

**ME/CFS : stakeholder engagement meeting**

<b>Questions for discussion</b>	<b>Stakeholder discussion</b>
<p><b>People’s experiences of living with ME/CFS or caring for people with ME/CFS</b></p>	<p>Stakeholders discussed their experience of ME/CFS. The condition is characterised by great variability of severity and with symptoms often changing. People with ME/CFS can experience a very rapid decline and this can be difficult for people (including healthcare professionals (HCPs) to understand. People generally felt vulnerable, particularly parents of children with CFS. There can also be a change in the problems and symptoms experienced as children and then later as adults.</p> <p><b>Issues for people with severe ME/CFS</b></p> <p>ME/CFS has a spectrum of severity. For most people with ME/CFS standard everyday tasks can be challenging at some time. This can create difficulties for access to services such as GP and hospital appointments and social service assessments. People with severe symptoms can be housebound and bedbound and may have no access to care</p>
<p><b>What has worked well and what has not worked well in accessing health and social care</b></p>	<p>Some strengths in the current guideline were acknowledged around person-centred recommendations but it was noted they aren’t always been implemented. There are examples of good care and access to services but these are few and far between.</p> <p>The stakeholders agreed they had encountered many obstacles to accessing health and social care from identification to the management of CFS/ME and associated symptoms.</p> <p><b>Recognition and awareness</b></p> <ul style="list-style-type: none"> <li>• Recognition and awareness is seen as generally poor among healthcare professionals. There is often disbelief and negative attitudes by some HCPs.</li> <li>• There is variation in the approach of GPs, with some being some helpful.</li> <li>• Professional services lack of belief in people’s symptoms and their severity and in the person’s own understanding of how they respond to exercise and to interventions. People are met with beliefs held by health professionals about the nature of ME/CFS including that this is a psychological illness and not a physical illness.</li> <li>• This lack of belief and of understanding is also experienced in interactions with social services, work and educational services and has particular implications for the care of children.</li> <li>• There can be disbelief from family and friends.</li> </ul>

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### Questions for discussion

### Stakeholder discussion

#### Assessment and diagnosis

- The first assessment is critical and there is a variety of methods used (for example, Perrin technique).
- Diagnosis can take a protracted time.
- The diagnostic criteria currently used can require people to be unwell for several months and for other conditions to be excluded. Patient and healthcare professional experience is that it can be clear within a shorter time that a person may have ME/CFS and useful assessment and advice should be possible earlier.
- The exclusion of other conditions can be unhelpful as the presence of ME/CFS does not mean a person cannot have other problems and there are other conditions that may occur more commonly with ME/CFS. There needs to be a balance in testing to diagnose ME/CFS and to diagnose other conditions while recognising the avoidance of excessive testing.
- Misdiagnosis or failure to consider multimorbidity , examples of people being diagnosed with mental health problems and disbelief in the ME/CFS resulting in people being sectioned.
- Strict diagnostic criteria may not be helpful and symptom based approach may be better to ensure people not fitting strict diagnostic criteria are not left without support. Assessments of disability using questionnaires may be helpful during diagnosis and management.
- Stakeholders agreed that joint decision-making was vital and highlighted the importance of including patient experience

#### Access to services including specialist services is generally poor.

- There can be wide variability in quality and access to treatment and services
- Stakeholders discussed the wide variability in the way current services are configured, reflecting different histories
- There is a lack of services for GPs to refer people to and lack of clinics where multidisciplinary assessment and care is available.
- Problem of access to specialist care – one stakeholder gave an example of a 4-year delay
- Problem of local services being closed down due to NHS financial pressures
- Needs to be an improvement in access to care. The problem is with continual access to care. This is due to 'reablement' – which means that social care is withdrawn.

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	<ul style="list-style-type: none"> <li>• People prevented from receiving community care assessment/ treatment due to concerns around deconditioning</li> </ul> <p><b>Management</b></p> <p><i>Information and support</i></p> <p>Detailed information on nature of illness and its course is required for people with ME/CFS and their carers. This should include :</p> <ul style="list-style-type: none"> <li>• the fluctuating nature of symptoms</li> <li>• signposting to support groups is useful.</li> <li>• the impact of a diagnosis – potential for condition to worsen</li> <li>• Lifelong condition- shouldn't be seen as a short limited pathway</li> </ul> <p>Information and support for healthcare professionals.</p> <p>This should also explain the nature of the symptoms. Improving awareness of symptoms and how they fluctuate – appearances/snapshot should not be used for judgement by healthcare professionals .</p> <p><b>Course of illness</b></p> <ul style="list-style-type: none"> <li>• Services may not recognise this and discharge people when their symptoms are less severe even though services will be required again in the future. People do not get regular review and assessment.</li> </ul> <p><b>Interventions</b></p> <ul style="list-style-type: none"> <li>• Diagnosis can be made and no intervention offered or very limited support offered.</li> <li>• Patient experience is that patient involvement in decision-making about management and the choice to opt-out of an intervention is respected as available interventions will not be appropriate for all patients. More individualised approaches are required rather than a one size fits all approach. This is particularly important while evidence base is poor.</li> <li>• People's experience of interventions does not tally with the evidence. The studies used to support recommendations for interventions may use discredited diagnostic criteria and the evidence of effect may not</li> </ul>

