Questions from the public: September 2021 board meeting

This is a summary of the answers given to the questions raised at the meeting.

# The Long Covid Community is concerned that the delay in the NICE ME/CFS Guidelines will impact them if it is not published in the August 18th format. Can we be reassured that Exercise/Activity & CBT won't be given as treatments for Long Covid?

The ME/CFS guideline is distinct to the COVID guideline and so it should not be assumed the recommendations for ME/CFS apply to long COVID.

# Can you please explain why the round-table consultation on the new ME/CFS guidelines is surrounded by so much secrecy? Would it not be better to be open and transparent so that the public can have confidence in the process?

NICE will publish statements providing information on the agenda and the constituents who are attending the roundtable.

# In Long Covid & ME/CFS NICE guidelines if exercise or CBT is given can NICE help establish patient harm reporting through the MHRA yellow-card scheme?

This is an interesting suggestion. Currently the yellow-card scheme only applies to medicines, vaccines, medical devices and diagnostics. However, we will consider with partners whether it could be extended further.

# Can you please explain how you claim that you are at the front of research etc and yet are willing to capitulate to psychologists who aren’t following the latest science? And why is the round-table so secretive? Surely an open and transparent round table makes more sense? In addition, Dame Carol Black has been involved in the fit for work schemes etc, and has worked with the PACE authors. How is she independent?

NICE has not capitulated to any particular group. We have heard concerns from a number of groups about the proposed guideline, which would affect its implementation. As noted above, information on the agenda and the groups attending will be publicly available. Dame Carol Black is felt to be sufficiently independent and has been invited to chair in order to achieve a collaborative and constructive meeting.

# I am a Carer of a young man with severe disabilities and complex needs. I noticed in your reports you consider inequalities. Have you looked into statistics for Learning disabilities who die sooner than the National population and in some areas like Sandwell die even younger? What recommendations can NICE give?

NICE has a range of recommendations in this area and a future impact report to the Board will look at the impact of our guidance in relation to learning disabilities. Health inequalities is also the first topic for our new mechanism for deliberative public engagement – NICE Listens – which will look at how we can enhance our consideration of health inequalities.

# Patient safety is the key concern for those with ME/CFS & Long Covid. How can NICE guarantee patient safety when there isn't pharmacological intervention yet harm can come from physical or mental intervention i.e. exercise/activity?

We agree it is important to ensure there is a mechanism to report concerns about non-pharmacological interventions. Please see the answer to question 3.

NICE’s advisory committees use their own discretion when developing guidance and standards. But their decisions are guided by the principles that every intervention has the potential to cause harm and may not always benefit everyone. So it is important consider the balance of benefits and harms when deciding whether an intervention is appropriate, and our guidance should help people make informed choices about the care they receive.

# Is there an action plan/timeline to give certainty to the huge amount of staff in temporary/acting up arrangements at NICE?

These arrangements are managed locally in the relevant centre/directorate rather than through a centralised action plan. The recently established role of workforce planning manager will help support managers with this.

# When will further details be released on the draft HTA collaboration with Australia and Canada? Will it involve other countries as well? And can you provide any additional information about this scheme and why it will benefit NICE/UK patients?

This collaboration is a key part of NICE’s international strategy, and also includes working with Scotland and Wales. A collaboration agreement is being drafted, which we hope to publish when finalised.

# The focus on CVD is welcomed, in reference to Meindert Boysen’s earlier comment that med tech topic selection is being strategically focused, would this disease area be a helpful starting point for selecting technologies of meaningful impact, equally the TA programme may benefit from a balancing of disease area versus the bias to cancer of recent years? If so, should this be a reportable measure to the board?

NICE’s health system partners are a key part of the topic selection process, which ensures NICE’s guidance meets system priorities. The topic selection process requires the balancing of priorities and resources. Simplifying and making the evaluation process more efficient where possible, will provide more capacity for a broader range of topics.

# What can we do in terms of policy? For instance, regarding salt, the new trial presented at the ESC meeting showing that salt substitutes reduce BP at population level? Can we have guidance for industry or for government regulation? Rather than a very individual-focused or agentic approach? For implementation more generally, the whole system needs to support those who deliver healthcare.

Responsibility for reviewing evidence to inform policy development has previously sat with Public Health England rather than NICE, and this will transfer to the Department of Health and Social Care.