

Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Breathworks CIC	8	198-201	Mindfulness is a non-pharmacological intervention and self-management approach that has been shown to significantly improve quality of life in chronic pain patients, with some evidence that it can reduce pain levels. It is increasingly used in clinical and non-clinical settings, and should be covered by the new guideline.	Thank you for your comment. The specific interventions that will be included within the review will be discussed and agreed with the committee when setting the review protocols.
Breathworks CIC	8	198-201	Mindfulness is an acceptance-based approach, and is sometimes grouped alongside Acceptance and Commitment Therapy (ACT) as a form of 'Third Wave' CBT, however, despite similarities, effective mindfulness teaching requires specific training and on-going personal mindfulness practice as per the Good Practice Guidelines: https://www.mindfulnessteachersuk.org.uk/guidelines/ , which are the most developed and widely used standards of good practice in mindfulness provision. (See also http://www.themindfulnessinitiative.org.uk/publications/mindful-nation-uk-report.)	Thank you for your comment and this information.
Breathworks CIC	8	198-201	Mindfulness is most-commonly introduced via 8-week courses, some generic (such as Mindfulness Based Stress Reduction - hereafter MBSR), or via a development of MBSR specifically tailored to the needs of chronic pain patients - the Breathworks <i>Mindfulness for Health</i> programme.	Thank you for your comment and this information.
Breathworks CIC	8	198-201	<i>Mindfulness for Health</i> was initially developed by a chronic pain sufferer and member of the British Pain Society, Vidyamala Burch, has been further developed over 16 years of use with patients, and is increasingly used in a variety of clinical and non-clinical pain management settings - examples include the Walton Centre Pain	Thank you for your comment and this information.

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			Management Programme, Dorset NHS Community Pain Service, Maggie's Cancer Centre in Dundee, Breathworks CIC in Manchester and London, and teachers around the UK. The course handbook <i>Mindfulness for Health</i> (Burch and Penman, Piatkus 2013) is a Reading Well Book on Prescription: http://reading-well.org.uk/books/books-on-prescription/long-term-conditions/mental-health-wellbeing .	
Breathworks CIC	8	198-201	While RCTs thus far have focused on the generic MBSR programme, <i>Mindfulness for Health</i> is a pain-specific form of MBSR, for which evaluations have found significant improvements in several of the main outcomes listed in the Guideline Scope - health-related quality of life, function and depression/anxiety. Published studies are listed at http://www.breathworks-mindfulness.org.uk/research/published-findings , also noteworthy is the data on clinical effectiveness presented to the British Pain Society's 2017 Annual Scientific Meeting, summarised at http://www.breathworks-mindfulness.org.uk/images/September_2017_Research_Update.pdf .	Thank you for your comment and this information. The specific interventions that will be included within the review will be discussed and agreed with the committee when setting the review protocols.
Breathworks CIC	8	198-201	Breathworks can provide contacts for patients who have used this approach for self-management, who could contribute to the Committee's work on the guideline. Breathworks can also assist with promotion of the guideline at the implementation phase.	Thank you for your comment and this information. However, please note that the deadline for applying for lay membership on the committee has now passed (the advert closed on 22 November).

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British HIV Association (BHIVA)	General	General	BHIVA recommends that the draft scope should include a recommendation to carry out HIV testing for unexplained peripheral neuropathy.	Thank you for your comment. The scoping group discussed this but was unable to prioritize this for inclusion in the scope..
British Pain Society	general	general	BPS welcomes the development by NICE of guidelines for the management of persistent pain which will help to further the proper recognition, assessment and management of such conditions.	Thank you for your comment.
British Pain Society	general	general	BPS emphasises the complexity of the lives of patients who have persistent pain including having high levels of psychological distress and previous difficult interactions with healthcare providers. Also, persistent pain problems frequently coexist with anxiety, distress and depression.	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain', section 3.5.
British Pain Society	general	general	It should be recognised that there are pain conditions that are not already covered by separate NICE guidance on individual pain conditions that cannot be included in a general guideline for persistent pain because they require more condition specific guidance e.g. Ehlers-Danlos syndrome and post-stroke pain. Treating persistent pain as a single clinical	Thank you for your comment. The scope has been edited to clarify that the guideline will cover all people with chronic pain. It is only reviews of specific pharmacological and non-pharmacological management in this guideline that will be limited to chronic primary pain conditions for which there is no existing NICE guidance.

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			condition will be inappropriate in many cases.	
British Pain Society	general	general	BPS agrees that treatments for persistent pain generally have low measured efficacy in controlled studies but are widely used with apparently greater benefit in the clinical setting - it welcomes the suggestion for better evaluation of these treatments together with their mechanisms of effect.	Thank you for your comment. The committee will discuss and agree the most appropriate study designs and outcome measures for each review question in order to that the most relevant and helpful evidence can be identified.
British Pain Society	general	general	BPS advises particular caution in designating pain treatments as having no clinical value on the basis of lack of published evidence of efficacy in trials that may have little relevance to the complex clinical situations that are often seen in pain clinics. The benefits of patients attending pain clinics usually go far beyond the effects of any specific treatments that they receive and include recognition of their persistent pain as a genuine phenomenon, insight into the mechanisms and effects of pain and an understanding of how best to approach living with the pain.	Thank you for your comment. NICE guidance is based on the best available clinical and cost effectiveness evidence. The appropriate type of evidence to inform the review questions will be carefully considered by the technical team and committee when setting the protocols for the reviews.

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			In this context pain treatments and psychological interventions may act as much as a vehicle for change as the specific agent of change.	
British Pain Society	general	general	The document Core Standards for Pain Management Services UK (Royal College of Anaesthetists, 2015) should be central to further developments in or recommendations for the assessment and management of persistent pain in the UK. It was drawn up by representatives of the Faculty of Pain Medicine, the British Pain Society, the Royal College of Nursing, the Royal Pharmaceutical Society, the College of Occupational Therapists, the Chartered Society of Physiotherapy, the Royal College of General Practitioners, the British Psychological Society and patient groups.	Thank you for your comment and this information.
British Pain Society	general	general	There remains mixed views on the terms persistent and chronic pain, and we request that the Guideline Development Group debate these terms as part of their review	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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Department of Health	General	general	I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you for your comment.
Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	Much research is focussed in the more specialist end of management where there are complex co-morbidities and therefore cannot be extrapolated to the whole pain population- some people manage pain very well and employ a number of strategies to do so. Needs to be clear what end points are being measured as if the desired result is pain reduction there may be little change and it is important to bear in mind the IMMPACT (Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials) recommendations on pain trials.	Thank you for your comment. The guideline committee will discuss and agree the most appropriate outcome measures for each review question in order to obtain the most relevant evidence regarding the potential benefits and harms of a treatment.
Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	The scope is very broad, in effect looking at evidence for an entire specialty. The concern is that this will result in broad conclusions rather than a more nuanced approach that may be needed. For example, the overall evidence for a drug such as carbamazepine managing pain may be very poor, but it is very good at managing specific conditions such as trigeminal neuralgia. Can all chronic pain be distilled into one guidance? Various sources of pain have evidence based therapy and the same therapy will not help all pain.	Thank you for your comment. We agree it is a broad scope, but consider that in some key areas it will be possible to provide some over-arching guidance. In areas where effectiveness or outcomes of the reviews may differ for certain populations, these may be considered as subgroups within the evidence reviews. This will be discussed and determined by the committee when setting the review protocols.
Faculty of Pain Medicine of the Royal	General	General	There is no guidance on abdomino-pelvic pain/widespread pain/headache and these require differing approaches. Should these be out of scope but referred to? Areas that	Thank you for your comment. The guideline will make overarching recommendation for assessment and management of all chronic pain conditions and will link

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College of Anaesthetists			already have NICE guidance for pain have been excluded but do talk about assessment, is this for all pain or just the non-specific? Other NICE guidance does not cover pain assessment. Should the guidance link with the other publications to help the reader understand where they join?	to other condition-specific guidance as appropriate. A NICE pathway will accompany the guideline which will link to the related guidance to the relevant sections.
Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	It is concerning that there is no mention of mechanisms that help guide management (somatic visceral, neuropathic) against condition label (fibromyalgia, CRPS) which may have more than one mechanism active.	Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines. Guidance in relation to specific discrete diagnoses may be made if sub-group analysis suggests that this is necessary.
Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	As this is a generic pathway it limits management to very generic pain conditions. The guidance needs to be clear that in some cases there is no guidance e.g. CRPS/fibromyalgia and needs to decide how and where the user would move from this guideline's scope to something else.	Thank you for your comment. Although this guideline is for all people with chronic pain and in general will provide overarching guidance, reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance. This has been clarified in the scope.

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Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	There needs to be reference to shared decision making about treatment as this improves outcomes especially in this type of condition.	Thank you for your comment. Shared decision making is considered as a principle underpinning all NICE guidance recommendations.
Faculty of Pain Medicine of the Royal College of Anaesthetists	General	General	<p>One member wanted to make the general points that are crucial to appropriate specialist care in pain medicine at the outset.</p> <p>1. Pain is a biopsychosocial outcome and arguably meets the criteria partly or wholly for a "complex adaptive system". The application of positivist evidence research methodologies is deeply flawed when applied to complex systems. By illustration, if evidence of randomised double blind trials were applied to social work, there may be little if any social care. Expert pain practice operates at the interface between medicine, psychology and sociology with complex and often unpredictable interactions. This must be understood.</p> <p>2. Low-cost interventions in specialist care may be used and may help with pain relief but more may enable engagement and help steer patients towards life-long self-management</p> <p>The value of some interventions with high numbers needed to treat (NNT) or borderline cost-effective profiles or non-qualifying research evidence is that they may prevent progression to very expensive, higher risk interventions</p>	<p>Thank you for your comment. The committee will discuss the most appropriate study designs to be included within each review while formulating the review protocols.</p> <p>As well as reviewing the clinical effectiveness of interventions, a review of the economic literature will also be undertaken for all areas of the guideline. The committee will consider cost effectiveness for each intervention reviewed to ensure recommendations reflect an efficient use of resources throughout the care pathway.</p>

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			<p>such as Dorsal Column stimulation (£70,000 -100,000 life-time costs) which is NICE approved and evidence based. Five "low value" treatments with an NNT of 8 may facilitate solutions in over half of patients where no alternatives may exist without treatment escalation. Considering quality adjusted life years (QALYS) in isolation of the total cost of care pathways is therefore a misguided approach if lowest cost and best value care is desired. The flux of patients through pathways must be considered.</p> <p>It is not proposed that treatments of borderline evidence be rolled out for widespread use. Restricting to cost-effective treatments in this way is essential throughout most of the care pathways. However, when it comes to the very end of care where expert care sits, a more flexible approach is needed to provide best care. Best care requires careful and trusted Governance from Pain Medicine and caution regarding procedure-based abandonment of respected but minority treatments.</p>	
Faculty of Pain Medicine of the Royal College of Anaesthetists	1	6	<p>The term Chronic Pain is the internationally recognised professional term not Persistent Pain. It will be the term used in the ICD-11 clinical classification system due out next year. This will allow Chronic Pain to be recorded and tracked as a condition in its own right and its association to other classifications. The introduction of ICD-11 will influence the UK recording systems. If the term Persistent</p>	<p>Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.</p>

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			pain is used it will not be correctly recorded and indexed. The term Chronic is also used by the International Association of Pain (IASP), by some patient organisations and within the NHS and its associated web sites. It is noted that Chronic Pain is not an ideal descriptor but there are limitations with persistent as well (suggesting it is present all the time) as is also true of intractable. No single word works. The title is also misleading as the management is for non-specific pain, see comment below line 114. It leaves significant risk for misinterpretation and variance in implementation of the guidance.	
Faculty of Pain Medicine of the Royal College of Anaesthetists	2	20-21	Pain can be a condition in its own right. Recognised by IASP and in ICD-11.	Thank you for your comment and this information.
Faculty of Pain Medicine of the Royal College of Anaesthetists	2	33	The definition of persistent pain is not clear. To describe one third of the population as having persistent pain overstates the population that are truly debilitated and need medical input.	Thank you for your comment.. The guideline is intended to cover all people with chronic pain, but we have updated this statement to clarify that the proportion debilitated by symptoms is unclear.
Faculty of Pain Medicine of the Royal College of Anaesthetists	2	33	Needs clarification: Is this clinical depression as a pre-existing condition in its own right? Or depression occurring in response to the persistent pain.	Thank you for your comment. The scoping group discussed this but do not think the complexity of the coexistence of depression and chronic pain and interactions between the two can be detailed within this brief guideline introduction.

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Faculty of Pain Medicine of the Royal College of Anaesthetists	3	55-72	There needs to be clarity about the methodologies when looking at some treatments e.g. acupuncture/Transcutaneous electrical nerve stimulation (TNS). There is a NIHR review on acupuncture from earlier this year that suggests acupuncture has a cost of £9,000 to £13,000 per quality-adjusted year of life gained for musculoskeletal, osteoarthritis or chronic headache pain. This is below the NHS willingness-to-pay threshold of £20,000 to £30,000 (MacPherson H, Vickers, A, Bland, M et al. Acupuncture for chronic pain and depression in primary care: a programme of research. Programme Grants ppl Res 2017; 5(3))	Thank you for your comment and this information. The published guideline will include a detailed methodology section describing how the evidence was searched, analysed and interpreted by the committee.
Faculty of Pain Medicine of the Royal College of Anaesthetists	4	95	Veteran, homeless, those with non pain mental health issues (e.g. PTSD) should be considered as specific groups	Thank you for your comment. The equalities impact form which accompanies the scope includes people who are homeless or in secure settings as a group that require consideration. Veterans and those with mental health issues are not excluded from the scope, and will be considered within the guidance.
Faculty of Pain Medicine of the Royal College of Anaesthetists	4	97	Pain and addiction is a highly complex area and deserving of its own guidance. General recommendations about medication in this area could be included in this guidance.	Thank you for your comment. This has been removed from the scope and added to the equalities impact assessment form to clarify that this will be a group that will be considered when recommendations are made. NICE has received a referral "safe prescribing and withdrawal management".

