Persistent pain: scope workshop discussions **Date: 04/10/2017**

Opening question:	**Stakeholder responses**
How do we distinguish ‘non-specific’ pain from discrete pain conditions? What would the definition of non-specific pain be? For example 1. Pain without obvious underlying tissue damage 2. Pain in 1 or more anatomic regions that cannot be better explained by another pain condition	**Terminology** Chronic versus persistent - It was pointed out that WHO used chronic pain. There is a risk that the guideline won’t be taken up if it doesn’t fit in with international definitions. - ‘Chronic’ was dropped as a term in the UK due to having negative connotations to patients, but ‘persistent’ hasn’t been universally picked up. Patients tend to think that ‘chronic’ pain refers to a high level of intense pain. ‘Persistency’ however, implies that the pain does not go away and this is appropriate for the guideline as its target population should be patients who are never, or are very rarely, pain-free. - It was highlighted that this guideline’s terminology needs to include a definition of persistent pain that includes people without a diagnosis. - It was highlighted that ‘persistent’ means ‘ongoing’ – it does not describe the level of pain that a person experiences. - ‘Intractable’ in the description of the condition was viewed as unnecessary; ‘persistent’ was considered to be more adequate to label the condition. Non-specific - It was discussed whether pain is ever non-specific and one group suggested that the guideline could refer to ‘pain not covered under other guidelines’. - Other groups accepted that ‘non-specific’ could be defined as pain without a diagnosis. - It was pointed out that the guideline does not need to distinguish between non-specific and discrete pain conditions because the cause of pain is not known. Therefore, it was suggested that the guideline needs to be generic. - It was pointed out that a diagnosis may be ultimately irrelevant from the point of view of the patient, who wants their pain to be managed with active involvement of the physician/health professional, not just self-management.

Opening question:	**Stakeholder responses**
	• A group pointed out that in terms of assessment, there is a need to look at the patient as a 'whole' person, and not just focus on their symptoms (pain could be physical, emotional, psychological, etc., in origin). • There was some disagreement for the examples provided for non-specific pain. Intractable • The groups rejected the term as it is obsolete and it may be incorrect. Other notes • One group suggested that 'Chronic/Persistent Pain' may be a better guideline title; alternatively, the definition should be clearly defined in the guideline introduction. • It was pointed out that if patients have non-specific pain, they aren't treated because there is no protocol and they fall into a gap – the Persistent pain guideline is supposed to cover this gap. • The importance of addressing persistent pain with generic treatments was stressed by some groups: non-specific treatments should be used regardless of diagnosis and the underlying cause of pain. • It was suggested that the guideline should become the foundation on which disease- and condition-specific guidance stands. • A group suggested that the guideline should provide a service model for the management of persistent pain; this would be consistent with the NHS's 'Health Living Agenda'. • Persistent pain was described as a wider public health issue. If approached as a public health issue there could be a greater impact in the provision of information for patients across both primary and secondary care. • It was pointed out that NHS services for the management of persistent pain are very variable across the service. • One group pointed out that patient preference in the management of pain is often not accounted for. Also, it was suggested that patients need a multi-disciplinary approach for self-management. • One group pointed out that issue damage is difficult to diagnose and should not be covered in the guideline. • A group pointed out that the title of the guideline needs to be more specific for clinical commissioning groups (CCG) for example, 'Non-specific chronic pain' or 'Assessment of chronic pain and management of non-specific pain' – management of conditions is the most important issue and needs to be highlighted. • It was pointed that pain is not a 'subjective' experience. It would be helpful to avoid idea that pain

Opening question:	Stakeholder responses
	is rooted in the brain or that it is psychosomatic. - It was suggested that a pathway is needed that doesn't force patients to be investigated, as this can be very traumatic for someone in distress.
Is there any current guidance on commissioning for pain services?	The following suggestions were received: - British Pain Society – however, it was highlighted that their guidance is very general. - Royal College of Surgeons – it was suggested that some investigators are working on pain in various populations. - IMMPACT (2002-2017) recommendations – US based. An interesting resource for patients' view. - It was pointed out that the Royal Society of Medicine only accepted chronic pain as a clinical area around 10 years ago. In many guidelines, the assumption for pain management is that there is already a diagnosis of an underlying condition when most of the time in fact this is not the case. - RCGP guidelines (3 years old) – first introduced at the National Pain Summit in 2011. - There is some guidance and a commissioning plan in place in Northern Ireland.

