



# **Invest in ME Research**

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Charity number 1153730

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Professor Gillian Leng CBE, Chief Executive, NICE

Cc:  
Dr Paul Chrisp, Director of the Centre for Guidelines

8 September 2021

## **NICE pauses publication of updated guideline on diagnosis and management of ME/CFS**

Dear Professor Leng,

Thank you for your brief reply to our letter of 20th August.

You stated that “Bringing interested parties together will provide an opportunity to talk everyone through the approach that has been taken,”

Yet we now understand that NICE has already chosen which interested parties will attend your roundtable.

This information was not obtained from NICE but from information provided via social media.

It seems that you are not providing us and nor, apparently, most other stakeholders with this “opportunity to talk” and neither are you attempting to bring interested parties together.

Instead, there has been no discussion amongst stakeholders – other than those secret discussions that seem to have been going on behind the scenes since August.

There should not be a different approach being exhibited toward different “categories” of stakeholders – that includes invitations to roundtable meetings as well as behind the scenes discussions that lack any transparency.

Likewise, the prioritisation of responses to letters to NICE (from stakeholders and others) on this topic should not be based on anything other than a fair and proper policy used in answering these requests and with due process followed.

There should be no favoured parties!

We have stated before that the NICE guidelines development process should be transparent. Your organisation has shown little transparency in its decision-making and covert discussions since you decided to pause the publication of the final guidelines, without all stakeholders being consulted.



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You now have selected your favoured groups from your chosen definition of the “ME community” to attend your roundtable in order to legitimise this whole process – none of whom represent us or, from communications received, many of our supporters.

There is still no clarity or justification for NICE's pause in publishing the guidelines after the development process had been completed.

You have still not supplied any detail on what this "clear the air" roundtable is meant to achieve - let alone whether it follows due process or not.

All stakeholders have received responses to their comments during the development phase and the due process so there is no need for further debate.

You have still not answered in detail our earlier email to you.

You have still not announced officially which interested parties you have chosen to attend your roundtable – but instead you have allowed patients (and stakeholders) to pick up scraps of information via the internet - causing anxiety to some and speculation amongst others. This is no way for NICE to behave.

So please may we receive answers to these questions - in order to begin to operate in a transparent manner?

- Why have you chosen not to communicate what is happening to all stakeholders, via standard procedures, and at the same time?
- Why have you not notified all stakeholders at the same time which groups or individuals you have selected to participate in this roundtable?
- Who is deciding which stakeholders are to be present at your roundtable?
- How have you nominated those stakeholders whom you have selected to be present at your roundtable?
- What criteria and what process have you used to select the stakeholders who would participate in your roundtable?
- Did this selection process follow standard NICE procedures?
- How can you be sure that all interests are being represented at your roundtable if all of the existing stakeholders have not been contacted for their views beforehand?
- Can you guarantee that no individuals who resigned or were "dismissed" from the



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guidelines working group will be allowed any role in future discussions of these guidelines, and certainly not in your planned roundtable?

- Please can you inform us what discussions have been going on behind the scenes with NICE since the embargoed guidelines were distributed to stakeholders, through the period when the decision was made to pause the publication, and up to the present day - and with which individuals or groups?
- Please can you explain what is the full intent of the roundtable?
- If the intent of the roundtable is merely to provide an opportunity to talk everyone through the approach that has been taken, with the aim of ensuring support for the implementation of the already-developed and approved guidelines, then please can you explain to us how this is legitimate and how it follows NICE guidelines development protocols?
- Why can this hastily arranged and irregular roundtable not be performed after the final guidelines are published?  
We should remind NICE that no such opportunity was given to patients following the final review of the CG53 guidelines prior to their publication in 2007. Instead, patients were forced to find the resources in order to take NICE to a judicial review to remove the harmful recommendations.
- As Invest in ME Research is not amongst the interested parties few whom you have selected to be invited to your roundtable then, as a stakeholder in these guidelines, please can we receive the agenda for this roundtable meeting prior to the meeting? In fact, please can this agenda be made public beforehand in order that that all patients can be appraised of the intentions with your plans?
- Please can you inform us which stakeholders you have decided to invite to this roundtable?
- Please can you inform us of the date and time of this roundtable?  
The phrase in your earlier brief reply to us - "We will progress this as quickly as possible." - belies the fact that the date has seemingly already been set for this roundtable meeting. Again, only the chosen few seem to have been made aware. So much for openness!
- Please will you make arrangements for this roundtable to be conducted online by making it a virtual meeting with all stakeholders allowed to listen in?  
There is no reason why all stakeholders could not listen, even if you have only chosen your preferred interested parties to be able to speak.
- Taking this request further then why can this roundtable not be made open to all patients so that they can listen to the proceedings as they occur and ensure that your chosen "representatives" are truly representing their interests?



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- If you deny ordinary patients and other stakeholders the opportunity from listening to this roundtable then can you confirm that this meeting will be minuted and that the full minutes will be made available to the public immediately after the meeting?

Without this information being known it leads to unnecessary and unhelpful speculation.

One is left to speculate what is really going on behind the scenes - from both sides of the artificial "balance" that your organisation created when the guidelines development group was set up.

Whichever "side" one takes on this "balance" of opinions it is a false premise to think that all can be resolved by a lack of transparency.

It is patients and their families that matter and it is the interests of patients that should be at the heart of all guidelines development.

Yet the lack of scrutiny that NICE is enforcing with its latest actions inevitably results in the certainty that it is the patients who will be the last to know anything.

Yours Sincerely,

The Chair and Board of Invest in ME Research