DO ONCE AND SHARE

Assessment of chronic pain in adults and older children

Final Recommendations

Appendix 41 v1.0

1. The brief

1.1. The DOaS Programme has been commissioned by the National Library for Clinical Rules and Tools (NLCRT) to develop standard assessments for pain. The project has been undertaken by a team based at Sykes House, The University of Sheffield and the Royal Hallamshire Hospital, Sheffield. The SHA sponsor is Yorkshire and Humberside SHA.

1.2. There is a plethora of chronic pain assessment methods and scales that are used across a wide range of care settings. Specialist pain scoring systems are used in cancer, arthritis care, neuropathic conditions, musculoskeletal diseases, etc. Many other chronic diseases are associated with significant degrees of pain but have not yet developed their own specific pain assessment tools. There are also different assessment tools for children and the elderly.

1.3. Specific patient groups may have special needs when it comes to communicating about pain and its management. For example, problems arise with assessment in children who have not yet developed sufficient language to communicate, with children and adults with learning difficulties and with older people who have dementia.

1.4. Pain is one of most prevalent symptoms of most chronic disease processes, as well as being a common side-effect of many medical interventions. It has relevance for the diagnosis and treatment planning of many conditions. Pain and the side-effects of pain management have a significant impact on the well-being, functioning and quality of life of patients and carers. However, pain assessment is not standardised even within individual clinical settings and certainly not across diseases or healthcare sectors. New technologies are emerging to improve pain diagnosis and characterisation but their use is not universal.

1.5. The National Programme for IT (NPfIT) is bringing modern computer systems to the NHS to improve patient care and services. This will ensure that the right information is available to the right people at the right time, with all those involved in the care of the patient having secure access to up-to-date, accurate information for diagnosis, treatment and care. It will also enable patients to have easier access to their own health and care information.

1.6. There is thus a need to identify current best practice in pain assessment in UK healthcare and to make recommendations for standardised approaches across and within each clinical scenario. These approaches should feed into the development of the new IT systems for recording information about patients

and transmitting it across care settings, in a way that is useful to clinicians of different disciplines.

1.7. The deliverables for this project are to:

1.7.1. Produce a national standard protocol for the assessment of chronic pain based upon national guidelines/ pathways, having gained agreement with the local health community and then with national stakeholders.

1.7.2. Identify the knowledge management, decision support, and communication system requirements with pain assessment, across the organisational structures where care is or will be delivered.

1.7.3. Produce a national standard protocol for pain assessment that will shape the design and the delivery of the NPfIT solution.

1.7.4. As part of the standard protocol for pain assessment, identify the key requirements from Connecting for Health (CfH) to assist in the implementation of NPfIT solution and/or the associated business change.

1.8. This appendix will focus on the first three of these deliverables.

2. Areas within and out of scope

2.1.1. 2.1 For the purposes of this appendix, the following issues came within the scope of the project –

2.1.2. Production and agreement of a national standard protocol for the assessment of chronic pain in adults and older children.

2.1.3. Identification of guidelines for the development of the pain assessments.

2.1.4. Identification of decision tools required to support the process of pain assessment.

2.1.5. Identification of patient decision aids for the assessment of pain.

2.1.6. Identification of the existing knowledge and evidence to be provided by CfH for the assessment of pain.

2.1.7. Identify current data items for pain assessment to populate the NLCRT assessment template.

2.1.8. Identify current best practice in assessing and reporting pain.

2.1.9. Link to Community of practices where available to including national expertise.

2.2. Areas that fell outside of the scope included –

2.2.1. Pain that is less than (3months) in duration.
2.2.2. Pain assessment in infants and younger children.

2.2.3. Identification of protocols for any other assessment other than “pain assessment”

2.2.4. Development of any new self help tools to support the process of pain assessment.

2.2.5. Development of new patient decision aids for pain assessment.

3. Methods used

3.1. The project has used a range of methods to achieve the targets it was set, including:

3.1.1. Systematic literature review (Appendix 26 Literature Review Methodology).

3.1.2. Stakeholder meetings (see Appendices 9-25).

3.1.3. Written consultation with organisations and individuals (Appendices 34-36).

3.1.4. Detailed engagement with the British Pain Society (this is not to be taken as an endorsement of the report by the society).

