Framework for Provision of Pain Services for Adults Across the UK with Cancer or Life-limiting Disease

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FRAMEWORK FOR PROVISION OF PAIN SERVICES FOR ADULTS ACROSS THE UK WITH CANCER OR LIFE-LIMITING DISEASE

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EXECUTIVE SUMMARY

1. This document presents a framework and operational guidance for improving pain services for adults across the UK with cancer or life-limiting disease.
2. This guidance is timely because of the importance to the public of pain associated with cancer and life-limiting disease, the evidence of under-treatment or poor access to care, the need to show evidence of better pain management in CQC inspections from 2016, and the need to meet new commissioning requirements for managing complex interventions (e.g. intrathecal pumps).
3. The guidance is designed to (a) inform and stimulate delivery of Level 3 services (linked Palliative Medicine and Specialist Pain Management) in secondary care offered by most district level hospitals, and (b) identify referral pathways to Level 4 services (Highly Specialist Pain Management).
4. Each of the 211 Clinical Commissioning Groups (England), 14 NHS Boards (Scotland), 7 Health Boards (Wales), or 5 Heath and Social Care Trusts (Northern Ireland) will ensure direct and rapid access to Level 3 services which will:
   a. Comprise a Consultant in Pain Medicine and a Consultant in Palliative Medicine leading a weekly multi-disciplinary meeting which includes nursing, physiotherapy and other health professionals, and covering outpatient and interventional sessions
   b. Be provided for patients with persistent or recurrent pain not adequately managed in primary care or generalist settings.
   c. Undertake assessment including confirmation of pain diagnosis and pain aetiology (using ICD-11 classification system), the need for further investigations, and an agreed management plan consistent with patient goals and preferences.
   d. Offer local expertise in management of complex analgesic combinations (methadone, ketamine) including high dose opioids, and interventional procedures including peripheral nerve blocks (e.g. coeliac plexus, lumbar sympathectomy) and intrathecal neurolytic block. Other procedures may be offered within the competency of the Consultant in Pain Medicine and the expertise of staff and local infrastructure such as external spinal infusions
   e. Determine onward referral to Level 4 (Highly Specialist Pain Management) services for those patients requiring direct referral to Level 4 or not responding to Level 3 pain services and who have a realistic possibility of improvement within Level 4 service.
5. Services should meet the standards and outcomes for patients described in the Faculty of Pain Medicine's 'Core Standards for Pain Management Services in the UK' relating to cancer pain and the European Pain Federation's standards for cancer-related pain.
6. Leads for Level 3 and Level 4 Specialist Pain Management services should have Advanced Pain Training or equivalent. Core competencies for managing cancer pain are described by the Faculty of Pain medicine and should be incorporated across all oncology and palliative medicine training curricula. Access to Advanced Pain Training should be available for palliative medicine and oncology specialties.

1. BACKGROUND

1.1. Cancer-related pain remains a challenge

Each year 350,000 people in the UK are diagnosed with cancer and 160,000 people die from this disease, which is expected to rise to 193,000 deaths by 2030 [1]. Pain is the commonest symptom of cancer at diagnosis [2]. Following chemotherapy, 60% of patients will experience peripheral neuropathic pain 3 months after treatment, persisting in 30% at 6 months. Overall, between 33% and 40% of cancer survivors (people with cancer whose curative treatment was completed) suffer from chronic pain [3,4]. Evidence suggests that 45-56% of patients with advanced incurable cancer (72,000 to 89,600 each year in the UK) experience moderate to severe intensity pain before they die, often for many months [2,5].

Longitudinal interview studies with cancer patients reveal that pain is very dynamic and complex, and that pain control is often a trial and error process that requires continuous work [6]. Bender et al [7] identified that patients are keen to understand the cause of their cancer pain, what to expect, options for pain control (including addressing concerns about strong opioids), and how to cope with cancer pain including talking with others and finding help. Although patients understandably express that they want to be pain free, in general they do not actually expect their pain to go completely [8].

Patients attempt to reduce interference from both pain and the cognitive effects of analgesia to maintain as much function as possible [9,10]. This often leads to trade-offs between pain and analgesia, impacting on medication adherence. Most patients seem to determine whether their pain is controlled by whether they can perform activities or tasks and maintain relationships with family or friends [8].

1.2. Evidence of persisting under-treatment

Greco at al [11] estimated the adequacy of treatment for cancer pain and identified that approximately 32% of patients were not receiving analgesia proportionate to their pain severity. This potentially represents an improvement on an earlier estimate [12] which suggested 43% of cancer patients were undertreated. Nevertheless, a considerable number of patients with cancer pain are not well managed. A retrospective cohort study from the UK identified for the first time the relatively short duration of strong opioid treatment in 6080 patients who died from cancer [13]. This study showed that only 48% of patients received a strong opioid before death (consistent with a previous UK study, [14]) and that median treatment duration was 9 weeks, suggesting that earlier pain assessment might lead to improved outcomes for patients.