Scope details	Questions for discussion	Stakeholder responses
1.1 Who is the focus		
Groups that will be covered: - Adults (18 and older) with persistent pain - Children and young people (under 18) with persistent pain (general principles but not specific interventions) No specific subgroups of people have	- Is the population appropriate? - Are there any specific subgroups that need special consideration?	Adults - In the adult guideline, it was noted it is important to consider the effect on the person's family and children. Children - All agreed that guidance is needed for children, but the majority of the group thought that Children need their own guideline, as there were very different specific requirements for this group. - One member suggested that transition from child to young adult to adult could be considered. It was noted that 8 years is the age when the person can communicate / understand about pain. - A group felt that the treatment and management of persistent pain in children was very different from the adult population. They felt this requires a guideline of its

Scope details	Questions for discussion	Stakeholder responses

been identified as needing specific consideration.		own.
		• A group also agreed that it would be difficult to make generalizable recommendations for children in different age groups as their management would also differ (that is, 1–5-year -olds versus 10–15-year-olds)
		• A member of a group also highlighted that services for children and adults were commissioned and funded separately.
		• A group agreed that there needs to be a separate guideline for children but it is important that children are recognised in this guideline.
		• A group questioned whether there is a biological or psychological reason for 18 versus 16 as a threshold.
		• A group observed that children and adults experience different kinds of pain: children tend to have non-specific headaches and abdominal pain whereas older people (adults) tend to have non-specific musculoskeletal pain.
		
		<u>Subgroups</u>
		• Possible subgroups suggested were:
		  ○ Homeless people
		  ○ Adults with mental health issues (including PTSD)
		  ○ Veterans
		  ○ People without spoken English
		  ○ Children/young people transitioning into adult services
		  ○ The elderly
		  ○ People with cognitive impairment
		    ▪ This is important because the management might be different or there might be a different assessment
		    ▪ There are risk factors for people with cognitive difficulties
		    ▪ The diagnostic and prognostic factors will be different.

Scope details	Questions for discussion	Stakeholder responses
		○ Individuals with addiction problems (**line 112 of the Scope should specifically mentions this) ▪ This group may not be a subgroup but this they represent a complexity of the condition that could affect pharmacological options. ○ Hard-to-reach populations (which poses an equality issue). • The importance of equality issues in this guideline was stressed. Ethnic background, religion and education need to be considered. <u>Other</u> • The community in general may be a subgroup: ○ There are people trying to build pain management practices in the community but they don't know exactly how (for example, what medication would be appropriate or available, doses, etc.). ○ The public is bombarded with advice and publicity for substandard 'remedies' and low value interventions – pain management advice needs to be standardised across community, health service & practitioners. ○ A lot of damage can and is done to patients in the process of assessment – for example, invasive or potentially harmful imaging techniques, etc. This aspect needs addressing. ○ Social prescribing – should be included in all this; we need to tap into the 3rd sector – for this and, especially, for the inclusion of complementary therapies (of high standard) which could not be supported by the NHS.
Groups that will not be covered: None		• Some attendees suggested considering children, although the age cut-off would be difficult to define as it varies between services.
		• A group suggested that the appropriate settings are