3.1.5. Consultation with patients and their representatives.

3.1.6. Personal communications with individuals within and outside the UK (eg authors of key papers).

3.1.7. The project website and an email discussion group (Appendices 39-40).

4. Recommendations

4.1. This section will describe in detail the final recommendations from the project. These will be cross-linked in the electronic version on the project website with specific source materials, eg key review papers, original research papers, guidelines published by professional bodies. In total, the cross-linked references will run into several hundred. In this document, examples of these references will be given where relevant.

4.2. The literature search and its subsequent sifting have yielded a wealth of measurement tools for the assessment of chronic pain in the target populations (older children and adults). During the literature search, we gathered information on national and international initiatives for the raising of pain awareness and development of pain assessment, eg the IMMPACT programme; Pain as the 5th Vital Sign; the Pain-free Hospital; the Chronic Pain Policy Coalition. Some of these are attempting to integrate into the NHS and other care settings (eg nursing homes) to varying extents, and those which do this successfully are most likely to have a significant impact on routine pain assessment (Appendices 26-33).

4.2.1. We recommend that future development of national guidance on pain assessment should take account of the national and international pain awareness

initiatives and, if possible, try to incorporate their relevant requirements into new NHS documentation and IT systems.

4.3. Our reading and consultation have shown that although these various initiatives are all aimed at a common set of goals, namely to improve the recognition and management of chronic pain, they have significant differences in terms of their target populations, methods and evidence base. For the purposes of the NHS and developing IT systems, it is important for there to be consistency wherever possible, so that patients passing between settings and disease areas can continue to be assessed in broadly the same way. However, if the patient is diagnosed with a new disease, the assessment system needs to be sensitive to the requirements of the new clinical area.

4.3.1. We recommend that measures are taken when incorporating current and new initiatives in chronic pain into NHS assessment and data systems that core consistency is maintained between the systems so that data may be exchanged between care settings and disease groups.

4.4. The stakeholder events and the email consultation exercise gave the project team much valuable feedback on choice and appropriateness of the tools. The email consultation with stakeholders also generated several strands of robust discourse about the role of holistic pain assessment in people with chronic pain and the appropriate ways of tapping into the global distress and suffering experienced by them.

4.4.1. We recommend that the e-community of practitioners and researchers which has been developed as a central part of this project should continue to feed into the development and refinement of pain assessment methods and their integration into NHS IT systems.

4.5. A further key strand of discussion and debate centred around the way that holistic assessment of pain and global distress could fit into the long-term management and especially self-management pathways for these patients, so that meaningful outcomes could be evaluated.

4.5.1. We recommend that outcome measurement in chronic pain management should, wherever possible, focus holistically as much on psychosocial impact, lifestyle adjustments and quality of life consequences of pain as on the measurement of pain intensity itself; and in some chronic pain scenarios, we recommend that these 'quality of life' issues should become the primary outcome measure.

4.6. Resulting from these discourses, we have assembled a model or protocol for holistic chronic pain assessment that provides a strategic framework, which is consistent across the whole spectrum of patients, into which specific measures could be placed according to age group, diagnosis group, cognitive functioning level and other patient or environmental variables.

4.6.1. We recommend a protocol for the assessment of chronic pain which consists of three key stages: Detect – Observe – Longterm. [The acronym for this model is

DOL, which is the root for the Latin word dolor, meaning pain.] These stages are conceptually discrete but it is important to recognise that they will overlap with each other chronologically to different extents, depending on the patient's needs and the care setting.

4.7. The proposed DOL protocol is an attempt to highlight the need for awareness of chronic pain at the earliest point of its development and the initiation of prompt referrals to relevant generic or specialist healthcare workers for rapid responses in terms of further assessment and intervention. However, it is recognised that although the components of the key stages are based, to varying extents, on research evidence or clinical consensus, there is a need for the protocol itself to be tested and validated.

