



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

Designed for People with Chronic Conditions

Service Development and
Commissioning Directives

Chronic Non-Malignant Pain

June 2008



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Designed for People with Chronic Conditions

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Chronic Non-Malignant Pain

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Foreword



I am pleased to introduce the Service Development and Commissioning Directives for Chronic Non-Malignant Pain.

This is part of a series of publications which will help remodel services to improve the management of chronic conditions and the quality of life of people living with those conditions.

This publication is issued at an important time. Health and social care services in Wales are facing growing pressures and the prevalence of chronic conditions is continuing to grow. The reviews of Sir Derek Wanless and Sir Jeremy Beecham have told us that new ways of working are needed to deliver health and social care services which are fit for purpose in Wales. Remodelling the way in which chronic conditions are managed is imperative in our drive towards more sustainable world class health and is a process which we must strengthen.

Improving services for chronic non-malignant pain is part of this process. These conditions can affect anyone at any age and from any social background, and can have a dramatic effect on people's lives. This impacts upon the wider social and economic aspects of life, restricts many life opportunities while also placing

significant pressures on health, social care and other services across Wales.

This document aims to ensure that the right services are provided at the right time, by the right person and in the right place. This requires refocusing services and improving the use of resources to meet local needs. Clear care pathways, supported by timely assessment and accurate diagnosis, will become the bedrock of service provision for these conditions, ensuring that both patients and professionals understand their responsibilities at all times. The integrated delivery of high quality services by multi-disciplinary and multi-agency teams should also become a standard feature for managing chronic non-malignant pain across primary, community, secondary and social care settings.

Planners and providers of services should use this document to plan and deliver necessary improvements in the management of chronic non-malignant pain. The approach must be based upon service integration and strong partnership working at local, regional and national levels. The results must be evident in the delivery of flexible, dynamic and dependable health and social care services that clearly meet patients' needs.

A handwritten signature in black ink that reads "Edwina Hart". The signature is written in a cursive, flowing style.

Mrs Edwina Hart AM MBE

Minister for Health and Social Services

Executive Summary

Chronic Non-Malignant Pain (CNMP) covers a wide range of painful conditions affecting individuals physically, psychologically and socially. These common conditions can result in disability and can affect anyone at any age and from any social background. They also have a significant impact on quality of life and the ability of individuals to undertake the activities of daily living. Managing these conditions calls for the input of a range of professionals as well as the support of the voluntary sector and other relevant services.

The growing need for services supporting individuals with CNMP is placing increasing demands on our health and social care system. Secondary care services particularly, experience a great deal of pressure and yet there are clear indications that most forms of CNMP can be managed in primary and community care settings, while ensuring appropriate access to specialists for more complex cases. The Welsh Assembly Government is committed to ensuring evidence-based service provision, underpinned by national and professional standards, to address the needs of the 21st Century. Reshaping services for the management of CNMP is a key building block in this process.

The Service Development and Commissioning Directives for CNMP outline a vision for services in Wales to improve health and well being, minimise the risks associated with living with CNMP, ensure access to the right services, while

also supporting and empowering people to maximise their independence in all areas of life. This will require the delivery of well integrated services where care is proactively planned and coordinated between statutory and non-statutory providers of services and where the health, social and broader issues of independence are effectively addressed for all patients.

This vision will be delivered by promoting healthy lifestyles, ensuring prevention and early interventions, and adhering to evidence based practice as well as national and professional guidelines and standards. Improving the management of CNMP will also be planned around care pathways to promote effective pain management within local communities as far as possible. Supporting the independence of individuals will be achieved by calling on the skills and expertise of statutory and voluntary sector organisations.

The Service Development and Commissioning Directives promote the key elements needed to effectively manage CNMP:

- Holistic (biopsychosocial) assessment
- Flexible and responsive services
- Proactive planning
- Evidence based interventions
- Care pathways
- Multi-professional teams
- Individual pain control plans

-
- Mechanisms to empower the individual to self manage their condition where possible
 - Regular monitoring and reviews of the individual's condition.

Key issues, case studies and other solutions for improving the management of CNMP are highlighted throughout this document to help inform planning decisions.

A number of key actions are also identified at the end of each chapter to ensure a more equitable and consistent approach to service provision across Wales.