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Faculty of Pain Medicine of the Royal College of Anaesthetists	5	100	The scope of the document does not include ages under 18. Some paediatric services stop managing patients at the age of 16, with transition to adult care at this age. Current guidance and services fail this population, as well as the broader paediatric population.	Thank you for your comments. The scope has been amended to clarify it will consider young people aged 16 and over. There is existing NICE guidance on transition between services (Transition from children's to adults' services for young people using health or social care services, NG49) therefore this is outside of the scope of this guidance.
Faculty of Pain Medicine of the Royal College of Anaesthetists	5	108	Is the guideline going to limit itself to risk factors, mental health and psychosocial factors? Or is it going to suggest how to assess chronic pain, in which case will there be a pathway?	Thank you for your comment. The draft questions included within the scope cover psychological, social and biological factors that may act as barriers to pain management. The committee will discuss this evidence and agree the best way in which to formulate recommendations relating to this evidence.
Faculty of Pain Medicine of the Royal College of Anaesthetists	5	108-111	It would better to phrase this as "biopsychosocial assessment" rather than using phrases such as "emotional problems" and then this explained fully elsewhere with agreement on best evidence for the content of such an assessment.	Thank you for your comment. This has been reworded as 'Assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain'.
Faculty of Pain Medicine of the Royal College of Anaesthetists	5	109	The evidence base for risk assessment for chronic disability is poor outside back pain but is a very important area and needs to be prioritised.	Thank you for your comment. Taking account of all stakeholder comments received, the scoping group decided to re-word the key area to be covered under assessment as 'Assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain.'

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Faculty of Pain Medicine of the Royal College of Anaesthetists	5	114	Could be pertinent to use some of the new diagnoses of non-specific persistent pain in the ICD11 which although is still in development are the first specific pain codes.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
Faculty of Pain Medicine of the Royal College of Anaesthetists	5	114	Non-specific is a new term and not mentioned in the title of the guideline that clearly suggests management of persistent pain. This leaves significant risk of misinterpretation of the guideline and inappropriate application of the guidance.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
Faculty of Pain Medicine of the Royal College of Anaesthetists	5	120	It is not clear what "supported by evidence" means. Some clarity of what evidence is and is not acceptable is required along with clarity that lack of evidence is not evidence of lack of effect. A problem that has led to misinterpretation of other guidelines. Although always a risk it must be minimised to avoid patients being refused interventions that may help them.	Thank you for your comment. The committee will discuss and agree the most appropriate levels of evidence for each review question. Where no appropriate evidence is identified for a review question this will be clearly described in the linking evidence to recommendations section of the evidence review and discussed by the committee.
Faculty of Pain Medicine of the Royal College of Anaesthetists	6	124	The excluded groups also have chronic (persistent) pain. If a pathway is to be developed should it not integrate with those pathways? Accepting that there is no point in repeating their work but an integrated approach should be	Thank you for your comment. These groups are only excluded from the management reviews covering specific interventions, as NICE guidance already exists for the management of these conditions. They will

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			considered. Otherwise pain remains fragmented. Will this pathway link with those already produced?	otherwise be included within the scope of this guideline. We recognise there is an overlap of conditions. The appropriate attribution of evidence from mixed populations will be discussed by the committee when agreeing the review protocols. The pathway that will be included within the guideline will be developed based on the recommendations that are formed, according to the evidence.
Faculty of Pain Medicine of the Royal College of Anaesthetists	6	125 & 133	There is confusion about the place of Neuropathic pain and whether it will be included in the scope. It is not specifically mentioned nor excluded but CG173 is included as relevant.	This guideline will make overarching recommendations regarding assessment and management of all types of chronic pain and will make recommendations on pharmacological and non pharmacological treatment of chronic primary pain conditions that are not described in existing NICE guidance. There is existing guidance on the pharmacological management of neuropathic pain and this guideline will link to that guidance for that specific area.
Faculty of Pain Medicine of the Royal College of Anaesthetists	7	165	Will this encompass social care elements, loss earnings, tax, as well as effect on hospital and GP contact? Will it assess optimal drug and intervention use?	Thank you for your comment. In accordance with the NICE reference case this guideline will be developed from a National Health Service (NHS) and Personal Social Services (PSS) perspective. Therefore intervention use, social care elements, and physician contact will be considered where appropriate. However, loss of earnings and tax will not be directly included when assessing economic impact.

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Faculty of Pain Medicine of the Royal College of Anaesthetists	7	176	A Pathway already exists: British Pain Society Map of Medicine Assessment pathway. Is assessment going to look at mechanisms of pain: Many if not most pain is mixed, somatic, visceral, neuropathic. This helps guide management and is separate to the terminology used for the condition. There is also the contingency for individuals to have more than one problem e.g. fibromyalgia and IBS.	Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines. Guidance in relation to specific discrete diagnoses may be made if sub-group analysis suggests that this is necessary.
Faculty of Pain Medicine of the Royal College of Anaesthetists	8	186	No comment on looking at integrated management across a biopsychosocial model of pain management which is what happens in reality in many pain management services and in real clinical practice. There also needs to be clarity as to the levels and use of evidence especially if it is weak or absent.	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain' (section 3.5). Consideration of all of these elements will also be taken into account for the management reviews.
Faculty of Pain Medicine of the Royal College of Anaesthetists	8	198	What targeted support to give to people and when does it go beyond pain management programmes and to the heart of primary care? The scope of pain management programme which address beliefs and behaviours regarding pain need to be put into this context. Should a stepped care approach be considered?	Thank you for your comment. These draft review questions will be discussed and refined with the committee and stakeholder comments will be taken into account.

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Faculty of Pain Medicine of the Royal College of Anaesthetists	9	221	Will this be integrated with the other associated pathways, back, neuropathic, endometriosis?	Thank you for your comment. The draft pathway has been updated to reflect the changes in the scope.
Grünenthal Ltd	Q1	General	Existing guidance promotes the availability of a range of pharmacological and non-pharmacological treatment options in order to maximise the potential for a positive response, given that only a minority of people with persistent pain respond to any given intervention. The efficient use of NHS resources is best managed by the prompt discontinuation of ineffective therapies, rather than denying their use from the outset. Ensuring the availability of a wide range of treatment options increases the potential for a larger number of patients to achieve significant relief from persistent pain with a resultant decrease in the referral of patients to secondary care due to an inadequate response to treatment.	Thank you for your comment. We agree that efficient use of NHS resources is a priority, and the guidance attends to inform this for persistent pain. The clinical and cost effectiveness of a range of management options for persistent pain will be reviewed within the scope of this guideline.
Grünenthal Ltd	Q2	general	Chronic pain should be used as healthcare professionals (HCPs), patient and carers are more familiar with this term. Use of the term persistent pain may result in confusion thus reducing the usefulness of the guideline. Of note the draft WHO ICD 11 revision refers to chronic pain rather than persistent pain.	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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Grünenthal Ltd	General	General	A definition of persistent pain is missing from the scope. Persistent pain is typically considered as lasting for more than 3 months.	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain..
Grünenthal Ltd	2	40-43	Reference is made to further healthcare costs however these are not quantified. Healthcare utilisation cannot be quantified in randomised controlled trials (RCTs) as the structure imposed to ensure high interval validity of such trials interferes with the naturalistic use of resources observed in routine clinical practice. Healthcare utilisation can best be measured using observational study methodology. In order to quantify the healthcare utilisation associated with persistent pain, the study type filter in the systematic evidence searches should be relaxed to include observational studies.	Thank you for your comment. In addition to a review of the clinical evidence, a systematic review of the economic literature will be undertaken for all areas of the guideline. The economic literature search is not restricted to particular study types.
Grünenthal Ltd	3	51-53	It is important to note that response to treatment is bimodal. As a consequence the effect size of the average response in a population may be modest but this hides the larger clinically significant improvement observed in the subgroup of responders. Pain reduction should be measured in terms of the proportion of patients achieving a >30% and >50% reduction in pain scores or who result in not more than mild pain (≤ 3 on the 11-point NRS) ¹	Thank you for your comment which will be passed to the guideline committee. The committee will discuss and agree the most appropriate outcome measures to quantify pain reduction when formulating the review protocols.

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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			¹ Moore RA et al. Pain measures and cut-offs – no worse than mild pain as a simple, universal outcome. <i>Anaesthesia</i> 2013; 68(4); 400–412	
Grünenthal Ltd	3	51-53	Existing guidance promotes the availability of a range of pharmacological and non-pharmacological treatment options in order to maximise the potential for a positive response, given that only a minority of people with persistent pain respond to any given intervention. The efficient use of NHS resources is best managed by the prompt discontinuation of ineffective therapies, rather than denying their use from the outset. Ensuring the availability of a wide range of treatment options increases the potential for a larger number of patients to achieve significant relief from persistent pain with a resultant decrease in the referral of patients to secondary care due to an inadequate response to treatment.	Thank you for your comment. The committee will consider the evidence for the pharmacological and non-pharmacological management of chronic primary pain within the context of their clinical knowledge and experience in order to formulate recommendations that are relevant, implementable and provide the most clinically and cost effective management options for people with chronic primary pain.
Grünenthal Ltd	3	51-53	Given that no single medical intervention is helpful for more than a minority of people, specific consideration should be given to multimodal therapy and agents with more than one mechanism of action. Tapentadol is a centrally-acting analgesic that combines two mechanisms of action in a single molecule. Tapentadol acts as a μ -opioid receptor (MOR) agonist and	Thank you for your comment which will be passed to the guideline committee. The committee will discuss and agree the most appropriate interventions to be included in each review when formulating the review protocols.

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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			<p>noradrenaline reuptake inhibitor (NRI) throughout the whole duration of action of the drug, which may explain its synergistic effect on pain relief². Despite an 18-fold lower affinity for human μ receptors than morphine^{2,3}, tapentadol's NRI mechanism of action has an opioid-sparing effect resulting in strong analgesia, comparable to that of classical strong opioids, but with a reduced opioid load. This results in reduced opioid-typical side effects such as nausea and vomiting, constipation, and the potential for abuse².</p> <p>² Tzschentke T.M. et al. (2014). The mu-opioid receptor agonist/noradrenaline reuptake inhibition (MOR-NRI) concept in analgesia: the case of tapentadol. <i>CNS Drugs</i> 28(4): 319-329.</p> <p>³ Tzschentke T.M. et al. (2009). Tapentadol hydrochloride: a next-generation, centrally acting analgesic with two mechanisms of action in a single molecule. <i>Drugs Today (Barc)</i> 45(7): 483-496</p>	
Grünenthal Ltd	3	51-57	The Institute need to move away from the reliance on RCTs and to look at study designs appropriate to the clinical question. By failing to consider anything other than RCTs, the GDG will have little or no evidence on:	Thank you for your comment. The committee will discuss and agree the most appropriate study designs and outcome measures for each review question in order that the most relevant and helpful evidence can be identified.

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Persistent pain

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25/10/17 to 22/11/17

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			<ul style="list-style-type: none"> The long-term efficacy of treatments, which for ethical reasons tend to be collected in open-label extension studies and The relative risk of tolerance, dependency and abuse of treatments <p>Failure to consider these factors has the potential to put patients' safety at risk.</p>	
Grünenthal Ltd	4	97-98	It will be important to quantify the proportion of patients with persistent pain have a history of dependency on prescription medication in order to ensure that the specific consideration given in the guideline is proportionate to the extent of patient risk	Thank you for your comment. People with a current or past history of substance use disorder have been identified as needing specific consideration in the equality impact assessment section of the scope. This will be discussed in relation to the clinical evidence where appropriate and detailed in the linking evidence to recommendations section of the evidence review.
Grünenthal Ltd	5	114 - 115	Non-specific persistent pain has not been the focus of studies into the efficacy and safety of pharmacological and non-pharmacological therapies. It is important therefore to consider that lack of evidence is not evidence of a lack of effectiveness, which could unnecessarily restrict physician and patient access to treatments which could reasonably be expected to provide benefit for proportion of sufferers.	Thank you for your comment. The committee will discuss and agree the most appropriate evidence to search for each question. In the absence of any relevant evidence, the committee will discuss their knowledge and experience in the area and may make a consensus recommendation if appropriate. The committee can also make a recommendation for research to be undertaken in the area. This will be

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Persistent pain

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25/10/17 to 22/11/17

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				detailed in the linking evidence to recommendations section of the review.
Grünenthal Ltd	5	114-115	It is unclear what proportion of the prevalence and burden of persistent pain highlighted in the facts and figures section is attributed to non-specific pain, and therefore the relevance of the guideline to the end-users.	Thank you for your comment. The overarching focus of this guideline is all people with chronic pain and therefore these figures are of relevance.
Grünenthal Ltd	5	114-115	<p>Lessons should be learnt from the concerns that exist over the generation of other NICE clinical guidelines on pain management. In the neuropathic pain guideline (CG 173) the systematic literature searches conducted were inappropriately restricted to double-blind randomised controlled trials and, as a consequence, failed to comprehensively identify the published evidence to answer the review questions developed by the Guideline Development Group (GDG).</p> <p>The evidence reviewed by the GDG</p> <ul style="list-style-type: none"> • did not include estimates of clinical and cost effectiveness for 23 of the 43 products in the guideline's scope • was somewhat arbitrary in its attempt to produce unbiased estimates of effect, failing to control for sample size, methods of imputation or use of rescue and/or co-analgesia 	Thank you for your comment. The committee will discuss and agree the most appropriate evidence to search for each review question. They will discuss this evidence or lack thereof within the context of their knowledge and clinical experience and draft recommendations accordingly.