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	<p>be as clear as was previously considered. The use of cognitive behavioural treatment is not acceptable if addressing ME/CFS as a psychological illness but may help in coping with ME/CFS. Graded exercise can be experienced as harmful and people have been forced to exercise. Some stakeholders had discussed how this had led to deterioration and collapse.</p> <ul style="list-style-type: none"> <li>• Pacing is experienced of being of potential use. Heart rate monitoring is reported to be helpful in understanding exercise tolerance.</li> <li>• People use alternative and complimentary treatments as well as treatments reported as promising despite lack of evidence. People have a need for pain management and general holistic care including services such as dietary support and mobility aids.</li> <li>• As a result of poor access to care and variability in available treatments, some people have used private treatment (for example, Perrin Technique)</li> </ul> <p><b>Particular issues with care of children</b></p> <ul style="list-style-type: none"> <li>• Parents experience a lack of trust from health, social and education services. Some parents have had allegations of child abuse with perceived safeguarding issues when they withdraw children from school and do not agree with activity/exercise based interventions.</li> <li>• Communication between parents and social services and education is often poor.</li> <li>• Children and being forced into school when not well enough (loss of socialisation often quoted).</li> <li>•</li> </ul>
<b>Priorities for the guideline</b>	<p>Stakeholders agreed that the areas below should be priorities for the guideline taking into account that recommendations should be tailored accordingly.</p> <p>Recommendations need to be tailored for various groups of people with CFS rather than one rule for everyone:</p> <ul style="list-style-type: none"> <li>• Adults and children separate strata.</li> <li>• Separate recommendations for pregnant women</li> <li>• Different severities</li> <li>• Different symptoms</li> </ul> <p>Guideline needs to be clear that this is a fluctuating condition</p>

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	<p><b>Identification, assessment and diagnosis</b></p> <ul style="list-style-type: none"><li>• Recognition/suspicion before diagnosis; crucial for primary care to recognise the signs and advise patients accordingly before symptoms becomes worse</li><li>• Misdiagnosis re mental health – needs addressing</li><li>• Which diagnostic criteria?</li><li>• Timing of referral</li></ul> <p><b>Management</b></p> <ul style="list-style-type: none"><li>• Need a multidisciplinary approach</li><li>• Guidance on interventions, including but not limited to exercise, CBT, pacing, dietary supplements / specific vitamins, Vitamin B12 treatment for children, pain management</li><li>• Role of education needs to be addressed in the guideline, as well as health and social care services</li><li>• Awareness of multimorbidity</li><li>• Different care packages according to severity of ME and age-appropriate</li><li>• Need for home care services to support people who are severely affected. Most specialist services don't see people who are severely affected – they are not getting home visits and lack access to ordinary healthcare.</li></ul> <p><b>Information and support</b></p> <ul style="list-style-type: none"><li>• Education and training for a range of professions including GPs and other HCPs, schools and social workers</li><li>• Need for support for person and family – package of care including stabilisation for those who haven't recovered</li><li>• Need guidance on support and management for patients who are most acute and severe (those who are bed-bound and need home visits) as they are currently being neglected by the system. There are currently no inpatient services for this group of patients and community/primary services are lacking as well.</li><li>• More information provision for patients, carers and families about the condition.</li><li>• More guidance on medical training for HCPs due to current high level of misdiagnosis.</li></ul> <p><b>Education</b></p> <ul style="list-style-type: none"><li>• Children educational recommendations were good in previous guideline. Doesn't say 'don't put back into school' uses term 'education' which is broader and better for children with CFS.<ul style="list-style-type: none"><li>○ However might not be implemented in practice</li></ul></li></ul>

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	<ul style="list-style-type: none"> <li>○ Pressure from schools – not understanding chronic condition and therefore diagnosis not accepted, parents at fault (sometimes with child abuse allegations), forced back to school</li> <li>○ Problem that doctors aren't providing sickness notes to describe severity of illness</li> </ul>
<p><b>Terminology – what should the guideline be called</b></p>	<p>All stakeholders agreed that the terminology used should not be judgemental and should reflect people's views, with respect to:</p> <ul style="list-style-type: none"> <li>○ Definitions</li> <li>○ Criteria</li> <li>○ Descriptions</li> <li>○ Need for personalised goals/activities.</li> </ul> <p>Terminology was discussed at length with differing opinions, in particular:</p> <ul style="list-style-type: none"> <li>• ME/CFS is an umbrella term – there are many subgroups underneath. There are currently gaps in understanding the condition – there is a huge spectrum of characteristics/symptoms. A very narrow title would leave some people out and would not help them.</li> <li>• Some Stakeholders preferred including both ME and CFS in title. Some stakeholders favoured dropping 'chronic fatigue' (though 'chronic fatigue syndrome' is better than 'chronic fatigue'). 'ME' is preferable for some people but there is a lack of certainty about what the 'E' stands for. Encephalomyelitis was preferred to encephalopathy by some stakeholders.</li> <li>• The term 'Systemic exertion intolerance disease' was generally not supported. It was not recognised as capturing the whole patient group and is generally not known in UK.</li> <li>• Some stakeholders thought it important to include the term "neurological".</li> </ul>