

Revising the NICE guideline: stakeholder engagement workshop

18 January 2018



The importance of patients' views and experience shaping the revision of the National Institute of Health and Care Excellence (NICE)'s current guideline for M.E. was frequently highlighted at a stakeholder engagement workshop this week.

Attended by people affected by M.E., healthcare professionals including M.E. clinicians, and patient organisations including Action for M.E., the workshop was hosted by a NICE staff team including Prof Mark Baker, Director, Centre for Guidelines, NICE keen to understand why issues surrounding the current guideline.

Speaking at the start of the workshop, Prof Baker explained that the [guideline development process](#) does not usually begin with a stakeholder engagement workshop such as this, but that it was thought essential to do so for M.E., given that the current guideline does not accurately reflect the experience of patients. "This is the beginning of starting again," he said, adding later that the process of developing the revised guideline must be "significantly different" to what has gone before.

Also unique to the development of this particular guideline will be the inclusion of a lay member – a patient or carer – on the panel that appoints the Chair of the Guideline Committee. The Committee itself will also double the usual number of patient/carers members from two to four.

Those attending the meeting heard from Norma O'Flynn, Chief Operating Officer, National Guideline Centre, where a team including research fellows, an information scientist and a health economist will provide technical expertise and support to the Guideline Committee, in line with NICE's guideline development process.

Victoria Thomas, Head of Public Involvement at NICE, explained that patient and carer involvement and genuine consultation with stakeholders, were core principles underpinning this process. She also acknowledged that producing a revised guideline must be complemented by a programme of effective dissemination and implementation.

Clare Ogden, Head of Communications and Policy, Action for M.E., attended the meeting and took part in one of six table discussions, each of which addressed the same questions, chaired and recorded by members of the NICE team:

- What works well for people with M.E.?
- What are barriers to effective care?
- What patient populations should be prioritised within the scope of the guideline?
- What terminology should NICE use?

Clare comments: "The breadth of experience and expertise from patients, carers, professionals and third sector organisations evident at the meeting cannot have failed to impress upon the NICE team the need to advocate a personalised, person-centred approach. It felt like there was a genuine appetite from both stakeholders and the NICE team to address the failings with the current guideline, and a shared passion to get this right for people affected by M.E. whatever their age, illness duration or illness severity."

Closing the meeting, Philip Alderson, Consultant Clinical Advisor, NICE, explained that all discussion notes would be analysed thematically, and a summary published on the NICE website in due course. Having spent some time at each of the discussions, these themes would likely include (but not be limited to):

- attitudes to M.E. from health professionals and the public
- the significance of labels and terminology
- diagnostic criteria
- access to therapies and other support, and the wide range of patient experiences of therapies, from helpful to harmful
- the need for a personalised approach to supporting people with mild, moderate and severe M.E., whatever their age or life stage
- models of care and joined-up working.

These themes will then form the basis of a stakeholder workshop on the scope of the guideline (see timeline below), which will include discussions about what skills and experience it would be appropriate for Guideline Committee members to have. Following this, a guideline scope will then be put out to stakeholder consultation. At the same time, NICE will advertise for Guideline Committee members, including four patients/carers. A full role description and application criteria will be posted on the [NICE website](#), and we encourage anyone with an interest to consider applying.

This means that the current NICE guideline timeline is as follows, though please note it is subject to change:

- stakeholder workshop on the scope of the guideline – Friday 25 May
- guideline scope stakeholder consultation – Thursday 21 June to Thursday 19 July
- NICE invite applications for Guideline Committee members – Thursday 21 June to Thursday 19 July
- first meeting of Guideline Committee – late November 2018
- guideline development usually takes around 70 weeks
- launch of stakeholder consultation on draft guideline – April 2020.

It is Action for M.E.'s intention to attend each stakeholder event and submit detailed responses to consultations on the scope of the guideline and the guideline itself. In order to do this effectively, we will survey people affected by M.E., using a range of communication methods to ensure we hear from as many children, families and adults as possible.

As set out in our [individual](#) and collaborative (as part of [Forward M.E.](#)) responses to the consultation that led to NICE announcing a [full revision of the guideline](#), we will continue to reiterate the message that NICE must:

- acknowledge the lack of a conclusive evidence base for treatments for M.E. including those recommended in the guideline, such as CBT and/or GET.
- fulfil its ethical obligation to present a full, accurate and balanced picture of current international clinical practice when it comes to managing and treating M.E.
- not obstruct the right to access biomedical care for anyone with M.E.