4.7.1. We recommend that the DOL protocol should be subject to extensive clinical testing, trialling, validation and audit in a broad range of clinical settings, to ensure that it is backed by research evidence. There should be a programme of updating the protocol in the light of the emerging results from these studies and audits; and from new research evidence which is published in the field of chronic pain.

4.8. The first stage of the DOL protocol is:

4.8.1. **DETECT.** This key stage emphasises the need for positive actions that raise awareness of chronic pain amongst healthcare professionals, patients themselves and their carers.

4.8.1.1. We recommend that raising awareness of chronic pain in all healthcare settings should be a high priority for commissioners and providers in all sectors (primary, secondary, tertiary, private/charitable).

4.8.1.2. We recommend that awareness of undetected or inadequately treated chronic pain should be enhanced amongst all types of healthcare professionals who come into contact with such patients.

4.8.1.3. We recommend that awareness of the need to report undetected or inadequately treated chronic pain should be raised amongst patients themselves, and their family or other informal carers.

4.8.1.4. We recommend that patients should be placed at the centre of their own pain assessment and, where appropriate, of their pain control, by integrating pain awareness education and monitoring into the care plans and shared care records of all patients with chronic and long-term conditions.

4.8.2. Examples of actions within this stage include: raising of pain awareness amongst healthcare workers in all healthcare settings; regularly asking about pain, eg 'Pain as the 5th Vital Sign'; patient and carer information and education programmes.

4.8.2.1. We recommend that the following initiatives should be more widely implemented and facilitated in all relevant healthcare settings –

4.8.2.1.1. The Chronic Pain Policy Coalition (Appendices 27, 37a and 37b)

4.8.2.1.2. Pain as the 5th Vital Sign (Appendices 27, 37a and 37b)

4.8.2.1.3. The Expert Patient Programme (Appendix 37a).

4.8.2.2. We recommend that patients who are at risk of chronic pain (eg because of previous surgery or trauma; predisposing conditions such as osteoporosis, diabetes, cancer) should be asked about pain regularly by a healthcare professional or care assistant. The frequency of asking will depend on individual circumstances, eg previous chronic pain experience and the precipitating disease process. It may vary from once a month to once a week, the latter if the risk of a chronic pain developing is high.

4.8.2.3. We recommend that a formal method of asking about pain should be used, with appropriate language for the patient's age, mental state and culture. These should include use of alternative words to 'pain' such as 'aches', 'soreness', 'throbbing', etc. The responses of these questions should be recorded in a standardised way in the patient's care record, preferably in the form of a diarised chart.

4.8.2.4. We recommend that if patients report previously undetected pain, they should be asked to rate its severity by using one of the following measures, depending on the patient's mental ability and preference –

4.8.2.4.1. Verbal rating scale – eg, 'Mild-moderate-severe' (Appendices 27, 37a and 37b)

4.8.2.4.2. Numerical rating scale – eg '0-10', where 10 is the worst pain the patient has experienced (Appendices 27, 37a and 37b)

4.8.2.4.3. Pain thermometer (Appendices 27, 33 Page 54, 37a and 37b)

4.8.2.5. We recommend that if a patient reports a previously undetected chronic pain, its location should be sought and recorded using the patient's own description and in addition, by the completion of a body chart which can be kept in the patient's care record. (Appendices 27 and 37a).

4.8.2.6. <u>We do not recommend</u> the routine use of visual analogue scales for the detection of pain severity, except in the context of a clinical trial.

4.8.3. Care needs to be taken with children and older adults with cognitive impairment and who cannot verbalise their feelings, or express them in a self-rating scale such as those described above. In these situations, behavioural methods are appropriate, which are based on professionals' or family carers' observations of the child or adult in pain. These methods are under active research and there is not sufficient evidence at present on which to base a consensus to cover all situations.

4.8.3.1. We recommend that for children who have limited language ability, for children and adults with learning difficulties and for older people with cognitive impairment such as dementia, behavioural methods for detecting and initially assessing pain should be used alongside or preferentially to formal self-rating scales. These behavioural methods include observation of facial expressions, body posture and mobilisation; and also the use of specific pain behavioural assessment tools.