Scope details	Questions for discussion	Stakeholder responses
Settings that will be covered: - All settings in which NHS commissioned care is provided.	- Are the listed settings appropriate?	anything publicly funded at any level – including NHS funding within private services – 3rd sector – local authority funding. - It was suggested that publicly funded social care providers should also be included.
Key areas that will be covered in this guideline 1 Assessment of persistent pain - Red flags for serious pathology - Risk factors for non-specific persistent pain - Identification of co-existing mental health conditions 2 Management - Pharmacological and non-pharmacological management of non-specific persistent pain - Pain management programmes including pain self-management and peer-led programmes - Strategies to improve quality of life	These are the key clinical areas that have been prioritised for inclusion in the guideline. - Do you think that these prioritised areas are appropriate for the topic? - Are the excluded areas appropriate? - Have any key areas not been mentioned?	**1 Assessment of persistent pain** - Attendees highlighted the difficulties of covering these areas while not overlapping with the existing guidance. - Diagnosis was described as a difficult area for GPs: a test or a scan could be harmful or problematic in some cases – there are guidelines that specifically recommend ‘do not scan’ and for this reason it would be good to have a guideline that sets these limits because harm can be done with certain assessment tools / techniques, and also with certain treatments (as in the case of people prone to addiction). - The issue of who will assess was raised – is assessment performed by a single Dr (GP)? Or by various health experts? - A combination of mental health screenings and other pain-related areas was suggested for consideration in the guideline. - It was pointed out that addictions should be expressly added to the mental health conditions point; moreover, the mental health conditions explored should be those that specifically impact on ‘non-specific’ pain, like depression or stress. - It was pointed out that if GPs are provided with an understanding of the factors that ‘ramp up’ pain, they will then be able to ask relevant questions about sleep, emotional wellbeing, patients’ life and circumstances and conduct a more comprehensive assessment (for example, the Arthritis guidance looks at many aspects of assessment like sleep quality, loss of function/range of

Scope details	Questions for discussion	Stakeholder responses
		function, etc., but misses out ‘listening’ to the patient). • It was highlighted that it is difficult to provide a broad assessment during the short time available to the NHS GPs. However, if this is implemented gradually, a fuller assessment could be achieved. • It was suggested that longer assessment are already offered for addiction services. • A participant pointed out that homeopathies require a longer time for the assessment of patients. For conventional medicine, the assessment could be performed across different practitioners/services – but either way this would have a health economic impact. <u>Red flags</u> • One member suggested that if red flags are covered, amber flags should also be considered. Others agreed a broader approach may be required. • It was suggested that red flags should be rephrased as ‘indications of a condition that can be treated leading to a resolution of the pain’. • It was highlighted red flags would differ according to the population. • It was agreed that red flags should be general pointers to be used as a guide to rule out other conditions possibly impacting on pain. There was general agreement that the guideline cannot take responsibility for investigating from the physician; rather, it is general advice and cannot substitute clinical judgement nor remove diagnostic uncertainty. • Some of the group suggested removing ‘red flags for serious pathology’ as the evidence is limited. Other members of the group suggested it should be kept for consistency. • One group agreed that qualitative evidence is important; it is important the guideline addresses how a patient

Scope details	Questions for discussion	Stakeholder responses
		feels. Risk Factors for Intractable persistent pain • It was suggested that the assessment of persistent pain should include risk tools for persistent pain. However, the groups were not aware of how risk factors can be pulled together in a tool. • One group suggested the guideline should explore if there is a difference between pain as a symptom and pain as a disease. • One group noted that there is a link between acute and chronic pain which is related to previous trauma and depression at the time of the trauma. It was pointed out that social and emotional context around pain should always be explored. • A group pointed out that pain and not just risk factors should be assessed. Mental Health • A group agreed this is important and noted that it was good not to distinguish between the mental health conditions being a cause or result of the pain as both may be possible. • The groups agreed it was important to know the persons’ background to help with their pain management. • One group agreed that the identification of co-existing mental health conditions should include the identification of addiction. Specifically, addiction to painkillers was mentioned as a major public health consideration; this could possibly be addressed when addressing related health comorbidities. • Several members of a group felt that the identification of co-existing mental health conditions was insufficient and

Scope details	Questions for discussion	Stakeholder responses
		that a biopsychosocial assessment would be required instead. **2 Management** • One group pointed out that the order of the areas should be reversed, with ‘Strategies to improve quality of life’ coming first – as this should be the aim of any guidance. • It was suggested that the pathway for pain management should be: ○ Education ▪ Sometimes patients are only ‘educated’ about their pain at the end of the process, but it could help them self-manage better if they understood their pain at the start. ○ Biomedical ○ Psychological/psychosocial. Pharmacological and non-pharmacological management of non-specific persistent pain • It was noted that the evidence is not likely to be defined in this way. • One group member suggested a non-standard definition could be used, but it would need to be very clear in the guideline what the definition is. Two suggestions were received: ‘primary pain with no treatable cause’ and ‘pain that has persisted despite treatment’. • One group noted that if there is lack of evidence for a particular treatment, then it wouldn’t be funded. Therefore, it was pointed out that the guideline should not be biased by the definition used. It was also suggested that a lack of evidence doesn’t always mean a lack of effect. • It was suggested that this section is not patient-centric. There is no indication on how the patient should be managed through the process and it should include