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Persistent pain

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25/10/17 to 22/11/17

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			<ul style="list-style-type: none"> unnecessarily required the GDG to make recommendations based on their opinion <p>This resulted in a guideline that:-</p> <ul style="list-style-type: none"> is based on the availability of 'best' evidence rather than the best available evidence puts clinical opinion above consideration of RCT and other systematically collected evidence unnecessarily restricts physician and patient access to treatments which could reasonably be expected to provide benefit for proportion of sufferers. 	
Grünenthal Ltd	6	125-127	<p>Osteoarthritis and rheumatoid arthritis and post-herpetic neuralgia (PHN) and diabetic peripheral neuropathy (DPN) are accepted by regulatory authorities as models of nociceptive and neuropathic pain respectively. A significant proportion of the evidence for the effectiveness of pharmacological therapies are generated in patients with these conditions. Exclusion of the evidence from these conditions will significantly undermine the evidence base for the effectiveness of pharmacological therapies in persistent pain. The risk that lack of evidence is interpreted as lack of effectiveness may unnecessarily restrict physician and patient access to treatments which could reasonably be expected to provide benefit for proportion of sufferers.</p>	<p>Thank you for your comment. Although this guideline is for all people with chronic pain and in general will provide overarching guidance, reviews of specific pharmacological and non-pharmacological management in this guideline will cover chronic primary pain conditions for which there is no existing NICE guidance. This has been clarified in the scope.</p>

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Persistent pain

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25/10/17 to 22/11/17

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Grünenthal Ltd	6	125-127	It appears that a significant proportion of the burden of persistent pain highlighted in the facts and figures section is attributed to conditions such as low back pain and arthritis which are specifically excluded from this guideline. This calls into question the impact a guideline on non-specific persistent pain will have on patient management within the NHS and therefore the value of the guideline to end users.	Thank you for your comment. This guideline is for all people with chronic pain and in general will provide overarching guidance. It is only reviews of specific pharmacological and non-pharmacological management in this guideline that will cover chronic primary pain conditions for which there is no existing NICE guidance. This has been clarified in the scope.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	General	General	We are concerned that the proposed guideline development team only contains one Allied Health Professional. A minimum should include <u>both</u> a specialist pain physiotherapist and a specialist pain occupational therapist. In addition to panel membership reflecting the non-medical focus, special inclusion of the Physiotherapy Pain Association and British Psychological Society within the consultation process.	Thank you for your comment. The proposed committee composition was to include one AHP as a full committee member and one as a co-opted committee member, to cover both OT and physiotherapy. Recruitment is currently ongoing including confirmation of the composition of the full committee. Stakeholders are able to register on the NICE website so that they are able to contribute to the consultation of the final guidance: https://www.nice.org.uk/get-involved/stakeholder-registration .
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	General	General	Given that persistent pain is by its definition is the failure of medical management to cure and the focus is therefore on returning to function within society and reducing the medical costs associated with fruitless interventions, GP and A&E visits. The guidelines should focus on living a life of quality alongside persistent pain. We are concerned that these guidelines may inadvertently overly focus on medical models of care in persistent pain.	Thank you for your comment. The current scope includes a draft question regarding strategies to improve quality of life and pain management programmes (including pain self-management and peer-led programmes). The guideline committee will discuss this evidence when formulating recommendations regarding the management of persistent pain.

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Persistent pain

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Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	General	General	The guideline committee includes an alternative health practitioner, given that Acupuncture is widely used among Physiotherapists. A Physiotherapist with a specialist interest in acupuncture would be ideal to take this position. The Acupuncture association of Chartered Physiotherapists should be invited to submit a representative for the alternative therapist role.	Thank you for your comment. Recruitment for the committee is currently ongoing and is intended to represent the expertise required according to the scope. If during the development of the guideline, additional expertise is required to inform a particular area, the committee have the option to appoint an expert witness.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	General	General	We also have some concerns about depression/anxiety being a main outcome. We recognise that while it is important and interesting to look at but we need to be looking more at self-efficacy and behaviours. We are not targeting depression and anxiety specifically so this cannot be a primary outcome measure but considered within a broader focus on helping patients live a life of quality despite persisting pain.	Thank you for your comment. The outcomes included in the scope are not exhaustive and will be discussed by the guideline committee per review question to ensure that the most appropriate evidence is identified for each review.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	17	Perhaps there should be a link or at least reference to pain mechanisms here and the pain mechanisms / neurophysiology behind persistent pain considering we are trying to improve health care professionals understanding as well as the lay person.	Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines.

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Persistent pain

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25/10/17 to 22/11/17

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				Guidance in relation to specific discrete diagnoses may be made if sub-group analysis suggests that this is necessary.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	19-20	Could this statement be reworded to avoid misinterpretation particularly when read by potential patients. This guideline is about a non-specific persistent pain and majority of these cases will not have ongoing disease processes.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	22/23	Pain also has an impact on occupations (personal and domestic activities of daily living). Does 'mobility' cover all of these in one term or would patients/families think that this just relates to walking? Relationships with friends also should be included.	Thank you for your comment. The outcomes listed in the scope are not exhaustive. The committee will discuss and decide the most appropriate outcomes for each review when developing the review protocol.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	33	Please provide citation for 'diagnosis of depression'.	Thank you for your comment, we do not usually provide references within the scope introduction.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	34	Please provide citation for '2/3 unable to work outside the home'.	Thank you for your comment, we do not usually provide references within the scope introduction.

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Persistent pain

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25/10/17 to 22/11/17

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Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	2	37	Please reword 'attempts to treat persistent pain are costly to the healthcare system' with 'managing persistent pain is expensive'. Using the word 'treat' implies that we can cure persistent pain, which we know is not the goal of treatments and is not intentionally possible.	Thank you for your comment. We believe the wording should remain, as it is the approach to treat the pain that may cause it to be costly, a different approach to management may in fact be less costly and more effective.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	3	48	Link to lower back pain NICE guidelines	Thank you for your comment. We do not usually link to other guidance or references in the Introduction.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	4	82	It may also be relevant for: department of work and pensions	Thank you for your comment. We agree this guidance may be of interest to other departments, however providing guidance to other departmental bodies specifically is beyond NICE's remit.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	4	97	Could this be linked or looked at in line with the current Pharmacological Neuropathic pain guidelines?	Thank you for your comment.. The general recommendations made in this guideline are intended for use in conjunction with existing relevant NICE guidelines. The guidance will include overarching recommendations relating to the assessment and management of chronic pain as well as providing

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Persistent pain

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25/10/17 to 22/11/17

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				specific recommendations in relation to conditions not covered by existing NICE guidance.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	4	97	Consider replacing 'people with a history of addiction' with 'people who present with substance misuse and substance misuse'. This may help to clarify and distinguish between groups of people who are not addicts and actively seeking to fulfil pleasure and gratification needs and those who are less educated about medication effects and do not meet 'addiction' diagnostic criteria, but do misuse medication.	Thank you for your comment. This has been removed from the scope and added to the equalities impact assessment form, reworded as 'people with a current or past history of substance use disorder'.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	5	112	Consider adding 'psychological interventions'	Thank you for your comment. Psychological interventions will be considered within non-pharmacological interventions when the review questions are refined by the committee.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	5	114	Recommendations of non-medical prescribers (pharmacists, physiotherapists, nurses) to be included within the multidisciplinary team should be made. Many of these professionals are already working in persistent pain environments and could train at relatively low cost to prescribe. Use of non-medical prescribers has been proven to be cost-effective, causing reduction in GP appointments and reduction in medication usage as well as identifying potential substance misuse. This is recommended by the British Pain Society <i>Core Standards for Pain Management Services in UK page 86, point 9</i>	Thank you for your comment. The composition of the multidisciplinary team is beyond the scope of this guideline.

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Persistent pain

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25/10/17 to 22/11/17

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Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	7	166 -172	Within costing of pain services please consider that pain services will differ in both structure and cost. For example a therapy led specialist community pain service such as the Homerton Locomotor Pain Service will have lower costs and different structures to secondary or tertiary pain services.	Thank you for your comment and this information. We will bear this in mind.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	7	178 -182	Please re-word this as 'prognosis' is such a medical term and is not reflective of a pain management approach, i.e. self management. It would be better to consider the extent psychosocial issues impact on people's ability to self-manage their pain	Thank you for your comment. The draft questions have been reworded to clarify that the focus of these reviews is to determine the evidence for factors that may need to be identified to optimise effective pain management (including biological, psychological and social factors).
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	7 - 8	178, 182, 183	Consider replacing the word 'prognosis' which implies that people can get better and get 'rid' of the pain with 'self-management'. It is good practice to not imply that we can determine an outcome with persistent pain.	Thank you for your comment. The word prognosis has now been removed from the draft review questions.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	186	Under management – vocational and employment interventions have not been considered. Work is discussed in the British Pain Society Guidelines as an essential component. <i>British Pain Society Guidelines for Pain Management Programmes for Adults November 2013 p19 point 4</i>	Thank you for your comment. The specific non-pharmacological interventions that will be included in the review will be discussed and agreed with the committee when setting the review protocols.

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Persistent pain

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Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	187- 189	Pain management programs should include occupational therapists as standard. If no occupational therapist is present specialist pain services should be actively training up occupational therapists. Occupational therapists are well equipped to promote return to work, improve sleep hygiene, increase social engagement and independence within the home.	Thank you for your comment. However, it is beyond the scope of this guidance to specify the composition of pain management clinics.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	209	We do recognise that a small number of specialist pain interventions can reduce pain levels. However using pain reduction as one of the main outcomes for assessing evidence available in studies on persistent pain is unhelpful and does not reflect the message given by most clinicians involved in the delivery of non- pharmacological interventions. For non-pharmacological interventions like Pain Management Programmes the general aim is to teach patients to “live well alongside pain” in line of Acceptance Commitment Therapy philosophy, rather than to “reduce pain”. This is also clear within the British Pain Society <i>Guidelines for Pain Management Programmes for Adults</i> November 2013 p.12, Aims of Treatment 3.3	Thank you for your comment. The outcomes listed in the scope are not exhaustive. The committee will discuss and agree the most appropriate and relevant outcomes for each review question in order to capture the most useful evidence.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	210	The SF12 and SF36 are not suitable for patients with low levels of education and are poorly understood among our populations. EQ5D lacks sensitivity to change in this population and has floor and ceiling effects according to our audits.	Thank you for your comment and this information. The examples of QoL indexes included within the scope are not exhaustive. The committee will discuss and agree the most appropriate and relevant measures of

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Persistent pain

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25/10/17 to 22/11/17

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				QoL to be included within each review when formulating the review protocols.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	211	Function' is a very broad term. This should be broken down into different categories and also include work	Thank you for your comment. The outcomes included within the scope are intended to be broad in order that they can be further refined following discussion with the guideline committee. The specific outcomes to be included within each review will be finalised following discussion and agreement with the guideline committee while formulating the review protocols.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	211	Consider adding 'Mobility and Self-efficacy' to Function i.e. Function, Mobility and Self-Efficacy	Thank you for your comment. The outcomes included within the scope are intended to be broad in order that they can be further refined following discussion with the guideline committee. The specific outcomes to be included within each review will be finalised following discussion and agreement with the guideline committee while formulating the review protocols.
Homerton University hospitals NHS Foundation Trust - Locomotor Pain Service	8	212	Consider separating 'Depression/Anxiety' to 'Mood' as one point, then 'Anxiety' as another point Mood will cover varying ranges of depression disorders and non-depressive low mood. Anxiety will cover varying ranges of anxiety disorders e.g. health anxiety, generalised anxiety disorder, PTSD, catastrophizing that are relevant for the persistent pain population.	Thank you for your comment. The outcomes included within the scope are intended to be broad in order that they can be further refined following discussion with the guideline committee. The specific outcomes to be included within each review will be finalised following discussion and agreement with the guideline committee while formulating the review protocols.

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Persistent pain

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InHealth Pain Management	General	General	InHealth pain management would like to offer our support for the development of these guidelines which we feel and important and timely.	Thank you for your comment.
InHealth Pain Management	General	General	<p>1. Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?</p> <p>As pointed out in the scope the nature of persistent pain is complex so that identifying specific elements that may lead to cost savings is difficult. Pain management needs to be addressed from a Biopsychosocial approach and requires a complex integration of different approaches. We believe that recommendations that guide the balance of self-management and CBT based pain management programmes, based in community settings when compared to secondary care based interventional based approaches have the potential to generate significant savings. Pilot studies of community based pain management programmes that we have conducted for CCG's have identified a reduction in cost relating to injections and medication use.</p>	<p>Thank you for your comment and this useful information.</p> <p>The scope of this guideline includes the assessment of pain management programmes and therefore a review of the literature will be undertaken for this topic.</p>

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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			<p>There is the potential to reduce medication costs, but ensuring adequate information and support to patients with persistent pain through appropriate pain management programmes is essential to achieving this.</p> <p>We would welcome a review of the evidence on the effectiveness of different models of pain management programmes as by limiting their scope and length, initial costs savings may be at the cost of effectiveness and therefore longer term costs savings in relation to potential benefits associated with increased quality of life, social engagement, return to work and reduction in medication and other interventions and health care use.</p>	
InHealth Pain Management	General	General	<p>1. Persistent pain is the proposed title of the guideline by the Department of Health. This is also frequently called chronic pain. Which term should the guideline use? Please also provide a rationale for your choice.</p>	<p>Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.</p>

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			This has been discussed and debated quite extensively and the terms are frequently used interchangeably. We would prefer the term persistent pain as this is the term preferred by most patient groups and used in the widely used Pain Toolkit	
InHealth Pain Management	2	15-25	We feel it is important that at some point that this introduction refers to understanding pain within the framework of a Biopsychosocial model and not a medical model as many interventions relating to persistent pain focus on non medical aspects, outcomes measure social and psychological benefits not just function or pain levels.	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain'. Consideration of all of these elements will also be taken into account for the management reviews.
InHealth Pain Management	2	19, 20	It is really important that it is clearly recognised that persistent pain may be associated with changes in the functioning of the nervous system rather than associated with a 'tissue injury and disease processes.' The classification of pain associated with alteration in the neurological processing of pain such as seen in Fibromyalgia, irritable bowel syndrome and Complex regional pain syndrome has been referred to by a number of terms including Nocipathic pain, Nociplastic pain and Algopathic pain, but however categorised it is important that the guidelines to not perpetuate an association between persistent pain and tissue damage.	Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines. Guidance in relation to specific discrete diagnoses may

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				be made if sub-group analysis suggests that this is necessary. The guidance will include overarching recommendations relating to the assessment and management of chronic pain as well as providing specific recommendations in relation to conditions not covered by existing NICE guidance. The committee will discuss the importance of developing a shared understanding with the patient of the potential contributors and consequences of the pain experience.
InHealth Pain Management	2	22, 23	Pain affects need to add amongst other aspects as this is not an exhaustive list	Many thanks for your comment. We have made this edit as suggested.
InHealth Pain Management	3	51-53	It is important that psychological and socially focussed interventions are given equal consideration in this scope to medical, pharmacological and non pharmacological interventions.	Thank you for your comment. All interventions within the scope will be given equal consideration.
InHealth Pain Management	3	58-59	While we accept that patients often focus on the need to identify a cause and cure for pain, this is not just to do with complexity but also a focus on medical interventions and the failure to view persistent pain in a biopsychosocial framework by both healthcare practitioners as well as those experiencing pain, a failure to distinguish persistent from acute pain and a lack of education for health care practitioners about pain	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain'. Consideration of all of these elements will also be taken into account for the management reviews.

