

[REDACTED]

---

**From:** [REDACTED] (NHS ENGLAND & NHS IMPROVEMENT - X24) [REDACTED]  
**Sent:** 11 August 2021 22:29  
**To:** [REDACTED]  
**Subject:** Re: Following our discussion

[REDACTED],

I have read the new guideline. To me, it reads very much like the previous guideline with little change in emphasis and doesn't really address the key criticisms highlighted in the consultation. Appallingly, it continues to tell patients that there is nothing to "cure" ME, something I have never seen in another guideline (I haven't seen many of the physical health guidelines in detail, so perhaps some of these stress this?).

The main focus of the guideline is on the opinion of the GDG and it ignores the areas for the best evidence for interventions by excluding trials on spurious grounds. As NICE has approved this, which I do find extraordinary, the danger, as we discussed, is the damage to NICE's reputation and credibility. NICE has established itself as a world leader in evidence based medicine, through using processes now widely regarded as ones which remove bias, whether from poor/biased evidence or from the influence of key interested parties, whether that's the drug industry, academics/professionals with vested interests or pressure groups. This guideline, in my view, is fundamentally biased in ignoring and excluding important evidence; instead, substituting the opinions of the guideline committee. I am saying this as someone with no interests in the condition (ME/CFS) but with a strong interest in using the most reliable evidence available to underpin decision making in health. This guideline replaces the most reliable evidence available with opinion, in my view.

As I said when we discussed this, I think publishing this guideline will risk, in the short term, damage NICE's reputation by undermining professional confidence in NICE and harm people with ME/CFS by undermining public confidence in the current treatments available for ME/CFS. I am unsure what the impact will be long term. I am very happy to further discuss the way forward. Shall we try to speak tomorrow?

To reiterate, as [REDACTED], I would delay/postpone publication so as to find a way forward. I would be pleased to try to help find that way forward.

With best wishes,

[REDACTED]

[REDACTED]

---

**From:** [REDACTED]  
**Date:** Wednesday, 11 August 2021 at 18:20  
**To:** "[REDACTED] (NHS ENGLAND & NHS IMPROVEMENT - X24)" [REDACTED]  
**Subject:** Following our discussion

[REDACTED]  
National Institute for Health and Care Excellence  
Level 1A | City Tower | Piccadilly Plaza | Manchester M1 4BT | United Kingdom  
Tel: [REDACTED]