Scope details	Questions for discussion	Stakeholder responses
		pathways of care. However, it was noted that evidence for this is likely to be patchy and only available for specific conditions. • One group member noted that pathways need to be more flexible. There is currently one format for all patients because of time / money constraints and equalities factors are not always adequately considered. • One group suggested that it wasn't clear that interventions would be covered within non-pharmacological treatment, and this needed to be made more specific. • It was noted that non-pharmacological management of pain must take into account psychological/psychosocial, and cover both models. • It was pointed out that management should include considerations about addiction problems (not only from the point of view of mental health conditions impacting on pain but also from the point of view of the potential for addiction formation of some pharmacological treatments for pain). • It was noted that o primary care practitioners often just address pain by offering a pharmacological treatment. For psychiatrists it would be useful to know of other therapies available to manage non-specific pain (for example, complementary therapies) as offering combinations of these could be useful although it would be probably difficult to find high quality evidence to support this. • One group felt that pain management was usually deprioritised in tertiary care and was keen to see 'self-management' moved to the top of the list in the 'management' section. They stressed that it would be helpful to not see 'prescribing' as the key answer to the issue.

Scope details	Questions for discussion	Stakeholder responses
		Pain management programmes • The pain toolkit app was highlighted as an example that could be considered. • It was suggested that complementary therapies should be included in this section. It should be ensured that they are effective and of a high standard – yet there is not likely to be enough quality evidence to support their recommendation. • The importance of the social determinants of people with persistent pain was stressed as it may inform public health policy. Strategies to improve quality of life • It was suggested this could be measured by drug reduction or return to work. • Technological options for self-management were mentioned as useful tools, especially for information sharing • One group agreed that pain management programmes should include supported self-management as well as social prescribing. • One group was keen for 'strategies to improve quality of life' to cover the use of social media, strategies to improve the patient's awareness and understanding of pain, and help to support patient/doctor communication. Other areas • It was noted that interdisciplinary care was important to consider. • A query was raised about people who have a condition (for example, Parkinson's disease) and have pain which is unrelated to their condition. This situation is often overlooked and prompts are needed to remind practitioners to ask about that. • One group suggested the inclusion of a 'public health'-

Scope details	Questions for discussion	Stakeholder responses
		related element to address the existing gap in public health in the delivery of services for pain.
Areas not covered by the guideline • Benefits and harms of specific interventions in children and young people. • Specific management of pain covered by related NICE guidance: endometriosis, headaches, irritable bowel syndrome, low back pain and sciatica, neuropathic pain, rheumatoid arthritis, osteoarthritis and spondyloarthritis. • Pain management as part of palliative care. • This guideline will not cover the assessment and management of non-specific low back pain and sciatica, osteoarthritis, headache in over 12s or the pharmacological management of neuropathic pain		• A group agreed with the areas not being covered but felt it should include persistent facial pain, as this was a significantly different type of pain that would require different assessment and management. • One participant in a group mentioned public health guidelines missing from the list of related guidelines, including ‘management of long term capacity and sickness’.

Scope details	Questions for discussion	Stakeholder responses
because these areas are already covered in NICE guidance NG59, CG177, CG 150 and CG173 respectively.		
Key issues and questions 1 Assessment of persistent pain ☐ Red flags 1.1 What are the signs and symptoms that indicate the presence of serious underlying pathology in people with persistent pain? ☐ Risk factors for non-specific persistent pain 1.2 What risk factors are associated with the development of persistent pain?	- Are the questions appropriate?	**1 Assessment of persistent pain** Question 1.1 - One group highlighted that sensitivity and specificity of the features of a serious underlying pathology in people with persistent pain should be included in the question. - One group highlighted that it is more important to assess pain first and subsequently investigate sign and symptoms. - Moreover, it was noted that the question fails to identify that pain assessment and management run in parallel. - It was pointed out that the quality, location, behaviour and time of pain are all important to the assessment of pain. - . - It was noted that addiction problems should be considered under management in terms of the potential for habit forming of some pharmacological treatments for pain. - It was suggested that perhaps there should be a question concerning who should do a full assessment of pain and whether it would be an individual physician (for example, primary practitioner, GP)? or a groups of different experts. Question 1.2 - It was pointed out that the word 'development' indicates