4.8.3.2. We recommend the following tools for detecting and initially assessing pain behaviour –

4.8.3.2.1. Paediatric Pain Profile (Appendices 27, 33 page 30, 37a and 37b)

4.8.3.2.2. Abbey Pain Scale for older people with dementia (Appendices 33 pages 8 and 9, 37a)

4.8.3.2.3. DOLOPLUS 2 for older adults (Appendices 27, 33 pages 15 and 16, 37a)

4.8.3.2.4. DisDAT for all ages (Appendices 27, 37a and 37b)

4.8.3.3. We recommend that as research is conducted and published in this area, the choice of behavioural tools should be regularly reviewed.

4.8.4. It is important to recognise that parents of young children and family members of older people with communication difficulties may have much greater insight into the patient's pain experience than healthcare professionals. However, carers often have their own stresses and biases regarding chronic illness situations. They should play a part, but not necessarily the major one, in assessing pain.

4.8.4.1. We recommend that family and other informal carers of patients with potential and established chronic pain should be brought into the detection and assessment of pain, to the level of their own abilities and without relinquishing the professional's role.

4.8.4.2. We recommend that family and other informal carers of patients should be educated about the importance of detecting chronic pain; and they should be instructed in the use of simple self-rating measures or behavioural methods, as appropriate for the patients they are caring for.

4.8.5. The endpoint of the Detect stage is when a patient has been recognised as having chronic pain with a provisional diagnosis, and now needs a holistic assessment and investigation plan, which is appropriate and sensitive to their physical, psychosocial and other quality of life needs.

4.8.5.1. We recommend that the detection of previously unrecognised pain should be reported to senior clinical staff concerned with the patient's care and an appropriate action is taken and recorded.

4.8.5.2. We recommend that appropriate actions for newly detected chronic pains include the initiation of a more formal assessment of the physical, psychosocial and other quality of life consequences for the patient: this leads to the next key stage or OBSERVE.

4.8.6. To get to that endpoint, a patient needs to be recognized as having pain of at least three month's duration, and which has not responded satisfactorily to simple medication and other interventions.

4.8.6.1. We recommend that the detection and documentation of chronic pain for at least three months (but often detectable considerably earlier) which has not responded to simple medication and other interventions, should be recorded in the patient's care record as a specific diagnosis.

4.8.7. Usually, the patient will move to the next key stage by means of a referral from a generic setting (primary care or nursing home) to a secondary care setting, although some of the actions may be initiated by generic staff.

4.9. The second stage of the DOL protocol is:

4.9.1. **OBSERVE.** In this key stage, the main focus is on observing and, if necessary, investigating the patient for clues which lead to a better understanding of the nature, cause and impact of the pain.

4.9.2. Some of the actions needed in this key stage will require reporting the patient to a more senior or experienced healthcare practitioner (eg to GP attending a nursing home, or to a senior nurse/consultant/allied health professional in a clinic or ward). However, some of the actions could also be initiated by suitable trained healthcare personnel in the original setting.

4.9.2.1. *We recommend that all healthcare settings in which patients may be found to have chronic pain should have SOPs in place to guide staff in when and how to make a referral to a higher level for a patient with newly detected or unresponsive chronic pain.*

4.9.3. Important actions will include a detailed history and medication review, clinical examination and initial tests. Measures of pain in this (and the third) stage will include those which give more detailed assessment of severity, frequency and impact on daily living; a body chart to document sites and radiation of pains.

4.9.3.1. We recommend that the following items are recorded with any patient who has been newly detected with chronic pain or found to be unresponsive to initial simple interventions:

4.9.3.2. We recommend a detailed pain history, including

4.9.3.2.1. Location of pain using body chart, if this has not already been started in 'DETECT'. This should include radiation of pains as well as primary pain, eg pain radiating from the back down the leg or pain radiating from the neck down the arm.

4.9.3.2.2. Duration of pain, especially relating onset of pain to relevant events such as falls, trauma, surgery etc.

4.9.3.2.3. Frequency of pain, separating out if possible constant background pain and exacerbations of pain, eg Portenoy breakthrough pain measure (Appendix 37a).

4.9.3.2.4. Nature of pain, using words that are familiar to the patient but preferably from a standardised pain vocabulary, eg McGill Pain Questionnaire (Appendices 27, 33 page 51, 37a and 37b).