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InHealth Pain Management	4	74-87	As pain has significant psycho social impacts should this also not include social care providers and practitioners?	Thank you for your comment. These would be included within 'local authority funded care'.
InHealth Pain Management	4	94	Pain is a significant and more prevalent issue for the older adult population. While we acknowledge there is limited research focussing on older adults would it not be important to identify the older adult as a group for special consideration? There is good evidence that the experience in pain is different for older adults and issues with polypharmacy, cognitive and sensory impairment and social isolation and multiple morbidities mean that this group warrant special consideration	Thank you for your comment. The committee will discuss the appropriateness of population stratification per review question where they agree that a recommendation would differ in a specific population (for example older adults). This can enable the committee to make separate recommendations for these populations where appropriate.
InHealth Pain Management	4	96	Many adult services are provided from age 16	Thank you for your comments. The scope has been amended to include young people aged 16 and over.
InHealth Pain Management	5	116	While it will be important to review the evidence relating the elements of Pain management programmes, we would also suggest that this include a consideration of any evidence relating to advice about diet as this is often an area not addressed and it would be helpful to know if this should be included.	Thank you for your comment which will be passed to the guideline committee. The committee will discuss and agree the most appropriate interventions to be considered for each review when formulating the review protocols.
InHealth Pain Management	8	192-3	There has been a move to develop a range of online and informationa nd communication technology facilitated pain a management approaches and while this is attractive in terms of cost there is limited advice to commissioners about the relative benefit of online Pain management	Thank you for your comment. The specific interventions that will be included within the review will be discussed and agreed with the committee when setting the review protocols.

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			programmes's and apps compared to other approaches, could this be included in the review?	
InHealth Pain Management	8	200-201	Pain management programmes are very heterogeneous and may use very different approaches and models including Cognitive Behavioural Therapy, Acceptance and commitment therapy, Compassion Focus therapy, Mindfulness are these to be reviewed separately?	Thank you for your comment. The specific pain management programmes that will be included within the review will be detailed in the review protocol following discussion with the guideline committee. Where interventions are significantly different, they will not be meta-analysed and the committee will discuss the evidence for each separately.
InHealth Pain Management	8	200-201	It would be helpful to review the evidence relating to difference aspects of PMP's including the length of the Pain management programmes, delivered in community and secondary care centres, characteristics of those delivering it	Thank you for your comment. The committee will discuss the most appropriate way to analyse and review the evidence when formulating the review protocols.
InHealth Pain Management	8	206	As the focus of many approaches to persistent pain is to promote the individuals' ability to manage to live despite their pain rather than to reduce the pain itself we would argue that pain should not be the number 1 outcome. In some patients increased activity can lead to increased pain despite better quality of life and activity. We feel that self-efficacy and ability to cope with a range of activities despite pain is important and can be measured by tools such as Pain self-efficacy questionnaire. Function should also include for example concepts such as return to work or social engagement. While function is important activity is also important to assess.	Thank you for your comment. The order of outcomes in the list is not intended to infer a priority order. These have been edited to a bulleted list to avoid confusion. Health related quality of life is also included which will include consideration of aspects such as social engagement and ability to participate activities of daily living.

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InHealth Pain Management	8	206	Pain as an outcome is a very broad concept. Does this relate to pain intensity, or to a broader definition such as measured in the Brief Pain Inventory	Thank you for your comment. The draft scope lists pain reduction as one the outcomes to be considered when searching for and assessing the evidence. The committee will discuss and agree the most appropriate definition of this outcome for each review question in order to capture the most appropriate evidence.
NHS England	General	General	This is a huge problem in primary care with large numbers of patients without a clear diagnosis or adiagnosis such as fibromyalgia. There has been a trend to increase the dose resulting in many patient over the recommended 160mg daily of morphine. (over 1500 patient in plymouth alone). Clear guidelines on prescribing and de-escalation of dosing is required which can be adopted at system level. Leaving too much to individual discretion will not help the GP having a difficult conversation with the patient.	Thank you for your comment and this information. NICE has received a referral for a guideline covering "safe prescribing and withdrawal management".
NHS England	General	General	Speicifi consideration of patients who don't believe themselves to be addicts would be helpful.	Thank you for your comment. People with a current or past history of substance misuse disorder have been identified as a group to consider within the equalities impact assessment for this guidance.
NHS England	General	General	Specific consideration of patients with dual or triple addiction too and the role of the local addiction services.	Thank you for your comment. People with a current or past history of substance misuse disorder have been identified as a group to consider within the equalities impact assessment for this guidance.

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NHS England	General	General	This guidance is urgently needed and will be welcomed by primary care and I hope there will be a strong primary care representation at the discussion.	Thank you for your comment and support for the guideline.
NHS England CRG Specialised Pain	General	General	<p>We feel the term Persistent Pain although with merit is inappropriate for this document. The term Chronic Pain has greater international recognition. It will be the term used in the ICD-11 clinical classification system due out next year. This system allows chronic pain to be recorded and tracked as a condition in its own right for the first time. The ICD system is recognised internationally and within the UK and has association to other classifications currently used within the health service. The introduction of ICD-11 will influence the UK recording systems. If the term Persistent Pain is used there is significant risk that the pain will not be correctly recorded and indexed. The term Chronic is also used by the International Association of Pain (IASP), by some patient organisations and within the NHS and its associated web sites. There is guidance explaining the definition and use of Chronic Pain in ICD 11 via the IASP website.</p> <p>It is noted that Chronic pain is not an ideal descriptor but there are limitations with persistent as well (suggesting it is present all the time) as is also true of intractable. No single word works.</p>	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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NHS England CRG Specialised Pain	General	General	The title ' <i>Persistent Pain: assessment and management</i> ' is also misleading as the management component of the scope is for non-specific pain, see comment below line 114. It leaves significant risk for misinterpretation and implementation of the guidance for all chronic pain. The title should clearly specify the guidance content and aim with the objective of minimising any risk of misinterpretation or misunderstanding.	Thank you for your comment. The terminology used in the scope has been amended to refer to 'chronic pain' and 'chronic primary pain'. The scope has also been edited to clarify that self-management will be an area that is considered for all people with chronic pain and reviews of specific pharmacological and non-pharmacological management in this guideline will cover chronic primary pain conditions for which there is no existing NICE guidance.
NHS England CRG Specialised Pain	2	20-21	' <i>Sometimes no underlying disease process can be found</i> '. Pain can be a condition in its own right. Recognised by IASP and in ICD-11. It would be helpful to add this in as well for both clinicians and patients.	Thank you for your comment. We agree that is important to be aware of, but do not believe that this edit is required in the introduction.
NHS England CRG Specialised Pain	2	33	' <i>Diagnosis of depression</i> ' Needs clarification as many patients with chronic pain do have depression but there needs to be clarity between it being clinical depression as a condition in its own right or in response to the chronic pain. In many cases both coexist. The current terminology is suggestive of clinical depression in its own right.	Thank you for your comment. The scoping group discussed this but do not think the complexity of the coexistence of depression and chronic pain and interactions between the two can be addressed within this brief guideline introduction.
NHS England CRG Specialised Pain	3	67	' <i>Evidence for effectiveness</i> '. There should also be a recognition of the gaps in evidence and as well as where the evidence is poor. Lack of evidence does not mean evidence of ineffectiveness.	Thank you for your comment. The committee will discuss the evidence taking into consideration the quality of the evidence and magnitude of effect. The committee will also discuss where gaps in the evidence exist. In this instance it is possible to specify

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			The way evidence is to be used should be explicit including, difficulties in assessing evidence, weak or incomplete evidence and or where gaps exist. In clinical practice, it is common to use more than one modality of management for patients and have some clinical benefit. The hard scientific evidence may not be available or realistically ever be available. The population with chronic pain is complex with multiple confounders that does not lend itself to clear research populations.	a research recommendation in the area. The developers of the guideline follow NICE methodology which will be detailed in the full guideline.
NHS England CRG Specialised Pain	4	95	<i>'Groups that will be covered'</i> Should consider adding 1. Transition arraignments suggested children form 8yrs or younger as many are able to understand and be actively involved in their own management. Current guidance and services fail this population. 2. Other specific populations should be considered including: veteran, homeless, those with non-pain mental health issues (e.g. PTSD).	Thank you for your comments. The scope has been amended to clarify it will consider young people aged 16 and over. There is existing NICE guidance on transition between services (Transition from children's to adults' services for young people using health or social care services, NG49) therefore this is outside of the scope of this guidance. The equalities impact form which accompanies the scope includes people who are homeless or in secure settings as a group that require consideration. Veterans and those with mental health issues are not excluded from the scope, and will be considered within the guidance.

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NHS England CRG Specialised Pain	5	108	<i>'Assessment of persistent pain'</i> . Is the guideline going to limit itself to risk factors, mental health and psychosocial factors. Or is it going to suggest how to assess chronic pain as a whole, in which case it may be more appropriate to develop a pathway of assessment. Examples have been published such as that by the British Pain Society as part of its Map of Medicine project.	Thank you for your comment. The draft questions included within the scope cover psychological, social and biological factors that may act as barriers to pain management. The scoping group decided that is not feasible within this guideline to assess all aspects of chronic pain.
NHS England CRG Specialised Pain	5	114	<i>'non-specific pain'</i> . non-specific is a new term and not mentioned in the title of the guideline that clearly suggests management of persistent pain as a whole. This leaves significant risk of misinterpretation of the guideline and inappropriate application of the guidance.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
NHS England CRG Specialised Pain	5	114	<i>'non-specific pain'</i> The conditions mentioned within the non-specific group have a variety of definitions not all of which are widely accepted.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
NHS England CRG Specialised Pain	5	120	<i>'clearly supported by evidence'</i> . It is not clear what supported by evidence means. Some clarity of what evidence is and is not acceptable is required along with	Thank you for your comment. The committee will discuss and agree the most appropriate levels of evidence for each review question. Where no

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			clarity that lack of evidence is not evidence of lack of effect. A problem that has led to misinterpretation of other guidelines. Although misinterpretation is always a risk it must be minimised to avoid patients being refused interventions that may help them. This links to comment 5 above.	appropriate evidence is identified for a review question this will be clearly described in the linking evidence to recommendations section of the evidence review and discussed by the committee.
NHS England CRG Specialised Pain	6	124	<i>'areas that will not be covered'</i> . The excluded groups also have chronic (persistent) pain. There is significant overlap between the groups included in this scope and those excluded (e.g. there is significant overlap between fibromyalgia and back pain, both can coexist). If a pathway is to be developed should it not integrate with those pathways already in existence. Accepting that there is no point in repeating their work but an integrated approach should be considered. Otherwise pain management remains fragmented. Will this pathway link with those already produced.	Thank you for your comment. These groups are only excluded from the management reviews covering specific interventions, as NICE guidance already exists for the management of these conditions. They will otherwise be included within the scope of this guideline. We recognise there is an overlap of conditions. The appropriate attribution of evidence from mixed populations will be discussed by the committee when agreeing the review protocols. The pathway that will be included within the guideline will be developed based on the recommendations that are formed, according to the evidence.
NHS England CRG Specialised Pain	7	165	<i>'Economic impact'</i> . Will this encompass social care elements, loss of earnings, tax, as well as effect on hospital and GP contact. Will it assess optimal drug and intervention use. Will any lack of data be highlighted for future development.	Thank you for your comment. . In accordance with the NICE reference case this guideline will be developed from a National Health Service (NHS) and Personal Social Services (PSS) perspective. Therefore intervention use, social care elements, and physician contact will be considered where appropriate.

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				However, loss of earnings and tax will not be directly included when assessing economic impact.
NHS England CRG Specialised Pain	7	176	<p><i>'Assessment of'</i>. Pathway already exists BPS MoM Assessment pathway</p> <p>Is assessment going to look at mechanisms of pain: Many if not most pain is mixed, somatic, visceral, neuropathic. This helps guide management and is separate to the terminology used for the condition. There is also the contingency for individuals to have more than one problem, e.g. fibromyalgia and IBS.</p> <p>The terms used as diagnoses, syndromes, causes of pain frequently fail to distinguish between the cause of the pain. In reality there are frequently (usually in chronic pain) mixed mechanisms that coexist. Understanding these helps guide management.</p>	<p>Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines. Guidance in relation to specific discrete diagnoses may be made if sub-group analysis suggests that this is necessary.</p>
NHS England CRG Specialised Pain	8	186	<p><i>'Management'</i>. There is no comment on looking at integrated management across a biopsychosocial model of pain management. Which is what happens in reality in many pain management services and in real clinical practice.</p> <p>There also needs to be clarity as to the levels and use of evidence especially if it is weak or absent.</p>	<p>Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain'. Consideration of all of these elements will also be taken into account for the management reviews. The appropriate study designs will be discussed and agreed by the committee when setting the review protocols. Levels of evidence used to inform</p>

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				recommendations will be consistent with the principles set out in the NICE guidelines manual.
NHS England CRG Specialised Pain	9	221	Will the figure integrate with the other associated pathways, back, neuropathic, endometriosis?	Thank you for your comment. The draft pathway has been updated to reflect the changes in the scope.
NHS Gloucestershire CCG	General	General	What is the definition of Persistent Pain?	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain..
NHS Gloucestershire CCG	4	78,79,80	Line 81 should replace line78.Line 81 should be at the top of the list.	Thank you for your comment. This change has been made.
NHS Gloucestershire CCG	4	97,98	What is the definition of addiction? What is the 'thing' that the patients are addicted to? This will not always be associated with persistent pain medication.	Thank you for your comment. This has been removed from the scope and added to the equalities impact assessment form, reworded as 'people with a current or past history of substance use disorder'.
North West London Clinical Commissioning Groups	5	108	It would be helpful if assessment also explicitly included some support around investigation /referral thresholds when it comes to assessment. Particularly as unnecessary diagnostics (with iatrogenic consequences) as well as recurrent specialist referrals down inappropriate pathways of care is a common burden in patient care for persistent pain. Appreciate this may be difficult as many clinical scenarios are covered by other NICE guidelines.	Thank you for your comment. The draft questions included within the scope cover psychological, social and biological factors that may act as barriers to pain management, and the scoping group hope that this will help to reduce unnecessary diagnostics and referrals. Detailed guidance on the assessment of specific pain conditions would not be feasible within this guideline.

