[Your Address 1]

[Your Address 2]

[Your Address 3]

[Date]

Dear [insert name of MP]

I am writing to express my concern at the recently published draft guidelines by the National Institute of Care and Health Excellence (NICE) on the subject of managing chronic pain.

As a [chronic pain sufferer myself / a family member/spouse/partner/carer of someone who lives with chronic pain], the guidelines set out are extremely worrying.

While I welcome the recommendation to make exercise, acupuncture and counselling part of the chronic pain management toolbox, I feel that it is better to ‘add to the toolbox, not just change the tools’. The guidance talks of “shared decision making” when it comes to treatment, but by taking painkillers, anti-inflammatories and steroids off the table, NICE are taking the ability to make some decisions away from patients. If treatment plans are to be tailored to each individual as the guidance says it should, we need to have every option open to patients who can then work with their doctors to find the right short, medium and long term management plans for them.

It is of great concern that the guidelines don’t lay out how patients should be treated pre-diagnosis. Should chronic pain be treated as chronic primary pain until otherwise diagnosed? If it is suspected that they have a condition like endometriosis or IBS, should they be treated as having chronic primary pain until the diagnosis is confirmed, or should they be treated as they would be once diagnosed? These questions could have a significant impact on the thousands of people who are on (often lengthy) waiting lists to see consultants in order to get a diagnosis, who risk not getting the treatment most appropriate to their situation.

This is even more so the case where a patient is suffering from a less well-known condition, where diagnosis can take years. For example, [research has shown](https://www.raredisease.org.uk/news-event/living-with-ehlers-danlos-syndrome/#:~:text=The%20same%20survey%20found%20that,with%20EDS%20is%2019%20years.) that the average time from first symptoms to diagnosis for EDS patients is 19 years. EDS is known to cause widespread chronic pain, and patients typically see a number of consultants before diagnosis is reached. Will these patients be limited in their treatment options over this extended period of time or will doctors be able (or even encouraged) to change the way they treat patients over time to reflect their healthcare journey towards diagnosis?

What is more, just like the waiting times for diagnosis, current waiting times for the treatments being recommended like CBT are often long, and in many areas ACT, acupuncture and group exercise is not yet offered by NHS Trusts. The guidance does not outline how pain should be managed while a patient waits for access to the recommended treatments, potentially causing weeks or even months or years of unmanaged pain.

When it comes to the exercise classes, the guidance does not make clear how this intervention will be implemented. Will patients be allocated to classes at random? Or will patients be allocated to classes on the basis of the starting level of activity, or their area of pain or limited mobility? The ability for these classes to be effective is dependent on how they are allocated, tailored and run, and we are concerned that not enough thought or planning has been put into how this element of the proposed guidelines will work in practice.

Even where the proposed guidelines have been thought through, the short-term thinking is of great concern. By definition, chronic pain of any sort is not short-term. Yet it seems that at least two of the four recommended treatment paths are only short-term. The guidelines specifically state that only five hours of acupuncture should be available. When talking about exercise, the guidelines do not state how long the free NHS group exercise programmes would last, but they make clear that despite advising patients to continue to exercise long-term to help continue to manage pain, it will not be a funded provision. Our 2019 research showed that 37% of respondents said cost was a barrier to accessing movement and exercise, and it is therefore imperative that further planning is put in place to support patients to continue to exercise.

Finally, at the beginning of the draft guidance, NICE recommends that doctors “Foster a collaborative supportive relationship” by “knowing the patient as an individual, enabling patients to actively participate in their care, including communication, information, shared decision making, and [recognising] that chronic pain can cause distress.”

To those of us who have lived with chronic illnesses for any length of time, these recommendations feel almost laughable. In order to really foster collaborative partnerships, two things need to happen. First, appointment times need to be extended beyond 5-10 minutes, or multiple back-to-back appointments should be made available to chronically ill patients to allow for these discussions to take place. Current appointment times just do not allow for the above list to take place. Instead, appointments are rushed and patients often feel they have missed things they wanted to say or query in the rush of the appointment – especially where cognitive impairment from brain fog, fatigue etc. play a part. Second, more interdisciplinary collaboration needs to happen. It is extremely difficult to make collaborative partnerships that enable effective and informed care plans to be made when it is so difficult for doctors to talk to each other. Currently the GP tends to be the hub of contact from what can be a variety of specialist consultants who typically don’t communicate directly with each other, and this lack of collaborative partnerships between doctors greatly limits the ability for doctors to create collaborative partnerships with patients.

As you can see, the proposals laid out by NICE create a great many questions and concerns that must be addressed before they are approved or implemented. We ask and urge you to use your power and your voice to represent those in your constituency who would be affected by these proposals by raising these concerns in the forums of power and decision-making that they - that I - do not have access to.

Thank you in advance for your help in this matter.