4.9.3.2.5. Provoking factors

4.9.3.2.6. Relieving factors

4.9.3.2.7. *Previous attempts at treating the pain and record of success/failure and especially side-effects of medication*.

4.9.3.3. *We recommend for an initial assessment of the consequences of the chronic pain on activities of daily living and lifestyle, either the whole or specific questions from the Brief Pain Inventory – Short Form (BPI-SF) (Appendices 27, 33 page 48, 37a and 37b).*

4.9.3.4. *We recommend a clinical examination by a suitably qualified healthcare professional, eg doctor, allied health professional or specialist nurse.*

4.9.3.5. We recommend that the examination should include an assessment of muscle disuse or deconditioning, evidence of fear of movement and confirmation of areas of neuropathic pain, eg hypoaesthesia, hyperalgesia or allodynia.

4.9.4. Observation of body language and behavioural patterns is very important for specific populations, especially children and older adults with cognitive impairment, people who do not have English as their first language and from different cultures.

4.9.4.1. We recommend that if it has not already been done as part of the DETECT stage, patients who have difficulties in communication should have a formalised behavioural observational assessment of pain and lifestyle changes. This can be done by the measures described in 4.8.3.2 above.

4.9.5. In most cases it will be appropriate to make an estimation of the patient's mental (cognitive) and psychological states: this helps with understanding the ability of the patient to communicate pain and its consequences, as well as appreciating the emotional consequence of chronic pain.

4.9.5.1. We recommend that at risk patients with chronic pain should have their mental (cognitive) state assessed if not already known as part of their care package. This can be done by established measures including -

4.9.5.1.1. Mini-mental state examination (Appendices 27 and 37a)

4.9.5.1.2. Abbreviated mental state examination (Appendix 27)

4.9.5.2. We recommend that all patients with chronic pain and adequate mental capacity to complete questionnaires, should have their psychological state assessed by means of a standardised scale, such as –

4.9.5.2.1. Hospital Anxiety and Depression Scale (HADS) (Appendices 27, 37a and 37b)

4.9.5.2.2. Beck Depression Inventory (BDI) (Appendices 27, 37a and 37b)

4.9.5.2.3. Geriatric Depression Scale (Appendices 27 and 37a)

4.9.6. Some of these assessments can take place within the initial generic setting, if the staff have been suitably trained. Others will need to be undertaken in a secondary care setting, eg after referral to a rheumatology, orthopaedic, diabetic, osteoporosis clinic, care of the elderly service. In any setting, it is important to recognise that allied health professionals including physiotherapists, occupational therapists and also psychologists will play a significant role in pain assessment and monitoring.

4.9.6.1. We recommend that in all healthcare settings, identified members of staff should be trained to initiate some of the second key stage or OBSERVE assessments in the patient's original setting; this includes general practitioners, district nurses and community allied health professionals in the primary care setting.

4.9.6.2. We recommend that if there is not a suitably trained staff member in the patient's original setting, there should be a SOP which directs staff to initiate a referral to a suitable secondary or tertiary care setting where the assessments can be made.

4.9.6.3. We recommend that in each health community, there should be local protocols which inform staff whether to refer to a secondary care service, eg, rheumatology or diabetic clinic; or straight to a tertiary specialist pain service, eg chronic pain clinic or palliative care team.

4.9.6.4. We recognise that the availability of access to specialist facilities such as pain clinics or palliative care services varies between localities. We therefore recommend that each health community should formulate and disseminate a protocol for referral to such specialist services from generic settings.

4.9.7. Depending on the initial or differential diagnosis, specific assessment tools relevant to body areas or diseases may be used. In this stage, investigations such as X-rays if it is likely that there has been a fall or other trauma, may be requested by doctors or senior nurses with suitable training. We recognise that in some patients, more advanced tests may be required to determine the cause of pain if this is not readily apparent, eg request for further imaging of painful joints or bones or soft tissues. The full range of investigations and their priority is beyond the scope of this document.

4.9.7.1. We recommend that in all healthcare settings, the SOP for dealing with chronic pain should notify the professionals of the appropriate local senior staff who could initiate these.