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North West London Clinical Commissioning Groups	7	176	As well as identifying risk factors, it would be helpful for the guideline to develop a risk stratification model based on these (either the commonly mentioned 3 or 4-Tier epidemiological models) which are helpful for commissioners when it comes to funding on a population scale in deciding where resource and and capacity should be invested in, as well as referral thresholds again.	Thank you for your comment. The development of a risk stratification tools is beyond the remit of the guideline developers. The current review questions have been drafted in order that we capture both risk factors and any published and externally validated risk tools that exist. The guideline committee can also make research recommendations in these areas if little or no relevant evidence is identified.
Pain Concern	general	general	Persistent pain has been variously described as intractable, chronic, or long term pain. Literature searches for evidence to support that guidance should include all these terms.	Thank you for your comment. The committee will consider all of the possible classifications of persistent pain during the protocol setting stage of development, at which point we define the relevant populations for each review question. This will ensure that the most appropriate search terms can be agreed and the most relevant evidence searched for. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.
Pain Concern	3	51	Shared decision making with respect to pain treatments is important to patients – what is the level of evidence for its value in persistent pain?	Thank you for your comment. Shared decision making is considered as a principle underpinning all NICE guidance recommendations.

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Pain Concern	5	108	Assessment should include advice on distinguishing neuropathic and nociceptive pain, and detecting neuropathic elements in a patient with mixed pain	Thank you for your comment. There is existing NICE guidance on the pharmacological management of neuropathic pain so this is not within the scope of this guideline. The guideline will make overarching recommendation for assessment and management of all chronic pain conditions and will link to other disease specific conditions as appropriate.
Pain Concern	5	110	Pain is a complex biopsychosocial issue and so "biopsychosocial assessment" is preferred to phrases such as assessment of "emotional problems".	Thank you for your comment. This has been reworded as 'Assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain'.
Pain Concern	8	186	Advice on stratification of care should be incorporated, to ensure that not only do those with complex pain conditions who do poorly with standard care are identified and management appropriately, but also that those with less complex conditions are not over investigated or treated.	Thank you for your comment. The scope has been edited to clarify that assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain will be included, however during scoping it has been considered that there will be insufficient evidence to inform recommendations on stratified management for all people with chronic pain.
Pain Concern	8	186	The need for good support, either intensively at some points or in a continuous fashion, must be considered as patients report this helps considerably - what information is there on this and can it be stratified to differing levels and types of support in a person-focused manner?	Thank you for your comment which will be passed to the guideline committee. The specific details of areas to be covered within self-management and non-pharmacological treatments will be discussed and agreed by the committee when setting the protocols for the reviews.

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25/10/17 to 22/11/17

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Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Pain Concern	8	186	Pain education must be differentiated from treatments to bring about behaviour change – the educational element seems fundamental for all, and the behaviour change element needs to be targeted at those with more complex pain.	Thank you for your comment and this information, which will be passed to the guideline committee.
Pancreas North	6	126	The draft scope does not highlight Pancreatitis (Acute, Chronic and Hereditary) as a disease that can cause persistent pain. Would it be possible to add Pancreatitis to the list of areas that will not be covered please? A NICE guideline for Pancreatitis: diagnosis and management is currently under development and is due to be published in September 2018.	Thank you for your comment. The NICE guidance for the diagnosis and management of pancreatitis is currently in development and therefore hasn't been added to this list as it is uncertain whether the areas covered would exclude it from this guidance. After the pancreatitis guideline has been published NICE will assess how best to present both guidelines in the context of a NICE Pathway.
Pancreas North	6	130	Would it be possible to insert Pancreatitis: diagnosis and management into the related NICE guidance please? It is due to be published in September 2018.	Thank you for your comment. We have highlighted here key guidance that is most closely related. After the pancreatitis guideline has been published NICE will assess how best to present both guidelines in the context of a NICE Pathway.
Pancreatitis Support Forum	General	General	The draft scope does not mention patients whose quality of life with Chronic Pancreatitis is determined by constant pain and therefore we would wish the scope to include this group of people. CP is a disease which is characterised by pain which is not infrequently treated, with the best of intent, in primary care by the escalation of Opioid medication. Evidence would suggest that those patients who are	Thank you for your comment. The remit of this guideline is for all people with chronic pain and overarching recommendations will be made, therefore these will cover all chronic pain conditions, except for management relating to specific interventions which will not overlap with existing NICE guidance. The NICE guidance for the diagnosis and management of

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			referred to specialist pain clinics are less reliant on strong opioids and enjoy a better quality of life. Should patients have early referrals to the specialist clinics?	pancreatitis is currently being developed. Any overlap with this guidance will be considered during development of the chronic pain guideline.
Pelvic Pain Support Network	7	179-182	The comments on mental health need to be clarified. The document suggests that those with persistent pain tend to have co existing mental health conditions which makes them difficult to treat. This in many ways is damaging especially to females who often have a harder job trying to convince medical professionals they are in pain most of the time. This is especially true for gynaecological conditions. If mental health problems e.g depression or anxiety do exist in some people it needs to be explored whether this is a consequence of a delayed diagnosis for the medical problem in the first instance an secondly what part pain has played in a mental health condition developing. This is more useful to patients and their families as a significant amount of frustration will have developed when a patient has tried to get themselves diagnosed quickly and due to a lack of willingness that sometimes occurs with the medical profession patients can sometimes be waiting 5 years plus. This document needs to distinguish between those patients that have a mental health diagnosis before the onset of persistent pain and those that have developed depression and/or anxiety as a result of persistent pain. The prognosis and effect of treatment may have different success rates in	Thank you for your comment. This section has been redrafted and now focusses on draft questions on psychological, social and biological factors that may be barriers to pain management.

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			those patients with a primary diagnosis of a mental health condition and those that develop it secondary to persistent pain.	
Physiotherapy Pain Association	General	General	The proposed development group has representation from a variety of professions such as pharmacy, doctors (who are multiply represented) and psychology, however the allied health professional appears to cover both physiotherapy and OT. We would question the rationale for this and whether this provides full representation of professional groups.	Thank you for your comment. The proposed committee composition was to include one AHP as a full committee member and one as a co-opted committee member, to cover both OT and physiotherapy. Recruitment is currently ongoing.
Physiotherapy Pain Association	General	General	The term persistent rather than chronic pain is used which differs from the IASP definitions. This could lead to confusion and people not accessing the guidelines.	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.
Physiotherapy Pain Association	3	59	Would suggest" ...influence clinical interactions" not just "...clinical interactions around pain"	Thank you for your comment. We have edited this sentence as you suggest.
Physiotherapy Pain Association	3	64	Clarification: does this imply that the negative perceptions impact on therapeutic relationship or is this a question of recognition of the condition across specialties. Also, does GPs and other specialists refer to doctors or across professions?	Thank you for your comment. This is intended to highlight that uncertainties about the right way to support people with chronic pain and poor understanding of pain leads to everyone finding it difficult and generating negative perceptions that then are not good for therapeutic relationships.
Physiotherapy Pain Association	5	114	Why shift to non-specific persistent pain, and why would this be different to other persistent pain states? Is the footer	Thank you for your comment. On consideration of stakeholder's comments, this term has now been

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			note designed to be an exhaustive list of terms? This is unclear and could lead to patient and clinician misunderstanding.	removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
Physiotherapy Pain Association	5	116	How will pain management programme (PMP) be defined? Would suggest creating a distinction between peer-led programmes and therapeutic programmes with a clearly defined co-ordinating theory. Also can PMPs be uni-professional or is this covered under the broad terminology of "strategies to improve quality of life".	Thank you for your comment which will be passed to the guideline committee. The definition of interventions included within the reviews will be discussed by the committee when agreeing the protocols.
Physiotherapy Pain Association	8	188	The rationale for breaking down to strategies is unclear. How is confidence to manage condition etc defined? Also these are not usually delivered in isolation rather forming a package within a professional approach, a team approach or a peer delivered intervention.	Thank you for your comment. The questions in the scope are in a draft format and will be refined during discussions with the guideline committee. The committee will discuss the evidence from these reviews within the context of their clinical knowledge and experience to formulate relevant and implementable recommendations.
Polycystic Kidney Disease Charity	General	General	Many participants at the scoping workshop felt that 'chronic pain' was preferred to 'persistent pain'. We agree.	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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Polycystic Kidney Disease Charity	General	General	Given the nature of pain and the difficulty many patients might experience describing and /or locating it, would it be useful to develop a self-assessment tool for patients to accompany use of this guideline? A simple questionnaire to assist patients to recount, describe and relay the pain they are experiencing and how it is impacting their life. This is not mentioned in the scope.	Thank you for your comment. The scoping group discussed this but was unable to prioritize this for inclusion in the scope.
Polycystic Kidney Disease Charity	General	General	Children and young people are not included in this guideline. Care should therefore be taken to ensure effective coherence with other similar guidelines focusing on the younger age group to avoid gaps in care, medical attention and prescribing forming, particularly in general practice.	Thank you for your comments. The scope has been amended to include young people aged 16 and over. Consideration of relevant NICE guidelines will be taken into account during development of the recommendations.
Polycystic Kidney Disease Charity	2	25	We prefer the term 'experienced' rather than 'perceived, which is a weak term. The level of pain that patients endure is not easy to express. The impact has often not been taken seriously by professionals.	Thank you for your comment. We do not think that perceived is a weak term and prefer to leave the wording as is.
Public Health Agency; Northern Ireland Pain Forum	2	32	take out medical- there are other kinds of interventions. Medical implies doctor.	Thank you for your comment. This has been amended.
Public Health Agency; Northern Ireland Pain Forum	2	35	replace medical with long term conditions of ill health- there are surgical conditions also	Thank you for your comment. This has been amended.

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Public Health Agency; Northern Ireland Pain Forum	3	47	When? Per annum?	Thank you for your comment. This was the annual cost, in 1998. We are not aware of more recent data.
Public Health Agency; Northern Ireland Pain Forum	3	51	take out medical. I doubt that voluntary agencies would like to see their peer led self management programmes described as 'medical'.	Thank you for your comment. This has been amended.
Public Health Agency; Northern Ireland Pain Forum	3	52 53	need to change- there is a difference between practice and evidence. Suggest: that has been proven to be helpful for, and the existing evidence base suggests that benefits.... Remember that this is a very heterogeneous group of patients, so this state of the evidence base for interventions is hardly surprising.	Thank you for your comment. We believe the existing statement is correct and should remain unchanged.
Public Health Agency; Northern Ireland Pain Forum	5	100	Give reason	Thank you for your comment. Children and young people under the age of 16 are not included within the scope of this guideline because the needs and considerations for this group are substantially different to the adult population and therefore cannot be adequately covered within one joint guideline.
Public Health Agency; Northern Ireland Pain Forum	5	103	Add in 'could be'	Thank you for your comment. We do not agree that this should be added in. The settings included in the guideline are those currently providing NHS commissioned care.
Public Health Agency; Northern Ireland Pain Forum	5	107	Consider aetiology of persistent pain and need reference to prevention, public awareness, patient access to information and early intervention	Thank you for your comment, we expect that some of these factors will be considered within self-management.

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Public Health Agency; Northern Ireland Pain Forum	5	108	Need tools	Thank you for your comment. The draft questions included within the scope cover psychological, social and biological factors that may act as barriers to pain management. The committee will discuss this evidence and agree the best way in which to formulate recommendations relating to this evidence.
Public Health Agency; Northern Ireland Pain Forum	7	172	Given societal implications of pain and resulting disability, this perspective might not be appropriate.	Thank you for your comment. This perspective has been selected in accordance with the NICE reference case.
Public Health Agency; Northern Ireland Pain Forum	7	176	See comment 9	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.
Public Health Agency; Northern Ireland Pain Forum	8	209	Pain reduction might be better in 4th place, with QoL, function and mental state all moving up by one place.	Thank you for your comment. The order of outcomes in the list is not intended to infer a priority order. These have been edited to a bulleted list to avoid confusion.
Public Health Agency; Northern Ireland Pain Forum	8	222	In assessment box: these are known as yellow flags; in management box: You were advised in the scoping consultation meeting not to put this first. Information, self management, improvements in life style behaviours and other strategies to improve quality of life should come first as part of non pharmacological management, which include alternative/ complementary/ holistic therapies. The definition of pain management programmes can be	Thank you for your comment. The draft pathway has been updated to reflect the changes in the scope.

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			understood as referring exclusively to BPS approved 36 hour standardised PMPs, while there are many other effective group and individual therapeutic interventions of lesser intensity. Acceptance of symptoms, control of impact in life and rehabilitation are more useful concepts.	
Royal College of General Practitioners	5	110	No mention of awareness and assessment of cognitions such as fear-avoidance. Also omitted work-related factors, alcohol, smoking and substance abuse, activity level and sleep.	Thank you for your comment which will be passed to the guideline committee. The review questions included within the scope are draft and do not contain an exhaustive list of potential risk factors to be included. This will be discussed and agreed by the committee when they formulate the review protocols.
Royal College of General Practitioners	8	186	How are services set up to deal with patients with persistent pain? What are the delays in the system – by definition patients already have persistent pain if they have to wait for 3 months to see their first specialist? Are MDT pain services available in each region including a pain psychologist? Are IAPT services available with staff who are trained to deal with persistent pain? Does Public Health provide services to help people increase their activity levels, and reduce weight? What resources are available to patients to self-manage on the web, apps and in the community? What resources are provided to GPs to manage persistent pain including education and social prescribing?	Thank you for your comment. The scoping group discussed this but was unable to prioritize this for inclusion in the scope.