Scope details	Questions for discussion	Stakeholder responses
☐ Identification of co-existing mental health conditions 1.3 What co-existing mental health problems should clinicians be aware of when managing people with persistent pain? ☐ Identification of co-morbidities. 2 Management ☐ Pharmacological and non-pharmacological management of non-specific persistent pain 2.1 What is the clinical and cost effectiveness of pharmacological therapy for the management of non-		a pre-existing problem. This is confusing as the question should focus on the persistence of chronic pain instead of the development of non-specific pain. • It was pointed out that question 1.2 on risk factors should not sit under the ‘assessment’ heading. • . Question 1.3 • It was noted that the current wording suggests that mental health causes pain. • Similarly, mental health identification should be included under ‘management’, not ‘assessment’. • Another group suggested that the question should be included with the ‘red flags’. • It was noted that conditions that impact on pain are depression, stress, addiction problems. • One group suggested that this guideline should include physical and mental health issues together and not separate the issues. • ‘Issues of psychological wellbeing’ was suggested as a better term than ‘mental health conditions’. • **2 Management** • It was pointed out that non-pharmacological management typically refers to self-management (chiropractic, acupuncture, etc.). • It was noted that it is very important that all patients are reviewed regularly and promptly. • It was noted that there will plenty of evidence for the effectiveness of pharmacological interventions. The group questioned whether this may mean non-pharmacological interventions will be at a disadvantage. • One group noted that there has been a drastic change in how pain is managed in elite sport.

Scope details	Questions for discussion	Stakeholder responses
specific persistent pain? 2.2 What is the clinical and cost effectiveness of non-pharmacological management for non-specific persistent pain? ☐ Pain management programmes including pain self-management and peer-led programmes 2.3 What is the clinical and cost effectiveness of self-management programmes for the management of persistent pain? 2.4 What is the clinical and cost effectiveness of peer-led programmes for the management of persistent pain? ☐ Strategies to improve quality		• One group stressed that more support for long-term pain is needed. This could include maintenance work and additional support from healthcare professionals in addition to peer-led programmes.

Scope details	Questions for discussion	Stakeholder responses
of life 2.5 What is the clinical and cost effectiveness of strategies aimed at improving the quality of life of people with persistent pain for example, sleep management, mobility, social engagement and confidence in managing the condition?		
1.4 Economic Aspects		
An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked/**biggest cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice? • Which area of the scope is likely to have the most marked or **biggest health implications** for patients? • How would you **rank the areas to be prioritised** for economic analysis? • Do you have any further comments on economics?	• The main cost in primary care was related by the groups to costly drugs (although some drugs have a low cost, for example, paracetamol). • High-level interventions were identified as a large cost. • It was suggested that self-management may have large cost saving implications but that it is hard to find evidence for that because it is self-management is patient-specific. The groups agreed that mainstream pain services are undeveloped in the UK. If staffing levels were to rise, it would have a cost implication.

Persistent pain: scope workshop discussions **Date: 08/07/2016**		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.6 Main Outcomes		
1 Pain 2 Health related quality of life (for example, EQ-5D, SF36, SF12) 3 Function 4 Depression / anxiety 5 Adverse events	• Is the list of outcomes appropriate? Are any key outcomes missing?	The following points were made on outcomes: • 'Pain relief' should be specified, not just 'pain'. • Pain may be better analysed as responder criteria (30% response or 50% response). • BPI is a commonly reported pain measure and should be added. • Reduction in medication is a useful outcome – groups showed general consensus on this point. • QoL and function are the most important. • One group agreed with the included outcomes but felt that work participation/interference and social participation should be included. • One group noted that there is no international agreement on what outcomes should be. • It was suggested that measurement tools for pain and/or quality of life should be included. • Return to work was also mentioned as an outcome worth considering. • According to one group, reduction of suicide and attempted suicide could also be included.
GC Membership		