4.9.7.2. We recommend that medical staff in all healthcare settings and, if appropriate, senior nurses such as nurse consultants and community matrons, should be able to initiate general investigations to elucidate a chronic pain, eg X-rays after trauma.

4.9.7.3. We recommend that more advanced and invasive investigations for chronic pain should only be initiated by medical staff in secondary or tertiary services.

4.9.7.4. We recommend that whatever investigations have been undertaken, all the healthcare professionals caring for patients in their current setting should be made aware of the results and any consequent actions to be taken.

4.9.8. Patient and carer information and education are important, especially if new medications and interventions are initiated.

4.9.8.1. We recommend that patients and their informal carers should be fully informed and educated about the current pain diagnosis and treatment plan, including a list of potential adverse effects and how to report these as early as possible.

4.9.9. The endpoint of the OBSERVE stage is to have a patient with a reasonable working diagnosis of chronic pain and a good baseline assessment of pain and its impact on daily living.

4.9.9.1. We recommend that by this stage the patient's care record should have a clearly marked section for chronic pain, including the assessments of pain severity, location, full history as described above, current and previous medication history, current mental (cognitive) and psychological state, consequences on activities of daily living and lifestyle.

4.9.10. Individuals who do not respond to the interventions initiated in this stage are thus prepared for the next level by referral to a service specializing in chronic pain, eg pain clinic or a palliative care service.

4.10. The third key stage of the DOL protocol is:

4.10.1. **LONGTERM.** This key stage is where many – but by no means all – patients will proceed to, if pain does not respond satisfactorily to interventions and lifestyle adjustments made in the general or secondary care settings.

4.10.2. Such patients will usually have well established pain, such as chronic degenerative low back pain, complex regional pain syndromes, cancer pain syndromes.

4.10.3. Patients reaching this stage will also include those with chronic pain and previous substance abuse histories.

4.10.4. Important assessments in the stage will therefore include not only measures of pain severity and impact, but also of pain catastrophising, more detailed measures of psychological functioning, pain interference with daily living, rehabilitation needs, formal quality of life scales and substance abuse history.

4.10.4.1. We recommend that patients who reach a specialised pain service should have a very comprehensive pain assessment, including all the above measures and in addition:

4.10.4.2. For all adults with normal cognition –

4.10.4.2.1. The full version of the Brief Pain Inventory – Short Form (BPI-SF) (Appendices 27, 33 page 48, 37a and 37b)

4.10.4.2.2. Pain Catastrophising Scale (Appendices 27, 33 page 53, 37b)

4.10.4.2.3. McGill Pain Questionnaire – Short Form (MPQ-SF) (Appendices 27, 33 page 59, 37a and 37b)

4.10.4.3. We recommend that the standard pain assessments will need to be adapted or supplemented with specific measures for children and older adults who have cognitive impairment and who cannot verbalise feelings.

4.10.4.4. We recommend for older children and adolescents, the following measures which have been validated or are undergoing validation -

4.10.4.4.1. Bath Adolescent Pain Questionnaire (BAPQ) (Appendices 27, 37a and 37b)

4.10.4.4.2. Faces Pain Scale- Revised (Appendices 27, 33 page 50, 37a and 37b)

4.10.4.4.3. Paediatric Pain Profile (PPP) for children with cognitive/neurological deficits (Appendices 27, 33 page 30, 37a and 37b).

4.10.4.5. For adults with cognitive impairment -

4.10.4.5.1. Abbey Pain Scale (Appendices 27, 33 pages 8 and 9, 37a) or

4.10.4.5.2. DOLOPLUS 2 (Appendices 27, 33 pages 15 and 16, 37a) or

4.10.4.5.3. DisDAT (Appendices 27, 37a and 37b)

4.10.4.6. For specific types of pain, additional assessment tools, which are validated or undergoing validation, will be required by specialist staff -

4.10.4.7. For any neuropathic pain, one of the following –

4.10.4.7.1. Leeds Assessment of Neuropathic Symptoms and Signs (LANSS) – preferably the self-report version (Appendices 27, 33 page 36, 37a and 37b)

