3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

Yes we took the following equality issues that were raised in the scoping process into consideration:

**Gender**- outcomes are worse for women with cystic fibrosis (CF) although there is no evidence that this is a consequence of difference in care.

The protocols reflected that men and women should be looked at as sub-groups in case differences were found for any of the interventions. However, there was no gender specific evidence available (as expected) so the committee was unable to focus on this area in any detail.

The committee did discuss gender differences related to fertility in that infertility is more common in men with CF than women with CF. These distinctions are reflected in the recommendations.

The committee also made specific recommendations about monitoring for diabetes during pregnancy for women with CF.

**Geographical issues** – care is given through specialist centres and this may be a problem if a person with CF is living in an isolated location.

The committee agreed that CF care should be provided by specialist CF teams at specialist CF centres. However the recommendations take into account that shared care models used for children and young people involve arrangements with a local paediatric team and that outreach care for adults, delivered by specialists can be provided at a local hospital.

The committee also agreed that in some circumstances routine reviews could take place through the use of home visits and telemedicine.

The committee also recommended that multidisciplinary teams should have a member available to advise people which CF with urgent enquiries at all times.

It was agreed that these recommendations would help make services more accessible for people living in isolated locations.
3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?

**Psychological and behavioural issues are more likely in people with a lower socioeconomic status.**

The committee agreed that both specialist clinical psychologists and social workers should be members of the specialist multidisciplinary team. The committee agreed that the clinical psychologist should be available to see the patient at outpatient clinic visits and during inpatient admissions and should also assess the needs of family members and carers (as appropriate). Annual reviews should look at factors making treatment adherence difficult as well as quality of life and psychosocial indicators. There was a lack of quality evidence in this area so the committee agreed a research recommendation: *What is the most effective measure of psychological functioning to use as a screening test for thresholds of concern in people with cystic fibrosis?*

It was agreed that these recommendations could be beneficial for people with CF with a lower socioeconomic status.

3.2 Have any other potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

Yes, the Committee considered the importance of information and support being individually appropriate and offered in a variety of formats and through a range of channels (e.g. face to face, printed documents and digital media). Also, that it was important to offer people with CF, their families and carers, opportunities discuss concerns from diagnosis onwards in a way that was appropriate for them. To improve communication and information provision we have cross-referenced the NICE [Patient Experience](https://www.nice.org.uk/quality-standard/patient-experience) guideline which refers to the need for interpreters and recommends an individualised approach which takes into account individual communication needs.

3.3 Were the Committee’s considerations of equality issues described in the consultation document, and, if so, where?

The recommendations address the equality issues and the considerations are detailed in the ‘Linking evidence to recommendations’ sections of the full guideline.
3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

No

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

No.

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE’s obligation to advance equality?

N/A

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

A stakeholder raised a potential equality issue related to a recommendation not to use high-frequency chest wall oscillation as an airways clearance technique for people with cystic fibrosis.

Although the stakeholder agreed that this should not be offered as a first line treatment the stakeholder said that there were instances where it was beneficial, particular for people with autism and people with learning disabilities and that those considerations were set out in the Standards of Care and Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis Third Edition April 2017 (Cystic Fibrosis Trust publication).
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td>4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?</td>
<td>The committee agreed with the stakeholder and added to the recommendation “except in exceptional circumstances. The specialist fibrosis team will decide whether these circumstances apply, and their decision would then be subject to the NHS England policy on Individual Funding Requests” to ensure that provision of this technique was possible for this group if needed.</td>
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<tr>
<td>4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?</td>
<td>None such groups were identified.</td>
</tr>
<tr>
<td>4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?</td>
<td>No.</td>
</tr>
<tr>
<td>4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE’s obligations to advance equality?</td>
<td>Not applicable.</td>
</tr>
</tbody>
</table>
4.5 Have the Committee’s considerations of equality issues been described in the final guideline document, and, if so, where?

The Airway clearance technique section of the full guideline has been updated to include the justification for the ‘exceptional circumstances’ in which high-frequency chest wall oscillation is to be used.

The recommendations address the equality issues and the considerations are detailed in the ‘Linking evidence to recommendations’ sections throughout the full guideline.