These Service Development and Commissioning Directives are aligned to the overarching principles and actions for improving the management of chronic conditions as outlined in *'Designed to*

Improve Health and the Management of Chronic Conditions in Wales: An Integrated Model and Framework for Action'. The document is aimed at planners of health and social care services, providers of statutory, voluntary and independent services and individuals living with CNMP as well as their families and other carers. A whole system approach is required to strengthen planning, management and partnership working across traditional organisational and professional boundaries to ensure that care can be provided in the most appropriate and effective way. Delivering this vision for services requires concerted action by a wide range of organisations and demands the commitment of key local decision makers in joint planning and the use of joint resources.

Chapter 1: Setting the Scene

1.1 Introduction

“Chronic pain turns a life into a mere existence. The effects are devastating and often demeaning. It has a negative impact on relationships, inside and outside the home. It involves the loss of independence, dignity and control”

(CNMP focus group, Pontypool)

1.1.1 Health care services are currently unsustainable with an over-reliance on historical, and often inappropriate, models of care. Action is needed to ensure all resources in the community are used to best effect to prevent admission to hospital, to support better care and self-care within the community. Improvements to community services are necessary to ensure high quality services can be provided that are supported by a workforce for sustainable, primary and community-based models of care.¹

1.1.2 Currently there is wide variation in the organisation and delivery of CNMP services across Wales. Some LHBs offer no formal CNMP services, others offer services that only secondary care providers can refer to and the remainder invite GP referrals. Clinics range from small teams providing interventional treatments only such as nerve blocks, to others that offer a large range of options from pharmacology to psychological interventions. This diversity is not a result of patient

need and is not patient centred. These Directives aim to redress this variability and to ensure services are more consistent and patient centred.

1.1.3 The CNMP Service Development and Commissioning Directives aim to:

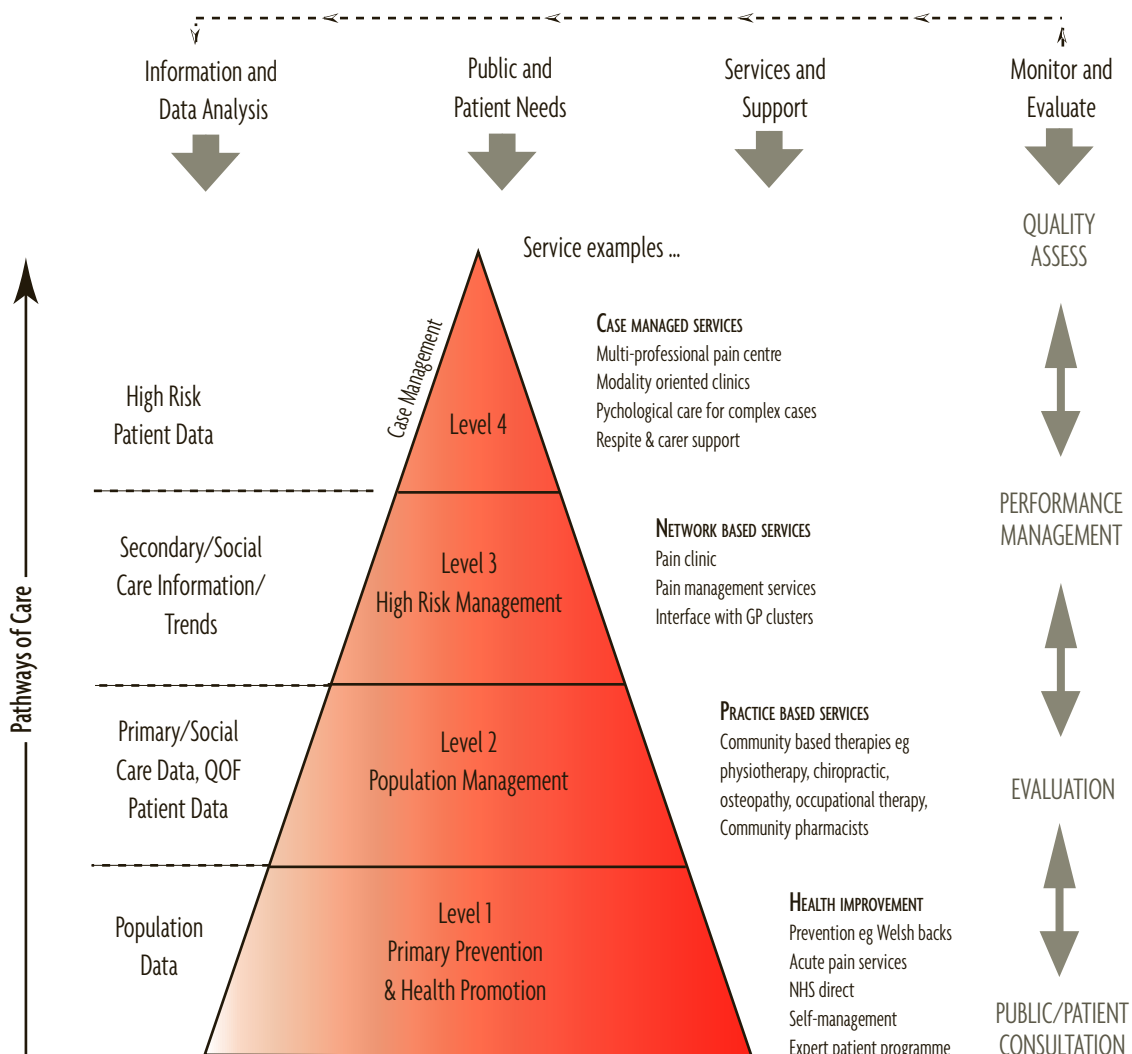
- Improve health and well being and minimise the risks associated with living with CNMP, while supporting and empowering people to maximise their independence in all areas of life
- Integrate and more effectively plan, manage and where appropriate, reconfigure existing pain services and support, to improve service delivery to patients over the next three years
- Simplify access to services and improve communication between patients and professionals ensuring that patients receive the right treatment, by the right person, in the right place and at the right time
- Reduce levels of morbidity and pain related disability
- Redress the balance of service provision across primary, community, social and secondary care
- Provide comprehensive, consistent, preventative and anticipatory care
- Build on the strengths within primary and community based care to integrate services across organisational boundaries