4.10.4.7.2. Neuropathic Pain Questionnaire (Appendices 27, 33 page 32, 37a and 37b)

4.10.4.7.3. PainDETECT (Appendices 27, 37a)

4.10.4.8. For trigeminal or other orofacial pain –

4.10.4.8.1. Oral Health Impact Profile (Appendix 37b)

4.10.4.9. For musculoskeletal and joint pain

4.10.4.9.1. Location-specific assessment tools (Appendix 27)

4.10.4.10. For low back pain

4.10.4.10.1. One of validated low back pain scales (Appendices 27, 33 pages 3-7, 37a and 37b)

4.10.4.11. For cancer pain

4.10.4.11.1. The Brief Pain Inventory- Short Form (BPI-SF) (Appendices 27, 33 page 48, 37a and 37b) and in addition a neuropathic pain tool (see above) and assessment of breakthrough pain (see above).

4.10.4.12. We recommend that this list of additional specialist assessment scales is kept up to date as further validation studies are published and as consultation with specific professional groups reaches greater consensus.

4.10.5. Patients with established chronic pain need to be assessed with respect to their coping mechanisms.

4.10.5.1. We recommend that pain coping mechanisms are assessed in specialist settings by means of a standardised measure such as –

4.10.5.1.1. Chronic Pain Coping Inventory (Appendices 37a and 37b) or

4.10.5.1.2. Coping Strategies Questionnaire (CSQ-24) (Appendices 37a and 37b) or

4.10.5.1.3. Pain Self-Efficacy Questionnaire (PSEQ) (Appendices 37a and 37b).

4.10.6. Patients with chronic pain should be assessed with respect to their quality of life. This is normally done in group assessments, eg for research or quality assurance programmes, but the following assessment tools can also be used in individual cases –

4.10.6.1. We recommend that quality of life is assessed in patients with chronic pain by means of

4.10.6.1.1. Medical Outcomes Scale – Short Form 36 or Short Form 12 (SF-36 or SF-12) (Appendices 27, 33 pages 57 and 58, 37a and 37b).

4.10.6.1.2. For cancer and certain other chronic diseases – European Organisation for Research and Treatment of Cancer (EORTC)

Quality of Life Questionnaire Core-30 (EORTC QLQ-C30) (Appendices 27, 33 page 45, 37a)

4.10.6.1.3. For health economic purposes – Euroqol 5D (EQ-5D) (Appendices 27, 33 page 49, 37a and 37b).

4.10.7. Most of these instruments will require trained staff and adequate resources as they are time-consuming.

4.10.7.1. We recommend that all staff working in specialist services dealing with chronic pain should receive formal training in the application and interpretation of the assessment tools described above.

4.10.8. Because of the impact of chronic pain, assessment of carer needs is also important.

4.10.8.1. We recommend that the informal carers of patients with chronic pain should have their own health and psychological needs assessed by the primary care and/or specialist pain service. The type of assessment to be used is out of the scope of this project.

4.10.9. More detailed investigations may be requested by specialists, eg MRI scans, nerve conduction tests for neuropathies, quantitative sensory testing for hyperalgesia and allodynia. The details of these assessments is beyond the scope of this document.

4.10.9.1. We recommend that if the nature of the chronic pain dictates formal 'objective' qualitative sensory testing and nerve conduction studies may only be ordered by specialists familiar with these techniques and trained in their interpretation.

4.10.10. Many of the patients in this stage may be invited to enter clinical trials.

4.10.10.1. We recommend that patients should be encouraged to enter clinical trials if there is a suitable study for their particular condition and their psychological and physical situation is appropriate.

4.10.10.2. For patients in clinical trials of chronic pain, the IMMPACT project has specific recommendations for the use of outcome measures. (Appendices 27, 37a and 37b).

4.10.11. Patient and carer information and education are therefore again of great importance.

4.10.11.1. We recommend that information and education for both patients with chronic pain and their informal carers should be an integral part of any chronic pain programme.

4.10.11.2. We recommend that the patient-oriented measures proposed by the Expert Patient Programme and the Chronic Pain Policy Coalition should be endorsed and put into action by specialist services caring for chronic pain patients (Appendices 27 and 37a).

