

## Chronic Pain: assessment and management

### Consultation on draft guideline

<b>Organisation name – Stakeholder or respondent</b>		Faculty of Pain Medicine		
<b>Comment number</b>	<b>Document</b> [guideline, evidence review A, B, C etc., methods or other (please specify which)]	<b>Page number</b> Or <b>'general'</b> for comments on whole document	<b>Line number</b> Or <b>'general'</b> for comments on whole document	<b>Comments</b>
				<p>Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.</p>
1	Guideline	General	General	<p>Thank you for the opportunity to comment on the draft NICE guidelines on <i>Chronic pain: assessment and management</i>.</p> <p>We have submitted our comments below, however we would like to reinforce that we have significant concerns with the guidelines in their current form. These concerns are strongly shared by the Royal College of Anaesthetists, our multidisciplinary colleagues and lay groups. In particular, we would like to note that the FPM ANZCA have reached out to formally raise their concerns with us.</p> <p>We trust that the outlined concerns will be seriously considered as part of the review process and addressed in the final product.</p> <p>Should you wish to discuss our concerns further we would be happy to assist.</p>
2	Guideline	General	General	<p><b>We are deeply concerned this recommendation uses confusing terminology.</b></p> <p>There is failure to succinctly distinguish between “chronic pain” and “chronic primary pain” in the document, made worse by the fact that the title is about chronic pain, and the content is predominantly about chronic primary pain.</p> <p>While assessment guidance is for “all types of chronic pain”, the only management guidance for “all types of chronic pain” given relates to Pain Management Programmes (more research needed) and Social Interventions (also more research needed). <i>Everything</i> else applies to “Chronic primary pain”.</p> <p>This runs the risk of being highly confusing and damaging and essentially results in the guidelines not being fit for purpose.</p>

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				<p>As a consequence, there is a serious risk that the recommendations will be taken to apply to all chronic pain. We have seen this in the way that the draft guidelines have been reported in the press.</p>
3				<p><b>We are pleased to see ICD 11 recognised, but have serious concerns in the way in which ICD 11 classification has been used does not reflect clinical practice or the current research base.</b></p> <p>An important part of the ICD-11 definitions is that “chronic primary pain” can be changed to another ICD-11 diagnosis (e.g. neuropathic pain, cancer pain, musculoskeletal pain) when more evidence becomes available. In other words, “chronic primary pain” can be used as a terminology to acknowledge or validate the presence of chronic pain whilst awaiting further investigations or assessment that could then lead to diagnosing a specific pain condition. Whilst the advantage of ICD 11 is that it recognises pain as a condition in its own right, (allowing patients to be coded even if the underlying mechanism is yet to be fully elucidated), it does not infer a single defined entity, and as such forms a very heterogeneous group of patients.</p> <p>In fact, it is important to recognise that the diagnosis of chronic primary pain is a new entity, that has not yet found general applicability in clinical use in pain medicine, let alone been applied to a body of research about treatment. In fact, in several places in the document, the committee itself either explicitly acknowledges this and decides to include ALL chronic pain in the analysis, or in other places it seems to do this without acknowledgement. This confuses the reader and makes drawing rational conclusions tenuous.</p> <p>See the ICD-11 paper at <a href="https://pubmed.ncbi.nlm.nih.gov/30586067/">https://pubmed.ncbi.nlm.nih.gov/30586067/</a></p> <p>ICD-11 defines “chronic primary pain” as “pain in one or more anatomical regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or functional disability (interference with activities of daily life and participation in social roles) and that cannot be better accounted for by another chronic pain condition”. The flowchart in Fig 1 is, I think, where NICE have fallen down.</p> <p>Further, in the literature searches NICE have used, they have applied a different definition, so their evidence cannot directly apply: “People, aged 16 years and over, with chronic primary pain (whose pain management is not addressed by existing NICE guidance). This includes chronic widespread pain, complex regional pain syndrome, chronic visceral pain, chronic orofacial pain and chronic primary musculoskeletal pain other than orofacial pain.” In particular, this does not include anything to do with distress or disability, and will exclude studies where patients from a related “secondary pain” group will have been included.</p> <p>Not surprisingly, few studies were found, of generally low quality, mostly comparing active treatment with placebo (which is always effective in itself), in each of the management categories, then concluded on the basis of these studies, that most treatments should not be offered on the NHS.</p>