- Help clarify the actions needed to implement these directives and improve service delivery

1.1.4 This document is aimed at commissioners of health and social care services, providers of statutory, voluntary and independent services and individuals living with CNMP, their families and other formal and informal carers. Its purpose is to improve the health, well-being and the quality of life for people

living with CNMP in Wales. It is firmly underpinned by the social model of disability, the need for broad ranging medical and psychosocial assessment, and the support of multiprofessional teams working along clear care pathways (see Fig. 1). This is consistent with the Model and Framework for Chronic Conditions Management which will deliver more proactive and planned approaches to managing chronic conditions across Wales.

Fig 1. Four tiers of the Chronic Conditions Management Model



1.1.5 This document is primarily aimed at adults living with CNMP. It acknowledges that the principles for the effective management of these conditions can be applied to all age groups, including children and young people. These principles, together with the *National Service Framework for Children, Young People and Maternity Services in Wales* and the work of the *Children and Young People's Specialised Services Project* addressing pain, should be applied in developing appropriate paediatric services for CNMP.

1.1.6 These Directives embrace the principles of equality of opportunity (*Sections 77 of the Government of Wales Act 2006²*) and aim to improve service provision across health and social care. This document aims to identify the need for improved professional and patient accountability and responsibility.

1.1.7 This document has been compiled in partnership with the Welsh Pain Society and its members. The Welsh Pain Advisory Group, a representative body of the Welsh Pain Society, was also established to help steer this work and will continue to provide advice to planners on evidence based and best practice to

support the delivery of effective care for CNMP across Wales. This document has built on previous work undertaken to develop services for patients with pain in Wales led by Professor Michael Harmer. Its overarching aim is to put the needs of people experiencing CNMP at the centre of services. It draws on the advice and views of patients and those who are engaged with supporting the patient including health care professionals, informal carers, the voluntary sector and social care professionals.

1.2 Why is this document needed?

1.2.1 The document is needed to improve pain services for patients across Wales, informing decisions made locally about service provision. Some of the changes outlined within this document have drawn on the work of Dr C Price and her colleagues in Southampton who run a fully integrated, multiprofessional chronic pain service in primary care. The Southampton service has improved patient care, reduced waiting times and has reduced drug spending within the Trust. It also has been cost effective with the average cost savings per patient averaging £204 (*Table 1*).

Table 1: The cost effectiveness of a pain management programme (PNP)

Health Care Resource	Before PMP (£)	After PMP (£)	Savings (£)
GP visits	307	197	109 (35%)
Physiotherapy Units	124	45	78 (63%)
Medication	153	137	17 (10%)

1.2.2 CNMP covers a wide variety of painful conditions which can lead to disability, not only because of physical symptoms but also psychosocial factors that accompany physical pain.³ It can be defined as pain that persists after the point that complete healing should have occurred (3 to 6 months), can be continuous or intermittent and can also be experienced by those who do not have evidence of tissue damage.⁴ It can lead to disability due to a range of interacting physical, psychological and social factors.