4.10.12. There is no single ‘endpoint’ for this stage, in that most of the patients will have such long-term pain and daily living needs that the main focus of management moves from the pain itself, to quality of daily living and coping strategies, with a substantial role for allied healthcare professionals and psychologists alongside doctors and nurses.

4.10.12.1. We recommend that all patients with chronic pain should be maintained under surveillance and reviewed for pain severity, impact of pain on activities of daily living and consequences for their quality of life on a regular basis, whether in a specialist service or not.

4.10.12.2. We recommend that this regular surveillance includes input from the patient’s usual healthcare professionals (eg GP, district nurse, nursing home staff); specialist services (eg chronic pain clinic, palliative care team or hospice); additional specialists with an interest in chronic pain (eg psychologists, allied health professionals).

4.10.12.3. We recommend that because of the longterm financial consequences for many patients with chronic pain, social and financial advisers (such as social workers and benefits advisers) should be included in the wider caring circle.

4.10.13. Outcome measures in the LONGTERM stage will therefore need to be very sensitively chosen to match the chronic nature of pain, its resulting disabilities and the aims of patient-centred management plans.

4.10.13.1. We recommend that assessment of outcomes for chronic pain in the LONGTERM stage should focus primarily on the holistic needs of the patients and their informal carers, including psychological adaptation, coping mechanisms, lifestyle adjustments and possibly issues regarding return to work or homecare.

4.10.13.2. We recommend that pain intensity and its essential biological characteristics as outlined in the DETECT and OBSERVE key stage should be intermittently re-assessed, especially if a new intervention has been started or one has been withdrawn.

5. Future recommendations

5.1. The DOL model has been designed to become the basis for a national standard protocol for holistic chronic pain assessment in the target population of older children and adults.

5.1.1. *We recommend that the DOL protocol becomes integrated into the care records of all patients who may experience chronic pain.*

5.2. Its structure allows for a modular system of tools and checkpoints which will allow service providers to follow individual patients through the various clinical pathways. The modular protocol can be the basis for an expandable electronic database of patient records within the NPfIT structure.

5.2.1. *We recommend that the DOL protocol should be reflected in the IT systems of the NHS care record and also in independent (private and charitable) sectors.*

5.3. This DOaS project has generated a large databank of over 100 measures which can be used in chronic pain assessment. Some of these are still undergoing validation and may become more firmly established as preferred tools; others may fall out of use because of poor performance in research and clinical practice. It is important that this accumulation of knowledge is not lost, but rather, it is built on and extended with time.

5.3.1. We recommend that the databank of measures and tools covered by this project which are considered of value in chronic pain assessment should be maintained and reviewed critically within the National Library for Clinical Rules and Tools (NLCRT); and that they should be made available to the pain and palliative care professional communities in a suitable environment, eg the National Library for Health.

5.4. Many of the issues covered in this report are also addressed by current and emerging National Service Frameworks (NSFs), Improving Outcome Guidance (IOGs) for cancer, NICE and QOF for primary care. It is important that the contents and recommendations of this document are kept in line with future relevant publications from these bodies and their own guidance.

5.4.1. We recommend that future relevant outputs from NSFs, IOGs, NICE and QOF should be tied in with appropriate sections of this document and the recommendations should be updated accordingly.

5.5. Some sections of this document fall within the remit of national organisations which are concerned with specific aspects of chronic pain, eg British Pain Society, Chronic Pain Policy Coalition, Expert Patient Programme. It is important that the evidence base for the recommendations in this document and the recommendations themselves are regularly reviewed in conjunction with these organisations. In some cases, there is justification for a further collaborative review of assessments between an organisation and the National Library for Clinical Rules and Tools (NLCRT).

5.5.1. We recommend that specific organisations should be invited to continue a dialogue with the purpose of reviewing the evidence base and recommendations of this document.

5.5.2. We recommend that the British Pain Society, because of its pre-eminent position in covering the widest range of chronic pain interests, should be invited to enter a long-term collaboration with NLCRT to review at regular intervals the above recommendations, and their implementation, in the NHS.

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