-term conditions recognises person-centred coordinated care as central to encouraging self-management and improving outcomes.</p> <p>For people with MS, particularly in crisis, having a single point of contact is a significant leap forward in improving self management and patient activation.</p>	<p>There is no agreed model for the single point of contact, but a reasonable assumption might be an MS specialist nurse or an MS specialist care coordinator where one exists.</p> <p>One key area for quality improvement would be identifying who might work as a single point of contact in a given locality, and what form that contact could take. Part of the metric for measuring quality improvement must be expected time of response/actual time of response, and outcomes of that response.</p> <p>There are two practical issues that will need to be resolved with this model: First, MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust</p>	<p>Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision. http://www.mstrust.org.uk/shop/product.jsp?prodid=480</p> <p>House of Care http://www.england.nhs.uk/resources/sources-for-ccgs/out-frwrk/dom-2/house-of-care/house-care-mod/</p>

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	<p>People with MS with a significant deterioration in symptoms will present anywhere they think can help them, eg GP/A&E/urgent care centres. There is a risk that without specialist input, health professionals will assume the person is in relapse, whereas symptom deterioration may be caused by infection, comorbidities as well as relapse. A single point of specialist contact that can triage such experiences should reduce NHS wastage in unnecessary appointment and prescriptions.</p>	<p>research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable. Offering these nurses as a single point of contact to people with MS risks burnout among professionals without significant increases in capacity</p> <p>Third, work in progress by the MS Trust as part of the Generating Evidence in MS Services project indicates that there are many people with MS who are not known to services. People with MS who were diagnosed some time ago, were seen by neurology services and then discharged, may be lost to the specialist service but still in need of specialist help. Identifying them and offering them a single point of contact must form part of this step for quality improvement.</p>	
<p>Key area for quality improvement 5</p> <p>Annual review.</p> <p>"Ensure all people with MS have a comprehensive review of all aspects of their care at least once a year. Ensure the comprehensive review</p>	<p>An annual review including medication review is recommended within the NICE Guidance for MS. The requirement for an annual medication review for people with long-term conditions forms part of the Medicines Optimisation NICE clinical guideline (2015).</p> <p>At the moment, people with MS who receive disease modifying drug therapy are monitored</p>	<p>At the moment there is no requirement for a comprehensive annual review. Consequently people with MS may be offered an annual appointment with an MS specialist health professional or they may not, but there is no consistency across the country. Each MS service follows its own protocols.</p> <p>We believe the metric for measurement should include: who conducts the annual review; whether it happens annually; what is monitored in the review; and what happens as a result, including</p>	<p>NICE. Multiple sclerosis. Management of multiple sclerosis in primary and secondary care (2014). Clinical Guideline 186, pp515-516</p> <p>NICE Medicines Optimisation: the safe and effective use of medicines to enable the best possible outcomes (2015).NG 5. http://www.nice.org.uk/guidance/ng5</p> <p>Mynors G, Bowen A. (2014) MS specialist nursing in the UK 2014: the case for equitable provision.</p>

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<p>is carried out by healthcare professionals with expertise in MS and its complications. Involve different healthcare professionals in different aspects of the review if needed.”</p> <p>“Refer any issues identified during the comprehensive review of the person with MS to members of the MS multidisciplinary team and other appropriate teams so that they can be managed”</p>	<p>normally several times a year (depending on the treatment), in the course of which most of the issues considered within an annual review will be discussed.</p> <p>However, people with MS who are not on disease modifying drug therapy may be discharged from MS specialist services and then go years without seeing healthcare professionals with expertise in MS; very often they may only become known to services again once they are in crisis.</p>	<p>monitoring other health inputs and outcomes over the following year.</p> <p>The following practical issues will need to be considered around implementation:</p> <p>First, people with MS who were diagnosed some years ago may long have been discharged from neurology services and may not be known to MS specialists. These people might particularly benefit from annual reviews which might prevent too many additional complications developing. A number of these patients are likely to be ageing and developing comorbidities which need to be identified, managed and treated before they develop into crises.</p> <p>Second, there are questions over who has sufficient expertise in MS to deliver the annual review. MS Trust research shows that access to MS specialist nurses is highly variable. MS Trust research has identified a shortage of MS nurses and many of them have caseloads that are more than twice the number that is practical or sustainable. As discussed in previous items, specialist neuro-therapists are coming under threat. Therefore, if, as we suspect, there are many people with MS who are not known to services, this is likely to exacerbate existing capacity issues.</p>	<p>http://www.mstrust.org.uk/shop/product.jsp?prodid=480</p>

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		<p>Third, the Guideline Development Group's discussions around the annual review, which indicate that the GDG suggested a framework for general items to be considered within an annual review. The MS Trust considers that this is an area that will benefit from further work, in particular in relation to symptoms that benefit from specialist assessment and management.</p>	

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Closing date: 18th March 2015, 5pm.