*CNMP can affect anyone at any age and from any social background but the incidence of chronic musculoskeletal non-malignant pain tends to be linked with socioeconomic deprivation.*⁵

1.2.3 Some people with CNMP can cope with little support from health care services. Others are less able to do so and in this situation pain needs to be effectively managed by taking account of the biological (medical), psychological and social factors that impact upon the individual's life. This is referred to as the biopsychosocial approach which looks into and beyond medical factors.⁶

*One in four people with CNMP report losing a job due to their pain, one in five say that sometimes their pain is so bad they want to die and a quarter of UK chronic pain sufferers have been diagnosed with depression as a result of their pain.*⁷

1.2.4 Those people who are less able to adapt their lives to cope with the pain experience may have accompanying quality of life issues including depression, anxiety, fear avoidance and social withdrawal.⁸ The burden of chronic pain not only affects the individual and his or her family, but also has wider ramifications affecting society,^{9,10} for instance:

- **Physical burden** - Pain can lead patients to seek rest because they fear that their pain is made worse on movement. This may result in reduction in physical fitness levels, the loss of muscle mass, and muscle and joint stiffness (de-conditioning). This increases physical disability as individuals associate hurt with harm. This can lead to heart disease, obesity and diabetes.
- **Psychological burden** - People may experience anxiety, depression, anger and fear due to feelings of vulnerability and lack of control when trying to cope with pain. Fear avoidance, fearing the worst (catastrophising) and excessive concern over physical signs (hypervigilance) can increase the pain, decrease pain tolerance and lead to increased use of medication, lower levels of functioning, poorer exercise tolerance, and increased disability. Self-esteem, self-efficacy and self-image may also suffer as a result of the pain experience.

- **Social burden** - People living with CNMP may become socially isolated as they find it difficult to interact with others, enjoy previous hobbies or work due to the debilitating nature of their pain.
- **Economic and occupational burden** - The overall economic impact of CNMP is considerable given the cost associated with health care provision, wage replacement, compensation and lost productivity. The economic effects for an individual living with CNMP can vary from little or of no importance to the catastrophic.¹¹

If even 10% of the population had pain every day there would be over 2 billion days of pain in the UK. That is 30-40 days of pain for every one of us.¹²

In 2002, nearly 4.2 % of the working population was on incapacity benefit, 24% of which was due to diseases of the musculoskeletal system and connective tissue and almost two thirds of which were male; this equated to a cost of £6.7 billion.¹³

1.3 Categories of CNMP

1.3.1 The key categories of CNMP are:

- **Musculoskeletal** - osteoarthritis, rheumatoid arthritis, fibromyalgia, other arthropathies, osteoporotic collapse, low back pain, post surgery, post-traumatic and neck pain
- **Medically unexplained pain syndromes** - including Chronic Fatigue Syndrome, Myalgic Encephalomyelitis¹⁴, chest, abdominal, and pelvic pain
- **Face and head** - migraine, headache, trigeminal neuralgia, atypical facial pain and dental pain
- **Neuropathic** - diabetic neuropathy, post herpetic neuralgia, multiple sclerosis, post stroke pain, repetitive strain injury, chronic regional pain syndrome, traumatic injuries and phantom pain
- **Vascular** - claudication, ischaemic rest pain, Raynauds and angina
- **Postoperative** - amputation including mastectomy; post surgery thoracic, abdominal and spinal; failed back and neck syndromes.¹⁵

1.4 The Strategic Context for Services in Wales

1.4.1 *The Review of Health and Social Services in Wales* by Sir Derek Wanless¹⁶ and Sir Jeremy Beecham's *Review of Local Service Delivery*¹⁷ have highlighted that new ways of working are needed to deliver health and social care services that are fit for purpose in Wales. The agenda to improve health services has been set in Wales, led by *Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century*.¹⁸

1.4.2 The improvements needed to address CNMP are extensive and complex. *The Model and Framework for Chronic Conditions* sets out a new vision for CCM services in Wales, outlining what needs to change to improve services for Chronic Conditions Management. The *Chronic Conditions Management (CCM) Service Improvement Plan - 2008-2011* identifies the actions needed to implement the *CCM Model and Framework*, improving prevention and the care of those living with chronic conditions as well as supporting people's independence in all areas of life.

