

With the publication of *'Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain NICE guideline [NG193]'* NICE has stumbled clumsily into a complex field. Arrogantly refusing any help, the guidelines are likely to make a terrible situation worse, substantially increasing the risks of harm patients face from mistreatment and the absence of care. We consider three examples of egregious failure in this report. The first is nosological, the second evidential, the third communicative.

Chronic primary pain is a recent category adopted in ICD11 (<https://icd.who.int/en>) to capture the experience of pain as the primary problem when there is no identified disease and thus disorder of the nociceptive system is the positive feature to assess. When recommending *'thinking about the possible causes of pain'* (points 1,1,3-1.1.7), NICE falls into the trap of presenting 'primary pain' as something out of proportion with observable disease or injury, or a diagnosis of exclusion. "1.1.4 ... if there is no clear underlying (secondary) cause or the pain or its impact is out of proportion to any observable injury or disease, particularly when the pain is causing significant distress and disability." This category error is well known in pain science and one that should have been avoided. Propagating it can only do people with chronic pain a serious disservice.

Further, this group of pain disorders is highly heterogeneous, including fibromyalgia, complex regional pain syndrome, chronic primary headache and orofacial pain, chronic primary visceral pain, and chronic primary musculoskeletal pain. That we cannot describe in detail the mechanism for each is testimony to the poverty of our science: ignorance should humble us. Too often ignorance in chronic pain emboldens observers to claim that patient suffering is disproportionate, exaggerated, unnecessary, and unworthy of medical attention.

NICE appears blinded by its methodolotrous concern with inclusivity, making well documented errors that lead to overconfident assertions of efficacy (ref). Cochrane has a review group dedicated to the treatment of evidence in pain, with expertise in how to avoid common errors. That group provided extensive feedback on the draft guidance which was made publically available (r), but all advice went unheeded. Psychological treatments they support as a class, enthusiastically promoting Acceptance and Committee Therapy for which there is poor evidence of efficacy and missing data on harms (refs). Among pharmacological options, they curiously give blanket approval for a wide class of antidepressant medicines, many of which XXX but dangerously disallow the remaining analgesic pharmacopeia: all drugs for all conditions?. More perplexing is the support for acupuncture, which has repeatedly been shown to be flawed (ref).

NICE has turned away from patients who asked that care be taken to avoid further stigmatising those whose suffering cannot be reduced to a radiographic image or biological test result. Self-report of pain is the gold standard of assessment. Implying that pain is exaggerated, that the only acceptable pharmacology is psychotropic, and that any physical or psychological therapy is safe, will undoubtedly add to stigma and social rejection that thrives when an illness and the validity of those experiencing it

are contested (ref). Extreme care should have been taken in how the scope, practice, and result of this guidance was written and communicated. While NICE makes many of its processes transparent, it goes to extraordinary lengths to justify making no changes, including in critical communication, in response to over 1000 pages of feedback (<https://www.nice.org.uk/guidance/ng193/history>). The response to consultation is long on reasons why changes will not be made, and why the process and methodological decisions should be protected.

The principal problem in this field is the challenge of a growing number of people with complex pain problems, made worse by poor investment in experimental medicine and analgesic discovery, and by the ignorance of the professional pain medicine workforce – those with most experience and skill (ref).

In chronic pain, common does not mean trivial, and ‘medically unexplained’ describes the state of the science not the patient. Patients deserve better, and we sincerely hope that those who make policy and commission services will take account of the whole complex picture before falling victim to oversimplification, a problem that haunts well-meaning attempts to guide, and one that can stop patients from progressing to effective self-management that they and their healthcare teams want.

## References

(<https://fpm.ac.uk/fpm-concerns-regarding-new-nice-chronic-pain-guidelines>).

Munglani R. Taking painkillers away from those in desperate need is a cruel health policy. Guardian 2021, April 9.

## Last paragraph

No pipeline, not new drugs, growing number of patients. Is this an attempt to define chronic pain out of medicine. Ignoring a problem does not make it go away.

Should not have included teens, for which there is no evidence.

To live with chronic pain is to live with the chronic alarm of threatened harm. Patients report being locked into a battle to be heard and understood, motivated only by the desire for a shared solution, by the need for action (ref).

Peer review is fundamental to quality scientific publishing. Knowledgeable people take time to read, digest, and offer frank criticism and praise to help editorial boards decide whether or not to publish. An editorial board that decided to publish in the face of multiple peer reviews with serious concerns would be regarded, at best, as 'courageous'.

Stakeholders comments and NICE responses to the guidance on "Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain" [1] amounts to 1148 pages. Many criticisms are serious and fundamental, and most are ignored. Criticisms are essentially of two general areas – the evidence synthesis to support the guidance, and how it relates to the real world of people with chronic pain and their professional carers.

Henry Beecher's seminal article on battle injuries and pain in 1946 [2] produced considerable detailed research into methods of measuring pain and assessing analgesic interventions. Pain was evidence-based before evidence-based medicine. The subsequent 75 years has seen the search for bias and truth continued, promoted by the widespread recognition effective interventions are few [3,4], and that treating pain is difficult [5].

The definition of chronic primary pain used includes: fibromyalgia, complex regional pain syndrome, chronic primary headache and orofacial pain, chronic primary visceral pain, and chronic primary musculoskeletal pain. The largest amount of good evidence, for duloxetine, includes fibromyalgia, chronic low back pain, osteoarthritis, and painful diabetic neuropathy. Is it right to gloss over this mismatch in what is a desperately complicated set of conditions to manage. [Words from Amanda on ICD-11]

There is probably no better examination of the possible negative impact of this NICE guidance than the opinion piece by Rajesh Munglani in the Guardian. He fears "*a foreseeable consequence of this new guidance will be the increased suffering of chronic pain patients with the indiscriminate withdrawal of powerful analgesics from many chronic pain patients by NHS commissioners.*" [5] He argues for the importance of the individual, echoing previous arguments by David Grahame-Smith [10] and Trish Greenhalgh and colleagues [11] in their critiques of evidence-based medicine.

Chronic pain is a life-changing condition, with very low quality of life, and with little knowledge of interventions effective in more than a small proportion. This guidance goes a long way down the road of promulgating stigma and rejection by misunderstanding primary pain disorder as a contested illness and promoting psychiatric drugs over pain management. This NICE report fails to use the best evidence synthesis methods for pain, fails by ignoring some interventions that might help and for which there is good evidence, and is reckless in advancing therapies where the best evidence urges caution. They have therefore failed people with chronic pain.

#### References:

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