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Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes the proposals by NICE to develop guidelines for the management of persistent pain which will help to further the early recognition, assessment and management of this chronic condition.	Thank you for your comment.
Royal College of Nursing	General	General	The RCN recognises the complexity of people who live with persistent (chronic) pain and are very happy to see that the proposed guidelines will be solely for adults.	Thank you for your comment.
Royal College of Nursing	General	General	There is a need to recognise that patients with persistent pain often have co-existing anxiety, depression and distress. The effective management of persistent pain requires a concurrent biopsychosocial approach.	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in the key area of 'assessment of chronic pain' (section 3.5). Consideration of all of these elements will also be taken into account for the management reviews.
Royal College of Nursing	General	General	The word 'non-specific' pain is used throughout the draft scope. We suggest that 'non-specific' is removed from the scope.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
Royal College of Nursing	General	General	Although there are separate guidance for some chronic painful conditions, it must be emphasised that certain	Thank you for your comment. We agree that there are specific causes of pain which may require separate guidance for management. The main body of this

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			conditions such as post-stroke pain require their own specific guidance.	guidance is intended to provide overarching guidance for all people with chronic pain.
Royal College of Nursing	General	General	Guideline development committee: We note that NICE has advertised for a 'nurse specialist or practitioner' to be on the development committee. Whilst we welcome this gesture, in order to ensure knowledgeable and informed expert input, we ask that nursing representation on the committee should be more specific and a 'nurse specialist in pain management' should be sought as a member of the guideline development committee.	Thank you for your comment. The recruitment process is ongoing but attracted a high calibre of applicants with significant expertise.
Royal College of Nursing	2	31	Sentence; suggest possible rewording rather than " <i>few data.</i> "	Thank you for your comment. The sentence has been reworded.
Royal College of Nursing	3	54-57	Quantifying whether the death is related to treatment, pharmacological issues e.g. suicide accidental or non-accidental may make this clearer as this specifically sounds like iatrogenic due to a condition.	Thank you for your comment. The statement in the introduction relates to morbidity rather than mortality, which may vary according to treatment.
Royal College of Nursing	3	61-63	Is there statistical evidence regarding negative perceptions of pain from General Practitioners (GPs)? This should be included here.	Thank you for your comment. We are unaware of specific statistics for this point, but qualitative studies do highlight this point.
Royal College of Nursing	4	97	Further to add a link http://www.indro-online.de/letter.html that people stable on opiate substitution treatments need the same treatment as others and may in fact need more medication due to the condition of hyperalgesia.	Thank you for your comment. People with a current or past history of substance use disorder have been identified as needing specific consideration in the equality impact assessment section of the scope. This will be discussed in relation to the clinical evidence

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				where appropriate and detailed in the linking evidence to recommendations section of the evidence review.
Royal College of Nursing	5	105	We suggest that the guidelines also cover the issue about the time it takes for referral for people in chronic pain and how services should be much easier to access.	Thank you for your comment. The scoping group discussed this but was unable to prioritize this for inclusion in the scope.
Royal College of Nursing	5	110	We consider that people with learning disabilities and mental health problems are seldom taken seriously about chronic pain. The guidelines need to be asking about pain when people have checks in primary care as part of the work done yearly as part of learning disability and mental health annual reviews.	Thank you for your comment. The equalities impact assessment form that accompanies the scope details groups that have been identified as requiring consideration within the guideline and states the following: "It was noted that people with cognitive impairment, learning difficulties, those whose first language is not English, people with sensory impairment, people who are homeless or in secure settings, and people with a current or past history of substance use disorder need to be considered in development of this guideline."
Royal College of Occupational Therapists	5	114	The term 'persistent pain' (vs 'non-specific persistent pain') should be sufficient to cover all persistent pain conditions. The term 'non-specific' runs the risk of causing confusion.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.

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Royal College of Occupational Therapists	7	171	When considering economic aspects, does this include the patient's perspective? Economic implications for the patient should be included and specifically stated.	Thank you for your comment. In accordance with the NICE reference case, this guideline will be developed from a National Health Service (NHS) and Personal Social Services (PSS) perspective. Therefore this will not include costs incurred by the patient.
Royal College of Occupational Therapists	7	176	Will the guidelines explore or specify important areas of assessment above and beyond prognosis? For example: assessment of the psychological, physical and occupational impact of persistent pain – which may not always indicate or affect prognosis, but will identify important areas to address in treatment.	Thank you for your comment. The draft scope has been amended to clarify what the assessment of chronic pain will cover. This includes biological, psychological and social factors that may cause or perpetuate the experience of chronic pain.
Royal College of Occupational Therapists	7	177	Would: "Risk factors for morbidity associated with long term persistent pain" make for clearer understanding?	Thank you for your comment. The review questions have been amended to assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain.
Royal College of Occupational Therapists	7	180 - 183	It would be useful to expand on 'social' problems to ensure employment and financial impact is specifically addressed; i.e. do co-existing social and employment problems (related to the person's pain) affect the prognosis of people with persistent pain.	Thank you for your comment. The draft review questions have been reworded to give examples (unemployment, isolation, caring responsibilities).

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Royal College of Occupational Therapists	8	186	The draft scope does not yet include the clinical cost effectiveness of vocational and employment interventions. We feel this is an important intervention that needs to be considered.	Thank you for your comment. The specific non-pharmacological interventions that will be included in the review will be discussed and agreed with the committee when setting the review protocols.
Royal College of Occupational Therapists	8	198 - 199	The term 'Pain Management Programmes, including pain self-management and peer led programmes' is misleading - Pain Management Programmes are very different and separate from peer management programmes and should therefore be evaluated separately.	Thank you for your comment. The review questions in the scope are draft and will be refined during discussion with the guideline committee. Interventions which are significantly different will be analysed and discussed separately.
Royal College of Occupational Therapists	8	211	The draft scope includes function as a main outcome, which may be interpreted several ways. Could this be expanded on and clarified in the scope so engagement in work and other meaningful occupational activity are specifically addressed?	Thank you for your comment. The outcomes included within the scope are intended to be broad in order that they can be further refined following discussion with the guideline committee. The specific outcomes to be included within each review will be finalised following discussion and agreement with the guideline committee while formulating the review protocols.
Sickle Cell Intervention	General	General	Research suggests that the view that Persistent pain in young adults and children has not been applauded, assessed, designated properly and thus gets in the way of delivering better health results. Persistent pain should be used on the proposed guidelines because most illnesses associated with pain can be very persistent for example pain is associated with Sickle Cell Disease and that's the key value of clinical Care, however the body is at war with the red blood cells and cannot cope	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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			with the dangers of this suckling blood trauma. Most often the joints are affected with people with people in Sickle Cell disease.	
SIRPA Ltd	7	165	<p>I have included references to studies below which demonstrate the negative effects the following have on the persistence and severity of chronic pain – e.g. adverse childhood experiences, negative beliefs about pain, personality traits which create self-induced stress and depression.</p> <p>Our findings are that when these are addressed, through education and self-empowering strategies, recovery is possible and at the least, significant improvement, often without the need for lengthy and costly talk therapy interventions. When these issues are identified and addressed early on, there can be a significant reduction in costs involved in the treatment/management of these individuals</p> <p>Currently, although mindfulness and CBT are used as a favoured approach within pain management programmes, the emphasis is still on the belief that pain is due to a physical cause. This is despite the evidence (below) that most of the brain activity found on functional brain scans with people in chronic pain, is in the emotional centres of</p>	Thank you for your comment and this information.

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			the brain, plus the large amount of evidence demonstrating the lack of link between, for example, pain and the amount of spinal degeneration found on MRI, as well as posture and biomechanical 'abnormalities'. For example,	
SIRPA Ltd	7	165	<p>A. Lederman E. The fall of the postural-structural-biomechanical model in manual and physical therapies: exemplified by lower back pain. <i>Journal of bodywork and movement therapies</i>. 2011 Apr;15(2):131-8</p> <p>B. Kim SJ et al. Prevalence of disc degeneration in asymptomatic korean subjects. Part 1: lumbar spine. <i>Journal of Korean Neurosurgical Society</i>. 2013 Jan;53(1):31-8.</p> <p>C. Carragee EJ. Discographic, MRI and psychosocial determinants of low back pain disability and remission: a prospective study in subjects with benign persistent back pain. <i>The Spine Journal</i>. 2005, 5: 24-35</p> <p>D. Matsumoto M et al. Tandem age-related lumbar and cervical intervertebral disc changes in asymptomatic subjects. <i>European Spine Journal</i>. 2013 Apr;22(4):708-13</p> <p>E. Borenstein DG. The value of magnetic resonance imaging of the lumbar spine to predict low-back pain in asymptomatic subjects: a seven-year follow-</p>	Thank you for your comment and this information.

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			<p>up study. <i>Journal of Bone and Joint Surgery (American)</i>. 2001, 83-A: 1306-11.</p> <p>F. Brinjikji W. Systematic Literature Review of Imaging Features of Spinal Degeneration in Asymptomatic Populations. <i>American Journal of Neuroradiology</i>. 2015, 36: 811-816</p> <p>G. Kaplan LD et al. Magnetic resonance imaging of the knee in asymptomatic professional basketball players. <i>Arthroscopy</i>. 2005 May;21(5):557-61</p> <p>H. Connor PM et al. Magnetic resonance imaging of the asymptomatic shoulder of overhead athletes: a 5-year follow-up study. <i>American Journal of Sports Medicine</i>. 2003 Sep-Oct;31(5):724-7</p> <p>I. Silvis ML et al. High prevalence of pelvic and hip magnetic resonance imaging findings in asymptomatic collegiate and professional hockey players. <i>The American journal of sports medicine</i>. 2011 Apr;39(4):715-21.</p>	
SIRPA Ltd	7	178	<p>Identification of co-existing mental health conditions, emotional problems and social problems related to the person's pain - In the past the focus on chronic pain being a physical problem has meant that psychosocial factors have only more recently come to people's attention as being relevant to consider during assessment and treatment. We would suggest that these are far more relevant than is</p>	<p>Thank you for your comment. The draft questions have been reworded to clarify that the focus of these reviews is to determine the evidence for factors that may need to be identified to optimise effective pain management (including biological, psychological and social factors).</p>

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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			<p>generally believed and improved outcomes are possible when these are assessed, identified and addressed, often with self-empowering approaches.</p> <p>A) Greater exposure to past traumatic events, depressed mood and early beliefs that pain may be permanent play a major role in whether an acute injury becomes chronic. More cumulative traumatic life events, higher levels of depression in the early stages of a new pain episode and early beliefs that pain may be permanent significantly are contributors to increased severity of subsequent pain and disability. (Young Casey C et al. Transition from acute to chronic pain and disability: a model including cognitive, affective, and trauma factors. <i>Pain</i>. 2008 Jan;134(1-2):69-79).</p> <p>B) In the following study, whether pain would become persistent was predicted with 92% accuracy from psychological profiling prior to a placebo crash. (Castro WH et al. No stress--no whiplash? Prevalence of "whiplash" symptoms following exposure to a placebo rear-end collision. <i>International Journal of Legal Medicine</i>. 2001;114(6):316-22.)</p>	

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			<p>C) Since the late 1990's adverse childhood experiences have been indisputably linked with ill-health in later life, including chronic pain. (Felitti V. et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. <i>American Journal of Preventative Medicine</i> 1998 May; 14(4):245-58</p> <p>D) ACEs were also strongly linked with specific chronic pain conditions - fibromyalgia 64.7%, myofascial 61.9%, facial 50% & other pain 48.3% (Goldberg RT et al. Relationship between traumatic events in childhood and chronic pain. Disability and rehabilitation. <i>Disability Rehabilitation</i>, 1999 Jan; 21(1):23-30.)</p> <p>E) As chronic pain is now being shown to be more of an emotional disorder, than due to a physical 'abnormality', our findings are that we should be addressing unresolved emotional factors due to past and current psychosocial stressors in order to address underlying, often hidden, 'drivers' of the pain cycle. (Hashmi JA. Shape shifting pain: chronification of back pain shifts brain representation from nociceptive to emotional circuits. <i>Brain</i>. 2013 Sep; 136(9): 2751–2768).</p>	

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25/10/17 to 22/11/17

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			<p>F) Anxiety, anticipation, fear and rumination have all been shown to exacerbate pain, with the amygdalae becoming sensitised. This demonstrates the need for approaches which include cognitive strategies as well as addressing any unresolved emotional traumas which might be 'fueling' the pain cycle, both current (e.g. the trauma involved in an RTA) as well as past (e.g. identifying and addressing any ACEs)</p> <ul style="list-style-type: none"> • Lamm C et al. Meta-analytic evidence for common and distinct neural networks associated with directly experienced pain and empathy for pain. <i>NeuroImage</i> 2011 54(3):. 2492-2502 • Apkarian AV et al. Human brain mechanisms of pain perception and regulation in health and disease. <i>European Journal of Pain</i> 2005 9(4): 463-463 • Weich K et al. The influence of negative emotions on pain: behavioural effects and neural mechanisms. <i>NeuroImage</i> 2009 47(3): 987-994 • Brown CA et al. When the brain expects pain: common neural responses to pain 	

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25/10/17 to 22/11/17

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			<p>anticipation are related to clinical pain and distress in fibromyalgia and osteoarthritis. <i>European Journal of Neuroscience</i> 2014 39(4): 663-672.</p> <ul style="list-style-type: none"> Lorenz J. Keeping pain out of mind: the role of the dorsolateral prefrontal cortex in pain modulation. <i>Brain: a journal of neurology</i> 2003 126(5): 1079-1091 <p>G) Severeijns RM. Pain Catastrophizing Predicts Pain Intensity, Disability, and Psychological Distress Independent of the Level of Physical Impairment. <i>Clinical Journal of Pain</i>. 2001, 17: 165 – 172</p> <p>H) “A history of emotional abuse and neglect was associated with increased anxiety, depression, posttraumatic stress and physical symptoms, as well as lifetime trauma exposure. Physical and sexual abuse and lifetime trauma were also significant predictors of physical and psychological symptoms” (Spertus IL. Childhood emotional abuse and neglect as predictors of psychological and physical symptoms in women presenting to a primary care practice. <i>Child Abuse & Neglect</i>. 2003, 27: 1247-1258)</p>	
SIRPA Ltd	7	179/180	There is now significant evidence that past and current trauma/stress, triggers and negatively impacts chronic pain	Thank you for your comment. The draft questions have been reworded to clarify that the focus of these