Patients at the end of life report their preferred place of care and death is home (or not in hospital) [15]. The National Survey of Bereaved People (VOICES) has evaluated the perceptions of the care given to recently deceased persons (not just those with cancer) since 2011 [16]. In 2015, only 18% reported that pain was controlled ‘completely, all the time’ at home compared with 38% in hospital and 63% in hospice. Not surprisingly, uncontrolled pain is the most frequent reason for community-based cancer patients to contact out of hours primary care services [17].

Many patients with pain related to cancer or life-limiting disease can be satisfactorily managed within primary care by their General Practitioner. However, a significant minority with persistent pain will need additional assessment and multidisciplinary management either due to the intensity of their pain, significant distress or the impact on functioning and substantial co-morbidities. Evidence indicates that improved cancer pain management is associated with integration with palliative care [18-20]. Closer integration of pain management, palliative care and oncology services is therefore needed to improve access to pain management for patients with pain related to cancer or life-limiting disease.

2. THE NEED FOR GUIDANCE

2.1. National policy context

In 2008, the Department of Health published a strategy for end of life care as it recognised that many people did not have what could be described as a ‘good death’: being treated as an individual with dignity and respect, being without pain and other symptoms, being in familiar surroundings, and being in the company of close family or friends [21]. A NICE quality standard was subsequently issued in 2011 to define and support high quality end of life care, specifically including pain management [22]. The Care Quality Commission has emphasised the urgent need to improve end of life care services in the NHS because of unacceptable variation in access to and experience of care [23].

In 2016, The British Medical Association interviewed 269 members of the public and 237 doctors regarding the provision of end of life care by the NHS [24]. For both the public and doctors, pain was the most feared aspect of dying and underlining the importance of good pain control at the end of life. In a follow-up review of analgesic use for pain management at the end of life, the British Medical Association identified several recommendations for improving patients’ experiences [25]. These included improving access to opioids, improved access to palliative care and pain services particularly for those with non-cancer diseases (at least one third of whom experience pain[26]), and better support for generalists from palliative care and pain specialists.

The British Pain Society published guidance on cancer pain in 2010 [27,28] that concluded by calling for:

(a) a multimodal approach to the management of cancer pain, and not just towards the end of life, but also pain at diagnosis, as a consequence of cancer therapies and in cancer survivors

(b) improvements in the management of cancer pain by better collaboration between the disciplines of oncology, pain medicine and palliative medicine in terms of funding, time for joint working and the education of all healthcare professionals involved in the treatment of cancer pain.

2.2. Existing integration and access to care

A recent review has summarised the current evidence regarding integration of pain management and palliative care services in the UK [29]. The review concluded that there was an ‘inconsistent partnership between the specialties of pain medicine and palliative medicine’. A variety of reasons were proposed for this under-utilisation which included a lack of formal structures, geographical isolation of hospice units, different management and governance structures between the services and a lack of experience among palliative medicine physicians.

The British Pain Society and Association for Palliative Medicine surveyed prominent pain and palliative medicine units across the UK and Ireland in 2015, to gather information on their current service provision and to identify good examples of closer integration [unpublished data]. Telephone interviews with 9 pain specialists and 9 palliative medicine specialists were conducted (40% response rate). Half of respondents stated they had a formal arrangement for integrated working. On average, palliative medicine specialists referred one patient per month to specialist pain services, but pain services reported a higher frequency of referrals suggesting that direct referral from oncology services is an important source of referral.

Palliative medicine consultants felt that working in a joint manner was helpful, and they would be open to the idea of working jointly. This is in marked contrast to previous surveys that suggested palliative medicine teams felt they needed little further input from pain services. However, most respondents felt joint working must be based on a clear evidence base. Both palliative medicine and pain specialists felt that integrated and joint services must be based on a national specification rather than ad hoc arrangements, which from their experience was based on an individual with an interest setting up a service. This was felt to have led to the national variation in service provision. It was also apparent that specific time allocated in job plans was an essential part to forming a successful cancer pain service.

There remains a consensus that patients are often referred too late to specialist pain services to benefit optimally from the available expertise. Anecdotally, there are reports of successful structured and funded collaboration between specialist palliative care and pain services, but this is not widespread. The scope for collaboration on clinical, research and teaching initiatives is enormous and remains seriously under-developed.