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				<p>There is a real risk that those classed as having “chronic primary pain” will include large numbers of people with a different, ultimately identifiable cause of pain, to whom this guidance should not apply. There is also the risk that patients who are diagnosed with chronic primary pain, and who subsequently develop secondary pain are neither recognised nor treated appropriately. Nor does the guidance make any allowance for the frequent co-presentation of chronic primary pain and chronic secondary pain.</p> <p>The guidance is unhelpful to the general or primary care professional who may not have access to the resources required to confidently diagnose an underlying pain condition and who may erroneously perceive the problem to be Chronic primary pain This may deny appropriate management/onward referral to some.</p> <p>Whilst the use of ICD 11 classification is welcomed to signpost pain as a disease, it is important to recognize that in clinical practice, pain diagnoses are not discrete. A useful change would be to discuss pain diagnosis as overlapping, contextual, narrative, biopsychosocial diagnosis in detail and the implications.</p> <p>Crucially, the treatment rejection list is not evidence based as some of the treatments work in the areas of overlap of the various classifications used.</p> <p>The ICD 11 classification of Chronic Primary Pain does not represent physiologically or even phenotypically distinct groups of pain disorders. For example, CRPS is widely regarded by experts as a distinct pain condition, with objectively verifiable phenomena- and either vaso- motor or neuropathic features often dominating. It is simply not reflective of our specialities attempts to help these patients that it is included in a “catch all” diagnosis of Chronic Primary Pain. It is not scientifically valid to assume evidence for one chronic primary pain condition can be generalised across all disorders included in the classification.</p> <p>NICE also does not consider the severity of the chronic primary pain condition in their treatment recommendations.</p> <p>A further personal member opinion was offered as follows:</p> <p>ICD-11 is confusing in my opinion: MJ60.1 – Primary chronic pain MJ60.11 – Chronic primary visceral pain i.e. reversal of “primary” and “chronic” Technically, “Chronic (unspecified) primary pain” does not exist. I think it would be helpful for NICE to substitute Primary Chronic Pain for Chronic Primary Pain in their document. However, what is more important in my opinion is clarity that pharmacological recommendations only pertain to Primary Chronic Pain (Chronic primary pain as defined by NICE).</p>
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4	Guideline	General	General	<p><b>We are concerned about the potential consequences of misinterpretation of these guidelines</b></p> <p>The conflation of chronic primary pain as defined by ICD 11 with chronic pain of other definitions and the subsequent rejection of efficacy of many established therapeutic options is likely to lead commissioning bodies gravely astray in their decisions regarding what treatments need to be provided by multidisciplinary pain units. The FPM harbour reservations about the possibility that the lack of clarity in the draft guidelines will lead directly to deskilling of pain services and adoption of ineffective modalities such as acupuncture instead of more appropriate and scientifically valid options.</p> <p>Specific concerns include:</p> <ul style="list-style-type: none"> <li>• Risk of decommissioning of Pain Management Programmes (PMP) because PMP is not recommended by NICE</li> <li>• Risk of secondary pain services being decommissioned due to confusion caused by this guidance</li> <li>• Potential withdrawal of useful medications from patients by GPs</li> </ul>
4	Guideline	General	General	<p><b>We have concerns about the approach to gathering and interpreting evidence used in these guidelines.</b></p> <p>The discussion of contentious areas such as gabapentinoids, acupuncture and opioids sees evidentiary standards inconsistently applied. The guidelines do not recommend pain management programs, for example, but do recommend acupuncture which has a highly suspect literature full of bias and extremely poor methodology, and is lacking in a rational scientific basis. The discussion of opioids is almost contradictory in places and seems to acknowledge that they may have short term efficacy but recommend against them on subjective grounds which are not made explicit.</p> <p>There are very significant difficulties with the application and the use of and approach to isolated areas of evidence in pain medicine in complex situations. The positivist or experimental method is methodologically unsound in this context and sociological approaches should be considered in some areas.</p> <p>Lack of evidence from one methodological approach (e.g. randomised double blind trials) is not evidence of lack of effect.</p>

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			<p>The FPM has concerns over removing treatments that are beneficial to individuals given the complexity of interpreting evidence whatever view is taken about future use of a treatment or procedure across the population of patients. Best pain practice requires a level of pragmatic support by experts in complex patients. Analysis of the cost-effectiveness of a specific treatment on an individual treatment basis could prove costly to the NHS if pathways are not considered as a whole.</p> <p>Management of these issues requires careful impact modelling on rebound costs from decision making around limiting treatments and new frameworks to determine the reliability of experiential, pragmatic evidence. (From FPM commissioning guidance 2020. In publication 2020). This NICE document risks showcasing these issues. It is expansive but confusing and therefore highly flawed to the potential serious detriment of patient care.</p> <p>Some specific points:-</p> <ul style="list-style-type: none"> <li>• PMPs when undertaken to defined National standards have a stronger evidence base than stated (See BPS document) notwithstanding the fact that many include CBT and ACT principles are used and reinforced which do have benefit. There is a large experiential type evidence much formally reported as well as trial data.</li> <li>• Strong opioids may be used for some (at a minimum intermittent, short term treatment of exacerbations of some chronic pain) from “opioids aware”. This is a much wider consensus “experience” than that applied in this document. This consensus has been deliberated at length by multiple organisations.</li> <li>• Evidence for social and many other rehab interventions are pragmatic, small-scale, context specific but often make good and logical sense with visible benefit e.g. guidance on return to work. Competent social interventions will likely not ever gain traction under the medical evidence frameworks used.</li> <li>• The key benefit of providing advice on self-purchased) TENS in avoiding harmful or expensive treatments is underemphasised and will not be resolved by the unhelpful trial data. The experience is that in contrast to acupuncture, this helpfully promotes self-efficacy and is much cheaper and saves money beyond its low cost even if the measure of efficacy is ultimately “n of 1” patient reports.</li> </ul>
5	Committee membership		<p><b>We have concerns the NICE committee is not representative of the majority of expert pain opinion.</b></p> <p>In many areas, there are references to subjective interpretations and “in the committee’s experience” but this is a somewhat weak, evidential approach for qualitative evidence. There are wider bodies of expertise available and better qualitative evidential approaches. In particular, we are concerned there is minimal pain medicine representation on the committee.</p>