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Persistent pain

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25/10/17 to 22/11/17

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			<p>conditions, yet these factors (especially past traumas) are not routinely assessed and then addressed when patients present with persistent pain. We believe that if they are identified and then addressed, not only can we help people manage their pain better, but by addressing the underlying emotional causes, recovery is more likely.</p> <p><u>A)</u> There are pernicious effects of ACEs across mental and physical domains (Sachs-Ericsson NJ. When Emotional Pain Becomes Physical: Adverse Childhood Experiences, Pain, and the Role of Mood and Anxiety Disorders. <i>J Clin Psychol</i>. 2017 Mar 22. doi:10.1002/jclp.22444. [Epub ahead of print])</p> <p><u>B)</u> Trauma has been shown to cause hypermnesia and hypersensitivity and up to 80% of people with PTSD have chronic pain. Our findings are that when we help patients address the underlying emotional traumas, outcomes improve. (Egloff N et al. Traumatization and Chronic Pain: A further Model of interaction. <i>Journal of Pain Resolution</i>, 2013; 6, 765-770)</p> <p><u>C)</u> 2,808 employees from 28 organisations, were tracked for 2 years. Conclusions: <i>'the most consistent predictors of back pain were lack ofdecision control, empowering leadership and fair</i></p>	<p>reviews is to determine the evidence for factors that may need to be identified to optimise effective pain management (including biological, psychological and social factors).</p>

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Persistent pain

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			<p><i>leadership.</i>' (Christensen JO et al. Work and back pain: a prospective study of psychological, social and mechanical predictors of back pain severity. <i>European Journal of Pain</i>. 2012 Jul;16(6):921-33. 21)</p> <p><u>D)</u> Nursing students were studied every 6 months during their 3 year training and a year later. Conclusions: <i>'Other than a history of LBP, pre-existing psychological distress was the only factor found to have a pre-existing influence on new episodes of LBP.'</i> (Feyer AM et al. The role of physical and psychological factors in occupational low back pain: a prospective cohort study. <i>Occupational and Environmental Medicine</i> 2000 Feb;57(2):116-20)</p> <p><u>E)</u> Conclusion: <i>'Stress seems to be a contributing factor in the development of fibromyalgia.'</i> (Kivimäki M et al. Work stress and incidence of newly diagnosed fibromyalgia: prospective cohort study. <i>Journal of Psychosomatic Research</i>. 2004 Nov;57(5):417-22.)</p>	

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Persistent pain

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25/10/17 to 22/11/17

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			<p><u>F)</u> Katon W. Medical symptoms without identified pathology: relationship to psychiatric disorders, childhood and adult trauma, and personality traits. <i>Annals of Internal Medicine</i>. 2001, 134: 917-925.</p> <p><u>G)</u> "These data offer support for the notion that the way adverse events are processed cognitively can be associated with physical symptoms in CD. Abnormal emotion (dorsolateral prefrontal cortex and right inferior frontal cortex) and memory control (hippocampus) are associated with alterations in symptom-related motor planning and body schema" (Aybek S et al. Neural correlates of recall of life events in conversion disorder. <i>JAMA Psychiatry</i>. 2014 Jan;71(1):52-60)</p>	
SIRPA Ltd	7	179/180	<p>J. Meta-analytic integration confirms that the four functional somatic syndromes (IBS, NUD, FM, CFS) are related to (but not fully dependent on) depression and anxiety (Henningsen P. Medically unexplained physical symptoms, anxiety, and depression: a meta-analytic review. <i>Psychosomatic Medicine</i>. 2003, 65: 528-533).</p>	Thank you for your comment and this information.

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25/10/17 to 22/11/17

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			<p>K. <i>"Stressful life events in childhood/adolescence and in adulthood seem to be very common in FMS. Furthermore, the life events were experienced as more negative than the life events experienced by healthy controls."</i> (Anderberg UM et al. The impact of life events in female patients with fibromyalgia and in female healthy controls. <i>European psychiatry : the journal of the Association of European Psychiatrists</i>, 2000 Aug;15(5):295-301.</p> <p>L. "Physical job characteristics and psychological aspects of work were more powerful than magnetic resonance imaging-identified disc abnormalities in predicting the need for low back pain-related medical consultation and the resultant work incapacity." (Boos N,et al. Natural history of individuals with asymptomatic disc abnormalities in magnetic resonance imaging: predictors of low back pain-related medical consultation and work incapacity. <i>Spine</i>. 2000, 25: 1484-92.)</p> <p>M. "Results indicated that greater baseline sensitivity to pain (lower pain unpleasantness thresholds) was associated with greater self-reported social distress</p>	

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25/10/17 to 22/11/17

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			<p>in response to the social rejection conditions. Additionally, for those in the social rejection conditions, greater reports of social distress were associated with greater reports of pain unpleasantness to the thermal stimuli delivered at the end of the game" (Eisenberger NI. An experimental study of shared sensitivity to physical pain and social rejection. <i>Pain</i>. 2006, 126: 132 – 138)</p> <p>N. "It is concluded that there is a significant association between health status and reported abuse among females presenting for pain management". (Green CR. The role of childhood and adulthood abuse among women presenting for chronic pain management. <i>The Clinical Journal of Pain</i>. 2001, 17: 359-364)</p>	
SIRPA Ltd	8	181	<p>With most brain activity being found to be in the emotional centres of the brain with people with persistent pain, it would suggest that we need to focus more on underlying unresolved, or avoided, emotions which often remain as 'drivers' of the pain when not addressed. Cognitive Behavioural Therapy (CBT) can be very helpful when working with thoughts, beliefs and behaviours, but there is</p>	Thank you for your comment and this information.

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Persistent pain

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			<p>very little awareness of the need to address the underlying emotional causes as well, which can often be done through cost effective and self-empowering strategies, such as emotional awareness and expression strategies, including therapeutic journaling and somatic tracking, as well as CBT tools and mindfulness.</p> <p>A. <i>“An intervention targeting emotional awareness and expression related to psychosocial adversity and conflict was well received, more effective than a basic educational intervention, and had some advantages over CBT on pain”</i> (Lumley M et al Emotional awareness and expression therapy, cognitive behavioral therapy, and education for fibromyalgia: a cluster-randomized controlled trial <i>Pain</i>. 2017 Dec 158(12):2354–2363)</p> <p>B. Hsu MC et al. Sustained pain reduction through affective self-awareness in fibromyalgia: a randomized controlled trial. <i>Journal of general internal medicine</i>. 2010 Oct;25(10):1064-70</p> <p>C. Burger AJ, A Preliminary Trial of a Novel Psychological Attribution and Emotional Awareness Intervention for Chronic Musculoskeletal Pain. <i>Journal of Psychosomatic Research</i>. 2016, 81: 1-8.</p>	

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Persistent pain

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25/10/17 to 22/11/17

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			D. <i>"Emotions are integral to the conceptualization, assessment, and treatment of persistent pain. Research should clarify when to eliminate or attenuate negative emotions, and when to access, experience, and express them. Theory and practice should integrate emotion into cognitive-behavioral models of persistent pain."</i> (Lumley MA. Pain and emotion: a biopsychosocial review of recent research. <i>Journal of Clinical Psychology</i> . 2011, 67: 942-68)	
SIRPA Ltd	8	188	<p>Our findings are that with an educational, emotionally-focused approach, when the underlying emotional stressors/traumas are identified and addressed (unresolved from the past or avoided in the present), as well as addressing the fears related to their condition/diagnosis etc, recovery is possible. With a primarily educational and self-empowering/emotionally-focused programme, where the emphasis is on pain resolution, significant cost savings can be achieved.</p> <p>A. Pennebaker J. <i>Writing to Heal: A guided journey to recovering from trauma and emotional upheaval</i>. New Harbinger Publications, Inc. Oakland, CA. 2004</p>	Thank you for your comment and this information.

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			<p>B. Pennebaker J. Opening Up by Writing It Down, Third Edition: How Expressive Writing Improves Health and Eases Emotional Pain. Guilford Press; 3 edition (20 July 2016)</p> <p>C. Gortner EM et al. Benefits of expressive writing in lowering rumination and depressive symptoms. <i>Behavior Therapy</i>, 2006 Sep;37(3):292-303. Epub 2006 May 30</p> <p>D. Smyth JM et al. Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis: a randomized trial. <i>Journal of the American Medical Association</i>. 1999 Apr 14;281(14):1304-9</p> <p>E. Baikie KA. Expressive writing and positive writing for participants with mood disorders: an online randomized controlled trial. <i>Journal of affective disorders</i>. 2012 Feb;136(3):310-9</p>	
The Pelvic Partnership	1	6	I understand the reasons behind using persistent pain instead of chronic pain but it is still likely to be confusing for patients especially until persistent pain is a universally accepted term. Many professionals still use the term chronic pain. I think it would be helpful for the guideline to be named 'Persistent/Chronic pain: assessment and management' until persistent pain is the widely used term.	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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Persistent pain

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The Pelvic Partnership	7	176	There is no question identifying who should assess people with suspected persistent pain and if this should be a GP or a multi-disciplinary assessment. Assessment and management of persistent pain is variable across the country so this would be helpful to clarify in this guideline.	Thank you for your comment. NICE guidelines generally recommend what should be done rather than who should do it, since the skills of individuals with similar job titles can be variable.
The Pelvic Partnership	7	178	It would be helpful to clarify this as many causes of persistent pain are often missed during assessment even if they should have been ruled out at an earlier stage e.g diagnosis of endometriosis or pelvic girdle pain which can mean effective treatment for peoples persistent pain will likely be missed.	Thank you for your comment. The guideline will make recommendations for the management of chronic pain symptoms: the importance of identifying potentially remediable pathology is an important general recommendation but reviewing evidence for the diagnosis of diverse specific medical conditions would not be feasible within this guideline.
The Pelvic Partnership	8	198	It would be useful to identify the best composition of these programmes as practice is currently so variable. Having a question in this section to capture this would be helpful. Also on-line tools/apps for self-management for example the pain toolkit would be helpful to identify in this section.	Thank you for your comment. These draft review questions will be discussed and refined with the committee and stakeholder comments will be taken into account.
The Walton centre NHS Foundation Trust, Liverpool	1	6	Persistent Pain: assessment and management: The term Chronic Pain has greater international recognition. It will be the term used in the ICD-11 clinical classification system due out next year. This will allow chronic pain to be recorded and tracked as a condition in its own right and its association to other classifications. The introduction of ICD-11 will influence the UK recording systems. If the term Persistent pain is used it will not be correctly recorded and	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.

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			indexed. The term Chronic is also used by the International Association of Pain (IASP), by some patient organisations and within the NHS and its associated web sites.	
The Walton centre NHS Foundation Trust, Liverpool	3	67	Evidence for effectiveness. There should also be a recognition of the gaps in evidence and as well as where the evidence is poor. Lack of evidence does not mean evidence of ineffectiveness	Thank you for your comment. The committee will discuss the evidence taking into consideration the quality of the evidence and magnitude of effect. The committee will also discuss where gaps in the evidence exist. In this instance it is possible to specify a research recommendation in the area. The developers of the guideline follow NICE methodology which will be detailed in the full guideline.
The Walton centre NHS Foundation Trust, Liverpool	4	95	3.1 Groups that will be covered: Should add 1. Transition arraignments suggested children from 18yrs or younger as many are able to understand and be actively involved in their own management. Current guidance and services fail this population. 2. veteran, homeless, those with non-pain MH issues (e.g. PTSD) should be considered as specific groups	Thank you for your comments. The scope has been amended to include young people aged 16 and over. There is existing NICE guidance on transition between services (Transition from children's to adults' services for young people using health or social care services, NG49) to which this guidance will cross-refer if appropriate. The equalities impact form which accompanies the scope includes people who are homeless or in secure settings as groups that require special consideration. Veterans and those with mental health issues are not

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25/10/17 to 22/11/17

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				excluded from the scope, and will be considered within the guidance.
The Walton centre NHS Foundation Trust, Liverpool	4	96	Who is the focus - "Adults with persistent pain". its very unclear what the guidelines will be specifically relating too in the definition of "persistent pain" - that a big area!! whats the missing gap they trying to fill??? (what conditions will they focus on?) and its unlikely that this overrides specific pain guidelines and then also surely they need to be somewhat commensurate with other guidelines recommendations, particularly around rehab/PMP where diagnoses are generally not seen as separate "entities" requiring vastly different approaches (for the most part)	Thank you for your comment. This guideline will make overarching recommendations regarding assessment and management of all types of chronic pain and will make recommendations on pharmacological and non pharmacological treatment of chronic primary pain conditions that are not described in existing NICE guidance.
The Walton centre NHS Foundation Trust, Liverpool	5	114	non-specific pain: non-specific is a new term and not mentioned in the title of the guideline that clearly suggests management of persistent pain. This leaves significant risk of misinterpretation of the guideline and inappropriate application of the guidance.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
The Walton centre NHS Foundation Trust, Liverpool	5	120	clearly supported by evidence: It is not clear what supported by evidence means. Some clarity of what evidence is and is not acceptable is required along with clarity that lack of evidence is not evidence of lack of effect. A problem that has led to misinterpretation of other guidelines. Although always a risk it must be minimised to	Thank you for your comment. The committee will discuss and agree the most appropriate levels of evidence for each review question. Where no appropriate evidence is identified for a review question this will be clearly described in the linking evidence to

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25/10/17 to 22/11/17

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			avoid patients being refused interventions that may help them.	recommendations section of the evidence review and discussed by the committee.
The Walton centre NHS Foundation Trust, Liverpool	7	165	3.4 Economic impact: Will this encompass social care elements, loss earnings, tax, as well as effect on hospital and GP contact. Will it assess optimal drug and intervention use.	Thank you for your comment. In accordance with the NICE reference case this guideline will be developed from a National Health Service (NHS) and Personal Social Services (PSS) perspective. Therefore intervention use, social care elements, and physician contact will be considered where appropriate. However, loss of earnings and tax will not be directly included when assessing economic impact.
The Walton centre NHS Foundation Trust, Liverpool	7	176	Assessment of; Pathway already exists BPS MoM Assessment pathway Is assessment going to look at mechanisms of pain: Many if not most pain is mixed, somatic, visceral, and neuropathic. This helps guide management and is separate to the terminology used for the condition. There is also the contingency for individuals to have more than one problem e.g. fibromyalgia and IBS.	Thank you for your comment. The biological mechanisms underlying different pain conditions are debated and often multifactorial. This guidance aims to provide recommendations relevant to assessment and general management of all chronic pain conditions with evaluation of specific interventions for chronic pain conditions not encompassed by other NICE guidance. The general recommendations are intended for use in conjunction with existing relevant NICE guidelines. Guidance in relation to specific discrete diagnoses may be made if sub-group analysis suggests that this is necessary.
The Walton centre NHS Foundation Trust, Liverpool	8	186	Management: No comment on looking at integrated management across a biopsychosocial model of pain	Thank you for your comment. The scope of the guideline has been amended to clarify that biological, psychological and social factors will be considered in