One barrier to earlier access to specialised pain management services is timing of referral to palliative care services. Data from 64 of 200 UK hospices on 42,758 patients that died showed that median timing of referral to community palliative care services before death was 48 days. Older age and non-cancer diagnoses were associated with significantly shorter duration of care [30].

2.3. Aims and objectives of new guidance

Existing standards have been important in highlighting the need for closer integration between pain management and palliative care services [28] and specifying that multidisciplinary teams are required for the delivery of specialised pain services [31,32], including management of intrathecal pumps [33]. Standards and guidance also describe good clinical care and outcomes for patients with cancer pain in the UK [34-36]. Finally, competencies exist for individuals involved in delivering cancer pain management [37]. However, there is no supporting guidance for NHS Trusts or existing pain management, oncology and palliative care services on how an integrated service might be configured, how it might be commissioned, and what activities it should undertake.

New guidance is required to collate existing publications into a pain service specification for clinicians and commissioners. This guidance is timely because of the importance to the public of pain associated with advanced disease [24,25], the evidence of under-treatment or poor access to care [11,13,16], the need to show evidence of better pain management in CQC inspections from 2016 [36], and the need to meet updated commissioning requirements for Highly Specialist Pain Management Services [33].

A framework for managing pain in cancer or life-limiting disease is presented below, adapted from recommendations for psychological services within NICE Guidance on Cancer Services [38]. The guidance in this document is designed particularly to inform and stimulate delivery of Level 3 services in secondary care. This is likely to have the greatest impact with least cost in relation to meeting the needs of patients with cancer and life-limiting disease.

Closer integration of pain management, oncology and palliative care services can result in more comprehensive pain assessment and a wider range of Level 3 and Level 4 for patients comprising pharmacological, interventional, rehabilitative and psychological approaches. Although this will certainly benefit patients with more complex pain syndromes, those with less complex pain but who require more skilful balancing of analgesic medicines might be helped too.

Framework for pain management in cancer and life-limiting disease

LEVEL	HEALTHCARE GROUP	ASSESSMENT	INTERVENTION
1	**All health care professionals**	Recognition of pain Screening for pain	Effective information giving and compassionate support Referral to oncology or palliative care professional Initiation of conventional analgesia
2	**All oncology and palliative care physicians and advanced practitioners**	Assessment of pain Diagnosis of pain disorder	Management and titration of conventional analgesia Support for self-management Referral to Specialist Pain Management as required
3	**Linked Palliative care and Specialist Pain Management in secondary care settings** Consultant in Pain Medicine jointly working with Consultant in Palliative Medicine, both with accredited training in pain management in cancer and other advanced diseases Access via referral from primary or secondary care professionals	Diagnosis of complex pain syndromes	Management of complex analgesic combinations, including high dose opioids Interventional procedures of varying complexity depending on local skills and resources Support for self-management Referral to Adult Highly Specialist Pain Management as required
4	**Adult Highly Specialist Pain Management in tertiary care settings** Specialist services across the UK with Consultant teams in Pain Medicine and Palliative Medicine Access only via referral from Level 3 services	Diagnosis of complex pain syndromes	Interventional procedures not available at local Level 3 and including some more complex procedures (e.g. implanted intrathecal drug delivery systems, cordotomy and other neurolytic procedures) Rehabilitative programmes Managing distress or other behaviours related to poorly controlled medication use

3. THE GUIDANCE

3.1. Service eligibility

Pain services for patients with cancer and life-limiting disease will follow the existing provision of chronic pain management services configured for secondary and tertiary care.

Level 3 services comprise specialist pain services along with a formal link with Palliative Medicine as described above. Specialist pain services are described in publications by the Faculty of Pain Medicine [32] and the Royal College of General Practitioners [39] and comprise those offered by most district level hospitals with access via primary and secondary care referral. Level 3 services will be for:

> Patients with persistent or recurrent pain not adequately managed in primary care.
>
> Patients whose pain is causing significant distress or functional impairment.
>
> Patients who may benefit from joint management with specialist pain and palliative care.
>
> Patients with pain directly associated with cancer or indirectly from its treatments, and other life-limiting disease for which local skills (including interventional options) are available
>
> ‘Cancer survivors’ are patients with cancer who have undergone treatment (e.g. surgery, chemotherapy or radiotherapy) and are deemed to be living with and beyond cancer but who have persistent pain.