<table>
<tr><th colspan="3">Persistent pain: scope workshop discussions
Date: 08/07/2016</th></tr>
<tr><th>Scope details</th><th>Questions for discussion</th><th>Stakeholder responses</th></tr>
<tr>
<td>Full members
<table>
<tr><th>Area of expertise</th><th>Number</th></tr>
<tr><td>Chair</td><td>1</td></tr>
<tr><td>Clinical Lead</td><td>1</td></tr>
<tr><td>Lay member</td><td>2</td></tr>
<tr><td>General Practitioner</td><td>2</td></tr>
<tr><td>Pain specialist</td><td>1</td></tr>
<tr><td>Liaison psychiatrist</td><td>1</td></tr>
<tr><td>Pharmacist</td><td>1</td></tr>
<tr><td>Physiotherapist or occupational therapist</td><td>1</td></tr>
<tr><td>Commissioner</td><td>1</td></tr>
<tr><td>Pain psychologist</td><td>1</td></tr>
<tr><td>Clinician with expertise in pain in children</td><td>1</td></tr>
<tr><td>Long-term condition nurse practitioner</td><td>1</td></tr>
<tr><td>Social worker (full member or co-opted member)</td><td>1</td></tr>
<tr><td></td><td>Total = 15</td></tr>
</table>
</td>
<td>Do you have any comments on the proposed membership of the committee? [Discuss inclusion of GP with paediatric experience]</td>
<td>Suggested additions:
Full Committee Member

2 Pain Specialists – 1 may not be enough.
1 Complementary Therapist.
1 Epidemiologist.
1 Social Care Worker with speciality/special interest in pain conditions.
MSK (musculoskeletal) physician.
1 Public Health Representative.
1 Behavioural Scientist.
1 Healthcare Practitioner with experience in public health.
1 Community-based background.
1 Psychological support, for example, a counsellor.
1 Paediatrician.
1 Physiotherapist (not either/or with Occupational Therapist).
Nurse Specialist is a better term to use for the nurse post.

Co-opted Members

1 Addiction specialist (perhaps as co-optee)
1 Neuro-Pathologist or Rheumatologist, possibly co-opted.
1 Occupational Therapist, can be a co-optee and specialise in pain conditions.
1 Acupuncturist, co-opted.

Other comments

All of the members should have a background in pain (pharmacist, liaison psychiatrist, etc.).
Skills and perspectives of individuals are important – a

</td>
</tr>
</table>

<table>
<tr><th colspan="3">Persistent pain: scope workshop discussions
Date: 08/07/2016</th></tr>
<tr><th>Scope details</th><th>Questions for discussion</th><th>Stakeholder responses</th></tr>
<tr><td>Co-opted members
<table>
<tr><th>Area of expertise</th><th>Number</th></tr>
<tr><td></td><td></td></tr>
<tr><td>Occupational therapist or physiotherapist (depending on full member appointment)</td><td>1</td></tr>
<tr><td></td><td></td></tr>
<tr><td></td><td>Total = 1</td></tr>
</table></td><td></td><td>non-pain specialist with an interest in pain would be useful.
• GC membership should include members from Northern Ireland.</td></tr>
</table>

Further questions:	**Stakeholder responses**
Scope details: Any recommendations that result in a significant resource impact (>£1m) to the NHS need to be supported by robust clinical evidence of effectiveness and health economic evidence of cost-effectiveness. In the absence of published economic evidence, the health economist on the guideline can perform original modelling on some priority areas of the guideline. **Questions:** Are there any specific areas of the	• In the area of assessment, assessment by more than 1 physician was mentioned to be an area that could have a health economic impact, if considered/recommended. • In the area of management, management by various different services/use of different services (group-delivered programmes) or combinations of conventional and complementary interventions were viewed as potentially having a cost/resource impact. • Considering a recommendation to offer complementary therapies was recognised to potentially have a considerable health economic impact. • More generally, a “holistic” or comprehensive assessment of “non-specific” pain patients was identified as having an impact in terms of time allocated to assessment for NHS GPs.

Further questions:	Stakeholder responses
guideline you can foresee potential recommendations leading to a significant resource impact? Are there any specific areas of the guideline you can foresee potential recommendations leading to cost savings?	