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25/10/17 to 22/11/17

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			management. Which is what happens in reality in many pain management services and in real clinical practice. There also needs to be clarity as to the levels and use of evidence especially if it is weak or absent.	the key area of 'assessment of chronic pain'. Consideration of all of these elements will also be considered for the management reviews. The appropriate study designs will be discussed and agreed by the committee when setting the review protocols. Levels of evidence used to inform recommendations will be consistent with the principles set out in the NICE guidelines manual.
The Walton centre NHS Foundation Trust, Liverpool	8	200	<ul style="list-style-type: none"> • there are a number of problems re-evaluating PMP efficacy & cost effectiveness: • the MDT nature – how can we reliably pull out what bit of a MDT programme is “the key ingredient” – which bit works and for whom and when? rather more likely, it all works together as a package and interplay with each other – in RCTs, hard to statistically measure this. • Variance across services – what classes as a PMP? And the guidelines have not helped with standardising this at all as no regulation. Therefore, meta analyses/reviews of literature are always weakened by studies being so different – 10 hours vs +100 hours – you can't clump this together to make general recommendations re effectiveness and outcome, but they do!! we even have different screening 	<p>Thank you for your comment. The specific interventions, and inclusion/exclusion criteria of the studies to be included within the review will be discussed and agreed by the committee when setting the review protocols. The committee will discuss to what extent interventions are similar enough to be meta-analysed. Where interventions are significantly different these will be analysed and discussed separately.</p> <p>A systematic review of the economic literature will be undertaken for all areas of the guideline. If there is a lack of published literature the committee can prioritise topics for original economic analysis subject to the availability of suitable data. If no published literature is available the committee will make a qualitative judgement of the cost effectiveness of interventions.</p>

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Persistent pain

Consultation on draft scope Stakeholder comments table

25/10/17 to 22/11/17

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			<p>processes, different inclusion criteria, different pain presentations, various complexities of patients, different speciality/experience of staff etc.... – yet lumped into one thing called “PMPs”</p> <ul style="list-style-type: none"> • Cost effectiveness almost impossible to measure in great detail. So little health economic data available. Individual services struggle to reliably measure impact on healthcare use (GP visits, medication reduction, A&E reduction) – because this entirely dependent on patient report. We have not got access to regional or cross centre information like this to provide robust data. We then certainly don't have access to data for social economics – return to work, benefits, education reengagement – again we rely on self-report. Most of which is not routinely asked for in some services. <p>Struggle to measure longitudinal outcome – most services only commissioned to provide follow up until 6 months. Therefore few data around 2yrs + although there is some. BUT then again, how to control for other mediating factors that could impact reported outcome/LT efficacy – e.g. change to meds, further Rx/surgeries, family issues, MH issues, work issues, new symptoms in that intervening time???? However, this effects ability for</p>	<p>This guideline will be developed from a National Health Service and Personal Social Services perspective.</p>

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Persistent pain

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			accurate longitudinal clinical data collection for most conditions I suppose.	
The Walton centre NHS Foundation Trust, Liverpool	9	221	Fig. Will this integrate with the other associated pathways, back, neuropathic, endometriosis?	Thank you for your comment. The draft pathway has been updated to reflect the changes in the scope.
UKCPA: Pain Management Group	1	6	Maintain the term "Persistent Pain" for the reasons stated at the "scope workshop discussions" – "'Chronic' was dropped as a term in the UK due to having negative connotations to patients"	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.
UKCPA: Pain Management Group	7	176	There are some useful specific questions regarding assessment, but there is no mention of which domains should be included and whether specific assessment tools are recommended.	Thank you for your comment which will be passed to the guideline committee. The details of the review questions and specifics that will be considered will be discussed and agreed by the committee when setting the protocols.
UKCPA: Pain Management Group	8	186	Clarity on the question of pharmacological therapy where misuse / dependence has been reported or is of concern would be of benefit. The guideline would also benefit from including guidance / signposting on how the issue of morphine (or equivalent) doses over 120mg should be managed in practice (especially in primary care)	Thank you for your comment. People with a current or past history of substance use disorder have been identified as needing specific consideration within the equality impact assessment section of the scope. The committee will discuss this group where appropriate and detail this in the linking evidence to recommendations section of the review. The committee will discuss and agree the most appropriate medicines and doses to be included within

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Persistent pain

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25/10/17 to 22/11/17

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				the review when formulating the review protocols. NICE has received a referral "safe prescribing and withdrawal management".
University College London Hospitals, (Pain Management Centre)	1	6	We recommend using the same terminology as used by IASP and in ICD 1, i.e. Chronic Pain rather than Persistent Pain, to avoid confusion	Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.
University College London Hospitals, (Pain Management Centre)	3	50	The importance of movement and activity in managing chronic pain should be included in this section	Thank you for your comment. The guidance will make recommendations relevant to manage all types of chronic pain. The specific interventions that will be included will be agreed by the committee when setting the review protocols for the questions, but it is likely to include activity based interventions.
University College London Hospitals, (Pain Management Centre)	4	82-84	Include Public health here	Thank you for your comment. Public health is included within 'all settings where NHS or local authority funded care is provided'
University College London Hospitals, (Pain Management Centre)	4	96-98	Unclear whether this means it will be covered in this guideline with special consideration, or covered elsewhere	Thank you for your comment. This section has been updated to clarify.
University College London Hospitals,	4	97-98	People with cognitive impairment, other non-pain related mental health diagnosis, young adults (transition patients), veterans, victims of torture and people who have	Thank you for your comment. The equalities impact assessment form that accompanies the scope details

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Persistent pain

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25/10/17 to 22/11/17

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(Pain Management Centre)			English as a second language or cannot speak English, also require special consideration	these groups that have been identified as requiring consideration within the guideline.
University College London Hospitals, (Pain Management Centre)	5	112	Exercise and activity should also be reviewed as this may be distinct from pain management programmes	Thank you for your comment, which will be passed to the guideline committee. The committee will discuss and agree the most relevant interventions to be included within the review protocols.
University College London Hospitals, (Pain Management Centre)	5	114	The term "non-specific persistent pain" may be problematic, some would not consider CRPS or Fibromyalgia, for example, to be non-specific.	Thank you for your comment. On consideration of stakeholder's comments, this term has now been removed and it has been clarified that reviews of specific pharmacological and non-pharmacological management in this guideline cover chronic primary pain conditions for which there is no existing NICE guidance.
University College London Hospitals, (Pain Management Centre)	6	124	We anticipate that this will limit the available evidence upon which to base these guidelines	Thank you for your comment.
University College London Hospitals, (Pain Management Centre)	7	176-184	The emphasis here is on psychological and social impact and we acknowledge the importance of this, however it may be helpful to consider whether co-existing physical health problems affect prognosis and management also.	Thank you for your comment which will be passed to the guideline committee. The committee will discuss and agree the most appropriate risk factors to be included within the review when formulating the review protocols.
University College London Hospitals,	8	186-191	Include physical activity and exercise here.	Thank you for your comment. The specific non-pharmacological interventions that will be included in

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(Pain Management Centre)				the review will be discussed and agreed with the committee when setting the review protocols.
University College London Hospitals, (Pain Management Centre)	8	192-197	Non-pharmacological is vague and needs clarification; what is covered by the term non-pharmacological and what is not?	Thank you for your comment. The specific interventions that will be included within the review will be discussed and agreed with the committee when setting the review protocols.
University College London Hospitals, (Pain Management Centre)	9	221	Red flag pathology whilst important should be addressed prior to a diagnosis of chronic pain so we recommend this is outside the remit of this guideline.	Thank you for your comment. The draft pathway has been updated to reflect the changes in the scope.
Warwick Clinical Trials Unit	2	21	Might it be better to describe the impact of pain as being substantial or burdensome rather than significant. It might be having a statistically significant impact at a population level that is clinically irrelevant	Thank you for your comment. When interpreting the evidence the committee will not be considering statistical significance but rather the clinical importance in the context of benefit versus harm. This is assessed per outcome based on predefined thresholds agreed by the committee.
Warwick Clinical Trials Unit	3	44	The statement that economic impact of pain is higher than for other medical conditions is not substantiated with any comparative data. The figures for indirect costs of back pain whilst correctly extracted from the relevant paper is really not pertinent to this guideline as it relates to data that are 19 years old and for a disorder that is explicitly excluded from this guideline. Also of course, NICE is precluded from taking such data into account when considering cost effectiveness	Thank you for your comment. This statement has been reworded to state that "the economic impact of pain is high due to absenteeism, poor productivity and people with pain leaving the work force." The economic impact is difficult to quantify; there are data available that demonstrate indirect costs of back pain but not of the more general costs of pain management.

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Persistent pain

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25/10/17 to 22/11/17

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Warwick Clinical Trials Unit	4	95	<p>The issue of describing the topic of interest as persistent pain or chronic pain is complex and we do not have consensus internally on this. However, WHO have lobbied to get 'Chronic pain syndrome' within the ICD-10 classification & is coming out as Diagnosis code G89.4 so probably worth linking with this The ICD-10 categories are G89, Pain not elsewhere classified (synonym – chronic pain with psychosocial dysfunction)</p> <p>http://www.icd10data.com/ICD10CM/Codes/G00-G99/G89-G99/G89-/G89.4</p> <p>Whatever the final decision here there does need to be clear explanation of the topic of interest and time lines used to define persistent or chronic</p>	<p>Thank you for your comment. On consideration of the stakeholder responses, and consistency with proposed WHO ICD 11 terminology, the guideline title has been changed to chronic pain, with clarification that this is also known as persistent pain or long term pain.</p>
Warwick Clinical Trials Unit	5	109	<p>Is '...long-term persistent...' tautologous?</p>	<p>Thank you for your comment. This has now been removed.</p>
Warwick Clinical Trials Unit	6	125	<p>As there are already NICE neuropathic pain guidelines should neuropathic pain also be excluded here? Thus guideline becomes persistent non-neuropathic pain?</p>	<p>This guideline will make overarching recommendations regarding assessment and management of all types of chronic pain and will make recommendations on pharmacological and non pharmacological treatment of chronic primary pain conditions that are not described in existing NICE guidance. There is existing guidance on the pharmacological management of neuropathic pain and this guideline will link to that guidance for that specific area.</p>

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Persistent pain

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25/10/17 to 22/11/17

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Warwick Clinical Trials Unit	7	173	The prevention of persistent pain is not included. There are opportunities for prevention and these should be considered. For example there is a good body of literature on the prevention of post-surgical pain	Thank you for your comment. The scoping group discussed this but was unable to prioritize this for inclusion in the scope. .
Warwick Clinical Trials Unit	7	176	There are a lot of items on the assessment of persistent pain that relate to risk factors for persistent pain (points 1.2, 1.2, and 1.3). It is difficult to see how these can be used to contribute to a clinically relevant treatment recommendation. Whilst very interesting information what might be more relevant is to focus on modifiable risk factors. This is still of little direct help since that a risk factor is modifiable still does not demonstrate the interventions to target this risk factor improve outcomes. Unless the data generated will allow a clear recommendation to be developed, or an empty search shows that there are not relevant data, there is little point in reviewing the literature This section could be omitted without harming the key section on producing management (and prevention?) advice. There would be merit in specifically looking for any studies of stratified care related to hypothesised treatment moderators The interventions of interest could be widened to include societal or public health interventions that might be of	Thank you for your comment. The areas to be covered within 'assessment of chronic pain' have been edited to 'Assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain'. We agree that modifiable risk factors are important, however identifying risk factors that may highlight people who are at risk of chronic pain early has been identified as a key area for this guideline.

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Persistent pain

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			benefit which would allow the factors identified in point 1.3 to be included	
Warwick Clinical Trials Unit	8	186	Suggest that as there are known harms from use of opioids that there should be a specific question set on interventions to reduce opioid use for persistent pain. This can include both quality of life and measured opioid use as outcomes.	Thank you for your comment. The guideline will make overarching recommendations regarding the assessment and management of chronic pain and will make recommendations regarding pharmacological and non-pharmacological management of pain conditioned not elsewhere described in NICE guidance. NICE has received a referral "safe prescribing and withdrawal management"..
Warwick Clinical Trials Unit	8	207	Work loss, or return to work, in those who are currently employed or wishing to be employed. Whilst NICE cannot take work loss into account in its economic analyses it would be reasonable to extract these data to help inform recommendations that might facilitate return to work as a clinical outcome.	Thank you for your comment. The outcomes listed are those that are expected to apply to the majority of key areas in the guideline. Additional outcomes specific to the review questions will be discussed and agreed by the committee when agreeing the protocols.
Warwick Clinical Trials Unit	8	209	Why has pain reduction been selected rather than pain? Surely absolute pain levels are more relevant, particularly if studies of primary or secondary prevention are included. There may be successful studies showing a reduction in the increase/onset of persistent pain	Thank you for your comment. Although the draft scope lists pain reduction as one the outcomes to be considered when searching for and assessing the evidence this list of outcomes is not exhaustive. The committee will discuss and agree the most appropriate definition of this outcome for each review question in order to capture the most appropriate evidence.
Warwick Clinical Trials Unit	8	209 -13	The five main outcomes are in numbered order. This has an implication that this is their rank order of importance. All	Thank you for your comment. The order of outcomes in the list is not intended to infer a priority order. These

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Persistent pain

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			of these are important and bulleted list that avoids implication of a hierarchy would be better.	have been edited to a bulleted list as suggested to avoid confusion.
Warwick Clinical Trials Unit	8	221	The proposed NICE pathway includes an item on red flags for serious pathology. Almost by definition those people who are in a persistent pain management pathway will not have serious pathology. Nearly all of the serious underlying diseases (most notably malignancy) will have become self-evident long before reaching this pathway. NICE have produced guidelines on when to investigate for suspected malignancy and these do not use single item red flags. Even for more specific problems such as low back pain red flag symptoms are largely uninformative. Red flags as triggers for investigation probably have little place in a care pathway for persistent pain	Thank you for your comment. The scope has been amended to remove the term 'red flags for serious pathology'. This has been replaced with the assessment of biological, psychological and social factors that may cause or perpetuate the experience of chronic pain.

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