Level 4 services are described in general within the draft ‘Adult Highly Specialist Pain Management Services’, due for publication later in 2018. These will comprise a limited number of specialised centres in the UK, and only accessed via referral from Level 3 services. Within the context of pain from cancer and life-limiting disease, Level 4 services will be for:

> Patients not responding to Level 3 pain services and who have a realistic possibility of improvement within Level 4 service.
>
> Patients with pain directly associated with cancer or indirectly from its treatments, and other life-limiting disease, and which may not fall within the scope or expertise of palliative medicine or local pain services. For example those who require an interdisciplinary pain management approach delivered by a highly specialist pain management service.
>
> Patients with complex and difficult to manage pain who may require more specific interventional treatment than are available at Level 3 services, e.g. cordotomy, intrathecal neurolytic block.
>
> Young people (under 18yrs) with significant pain should also have access to pain services with the skills to manage their pain and will require liaison between paediatric services and these joint pain and palliative care services.

3.2. Composition and function of the Multi-Disciplinary Team

Level 3 services should have a Consultant in Pain Medicine (FFPMRCA or with equivalent recognised training) and a Consultant in Palliative Medicine, with formal links to Consultants in Medical and Clinical Oncology. The service should also have access to a nurse specialist, a clinical psychologist and a physical therapist in line with other Level 3 pain management services [32]. The British Pain Society and Royal College of Anaesthetists recommend that pain specialists regularly working in palliative care require recognition of this commitment in their job plan and that these sessions should be fully funded [28,32]. Job planning must include recognition of the fixed and variable commitment to this area of care and the associated additional SPA session (supporting professional activity) above and beyond core revalidation requirements for other areas of practice (e.g. Chronic Pain, Anaesthesia, etc.). A minimum of one DCC session (direct clinical care) and one SPA session for each consultant would act as a likely safeguard to clinical safety.

There should be a weekly MDT involving a Consultant in Pain Medicine and Consultant in Palliative Medicine at which referrals can be discussed and arrangements made for clinical review in a weekly outpatient clinic. The MDT can be held in person or virtually via video link. This core team should have access to advice from oncology, radiology, pharmacy and other disciplines as needed.

Level 4 services should have a minimum of two Consultants in Pain Medicine (FFPMRCA or with equivalent recognised training) and one Consultant in Palliative Medicine with the associated MDT that are experienced in assessing pain mechanisms and determining pain management in those with complex cancer-related pain [31,33]. There should be a weekly MDT involving a Consultant in Pain Medicine and Consultant in Palliative Medicine at which referrals can be discussed and arrangements made for clinical review in a weekly outpatient clinic. The number of clinical sessions required is likely to be similar to that of a Level 3 service, but may well be greater depending on the volume and complexity of patients. This team must be able to provide all the pain medicine related care needs of the patient throughout the process, including long term management where necessary (this may be a shared care model with local services) [31,33].

3.3. Clinical interventions

Level 3 and Level 4 pain management services should arrange urgent review of patients with severe uncontrolled pain (within 1 week of referral), consistent with NHS and IASP guidance [31, 40, 41]. The assessment will include confirmation of pain diagnosis and pain aetiology (using ICD-11 classification system [42]), the need for further investigations, and an agreed management plan consistent with patient goals and preferences.

Level 3 services will include local expertise in management of complex analgesic combinations (methadone, ketamine) including high dose opioids, and interventional procedures including peripheral nerve blocks (e.g. coeliac plexus, lumbar sympathectomy) and intrathecal neurolytic block. Other procedures may be offered within the competency of the Consultant in Pain Medicine and the expertise of staff and local infrastructure such as external spinal infusions. Level 3 services should link regionally in order to maximise the skills and management options available to patients.

Level 4 services will also be Level 3 providers but will have additional skills and expertise to provide highly specialist pain services as found in the service specification. These would include specific multidisciplinary assessment and management of patients who have a realistic potential for improvement but have not responded to Level 3 services. These would include other neurolytic procedures where expertise is not available within specialist pain management (Level 3) services, inpatient drug optimisation (including opioid management programs) [33], neuromodulation, implantable spinal infusions and some centres will offer cordotomy. In addition, Level 4 services should offer access to rehabilitative programmes, and expertise in managing distress and other behaviours related to poorly controlled medication use. Provision for out-of-hours management of neuraxial infusions should be decided by local protocols and agreement [33,40].

3.4. Patient centred outcomes for pain from cancer and other disease

Key priorities in pain management strategies for patients with cancer and life-limiting disease should be to help patients achieve a balance between pain and adverse effects of analgesia to optimise physical function, and support for self-management [10]. In this context, greater collaboration between pain management, oncology and palliative care services could improve outcomes by offering a broader range of non-drug treatment options or interventional management.