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				Some members also have concern over conflicts of interest where the committees "experience" is used - Two of the members of the committee are involved with a company called Connect Health which offers community exercise programs and MSK education - two areas the guidelines recommend. They are likely to benefit from this personally.
6	Method	General	General	<p><b>We have concerns about the interpretation of evidence relating to acupuncture and the subsequent recommendations.</b></p> <p>The benefits of acupuncture are over-emphasised against the clinical experience of practitioners who have a range of other options, reflecting lack of weight given to technical flaws in the interpretation of trials. The potential harm of frequent practitioner dependency treatments in patients is not carefully considered.</p> <p>There is the assumption in assessment of studies relating to acupuncture and exercise, that 'other care' for both intervention and non-intervention groups was equal. This is - pragmatically - improbable.</p> <p>The evidence chosen for acupuncture is heavily biased towards those with a likely muscular component to their pain presentation. There are no included studies on patients with CRPS, yet this treatment is now recommended for them because they fall under the umbrella classification of 'chronic primary pain'.</p>
7	Guideline	Page 5	15 1.1.8	Good to see patient's concerns with negative or normal results are addressed and empathised with.
8	Guideline	Page 9	10 1.3.11	Not offering prescription medication could lead to patients not disclosing over the counter/non-prescribed medications they are taking for fear of criticism. Painkillers are available everywhere so they will be a person in pain's "go to" medication as a first choice and it is better for them to be prescribed and supervised rather than the patient self-medicate inappropriately.
9	Guideline	Page 9	28	Patients may be reluctant to disclose this information if they know they will be unlikely to receive any prescribed medications as above.
10	Guideline	Page 11	17	Limitations in availability of these services and it varies dramatically throughout England.
11	Guideline	Page 28	22	Patients with a long term chronic condition may feel lost if the referral to a specialist will become less likely and the GP would not have the clinical experience to manage these long term cases. This could cause strain on the GP/patient relationship as there is no onward referral pathway if the GP has to manage the patient themselves and is not expected to prescribe long term pain relief medications.
12	Evidence			Several large, high quality, randomised, double-blind trials that were used to judge evidence by, amongst others, the FDA, EMEA and Cochrane reviews have been excluded, thereby informed judgement in writing these guidelines will have been affected.
<b><i>The following comments were provided by the RCoA Lay Committee and are submitted on their behalf</i></b>				
13	Guideline	17	13	<b>RCoA Lay Committee comment:</b> This comment may imply there are no circumstances or individuals for which supporting the costs of ongoing physical activity costs are financially effective.

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### Consultation on draft guideline

14	Guideline	10	3	<b>RCoA Lay Committee comment:</b> The guidelines should include that patients can receive medical help and other help for withdrawal problems Withdrawal management is mentioned though it looks like only in passing.
15	Guideline	General	General	<b>RCoA Lay Committee comment:</b> The guidance recommends discounting some treatments currently used quite widely, e.g. some pharmacological therapies and electrical physical modalities. This will be challenging and may discourage patients if the alternative treatments which are recommended are not available in a timely manner, e.g. CBT therapy. The risk of this may be greater if the original and new treatments are provided by different organisations.  Where physical exercise is advised as a treatment there may be a challenge if local facilities, e.g. swimming pools, gyms etc. are less available or have ceased to be available because of COVID precautions.  The guidelines are overly full of do's and don'ts to the extent that it seems thin on what practitioners can usefully do. They should recommend a face to face consultation to examine what the issue is and what currently helps the patient.  As there wasn't enough evidence for anything except research recommendations, this makes the guidelines sound negative. The parts about exercise, patient involvement and recognition of patients' needs were good. Despite what they, the public may still look to Tens, ultrasound and over the counter meds when they have chronic pain.