All oncology and palliative care professionals (Level 2) should ensure that their services are able to meet standards described by the Faculty of Pain Medicine [34] and NICE Guidance on Opioids in Palliative Care [35]. Although these standards are incorporated into the Care Quality Commission inspection framework for end of life care [36], they are applicable to all patients with pain from cancer and other advanced diseases.

The Faculty of Pain Medicine’s standards on cancer pain [34] are as follows:

1. *Patients with cancer-related pain must receive a pain assessment when seen by a healthcare professional, which at a minimum establishes aetiology, intensity and the impact of any pain that they report.*
2. *Access to analgesia must be available within 24 hours following a pain assessment which directs the need for analgesia. This must include access to a prescriber as well as access to a dispensed prescription.*
3. *Patients and carers must receive adequate information on the use of analgesics, especially strong opioids (in accordance with NICE guidance on Opioids in Palliative Care). This must cover how to take analgesia, the likely effectiveness of this, how to monitor side effects, plans for further follow-up, and how to get help - especially out of hours.*
4. *Patients and carers must be referred for specialist support if pain is not well controlled despite initial management. Specialist support must be available in each region in the form of palliative care services, oncology services (including radiotherapy), and specialist pain services*

The NHS outcomes framework will guide the use of clinical outcome measures and standards of care for Level 3 and Level 4 pain services. There will be particular emphasis on identifying improvements in quality of life and the impact of pain on daily lives of patients and their families using Patient (and carer) Reported Outcome Measures recommended by the Faculty of Medicine and British Pain Society [43].

NHS outcomes framework

Domain 1	Preventing people from dying prematurely	√
Domain 2	Enhancing quality of life for people with long-term conditions	√
Domain 3	Helping people to recover from episodes of ill-health or following injury	√
Domain 4	Ensuring people have a positive experience of care	√
Domain 5	Treating and caring for people in safe environment and	√

Level 3 and Level 4 services should ensure that they contribute to setting standards of care for patients with pain from cancer and life-limiting disease within their local health care community. The European Pain Federation (EFIC) has developed 10 standards for the management of cancer-related pain [44] which can guide local care delivery:

Standard 1. Patients with a history of cancer should be routinely screened for pain at every engagement with a health care professional.

Standard 2. Patients identified with cancer-related pain should receive a pain assessment when seen by a healthcare professional, which at a minimum classifies the cause of pain based on proposed ICD-11 taxonomy and establishes the intensity and impact on quality of life of any pain that they report.

Standard 3. A multimodal pain management plan should be agreed with the patient that explains the causes of their pain and its likely prognosis, the need for further investigations, the multimodal treatment options, and includes the patient’s preferences and goals for treatment.

Standard 4. Patients should receive tailored multimodal treatment which reduces the pain and its impact on daily living and that may include a combination of medicines, nonpharmacological treatments, oncological interventions, physical rehabilitation, and psychosocial or spiritual support.

Standard 5. Support and advice for self-management should be provided.

Standard 6. The pain management plan should be reviewed regularly to assess outcomes and plan longer-term care.

Standard 7. Patients should be referred for more specialist advice and treatment if pain is not improving within a short time or if they are experiencing intolerable side-effects of analgesia.

Standard 8. Healthcare professionals who treat patients with cancer should receive ongoing education and training in order to undertake basic pain assessment, initiate basic management, and learn about correctly referring for more specialist support.

Standard 9. Regular review of service outcomes for all patients with cancer pain should be in place.

Standard 10. Each EFIC chapter should have national evidence or consensus based guidelines in place for cancer-related pain.

3.5. Audit, research and education

The British Pain Society [28] recommends that combined pain and palliative care cancer pain services should undertake additional activities including joint educational seminars (local and national), joint audit and research projects and publications, and attendance at national and international meetings. Level 3 and Level 4 services should have a role in ensuring that the importance of pain control is appropriately included in relevant training, as part of university undergraduate and postgraduate medical curricula.

3.6. Competencies

The Faculty of Medicine has published core competencies for managing cancer pain by all practitioners in Pain Medicine and more advanced competencies for those involved in delivering a cancer pain service, which are endorsed by the Association for Palliative Medicine [37]. It is important that nurses, physiotherapists, pharmacists and other healthcare professionals introduce the principles of multimodal pain management into their curricula.

Training curricula for Palliative Medicine, Medical Oncology and Clinical Oncology [45-47] should broadly map to the core competencies for cancer pain management in the Faculty of Pain Medicine document [37] rather than the advanced competencies. There is opportunity to share a common curriculum in cancer pain management for all palliative care and oncology trainees in order to provide a Level 2 service. Advanced pain training should be available to trainees in palliative medicine and oncology to develop skills as part of a Level 3 and 4 services.

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