1.4.3 The Welsh Assembly Government is committed to achieving high standards across the public service as set out in *Making the Connections*¹⁹. This emphasises the need to design and operate services around the needs of the users, not the provider, taking into account all associated risks, and ensuring high quality, easily accessible and responsive services. Strategic level partnerships, working across all key agencies, are needed to agree common goals, avoid duplication and support the sustainable development of effective and responsive services. Local Service Boards and future service planning arrangements will play an increasingly important role in this context.

1.4.4 CNMP is a key issue for all areas of Wales. Implementation of service change will be based on the assessment of local needs and existing patterns of service provision that must be consistent

with the strategic direction outlined in this document. Plans to implement the key actions in these commissioning directives will need to be considered by Local Health Boards and their local partners and should be taken into account in local *Health, Social Care and Well-Being strategies*²⁰, providing a co-ordinated response to all policy objectives and requirements relating to health and social care services in the local area.

1.4.5 This document links closely and is consistent with the overarching aims of *Fulfilled Lives, Supported Communities*, the *Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal Conditions*²¹ and the *Therapy Strategy for Wales*²².

1.5 Key Principles and Aims

1.5.1 These Directives focus on the needs of people living with CNMP and aim to ensure that:

- Acute painful episodes are effectively managed to reduce the incidence of CNMP with services adept to addressing psychosocial and physical predictors of chronicity (chronic disability due to pain) at an early stage of pain onset and where recovery is prolonged
- People with CNMP are partners in their management and the aim should be to optimise self-management and self-efficacy promoting independence in all areas of life

- Early assessment and diagnosis of CNMP occurs in order to minimise the burden of pain
- All people experiencing CNMP receive appropriate management that, where possible, is evidence based.

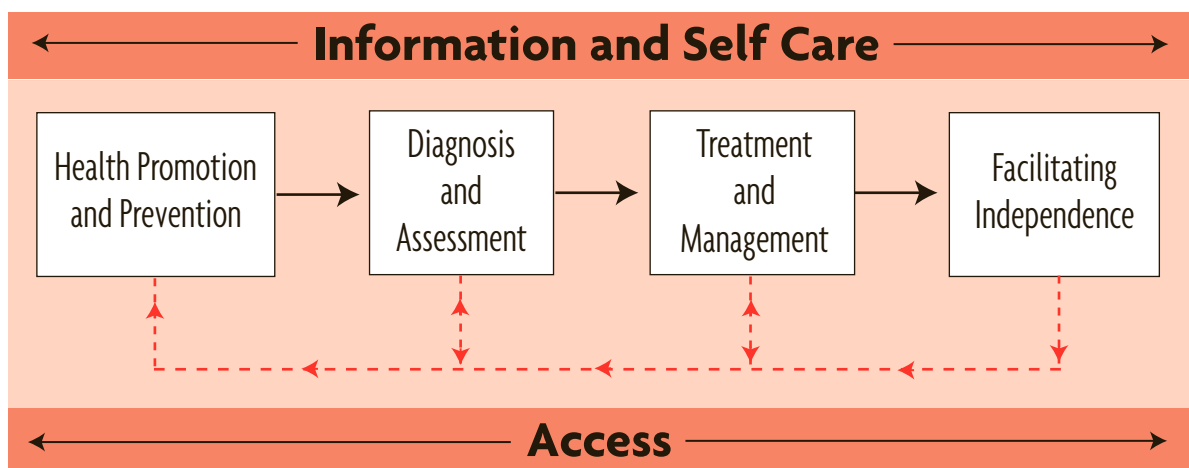
1.5.2 The vision will be delivered through:

- The promotion of healthy lifestyles and relevant support
- Prevention and early intervention as fundamental elements of care across all levels of care to reduce or prevent chronic pain related disability
- Services planned around care pathways to support the provision of effective pain management within local communities as far as possible

- Seamless care provided by integrated multiprofessional teams working across primary, secondary and social care to ensure effective pain assessment, management and evaluation
- Adherence to evidence based practice, national and professional guidelines and standards
- Community-based health care, social care and social support provided in a planned and integrated way by appropriate organisations
- Monitoring performance over time against clear actions and outcomes.

1.5.3 The foundation of these directives is a strategic pathway which underpins the patient journey where access to services, information and self care cuts across each component (*Figure 2*).

Fig 2. Strategic Pathway of Care



1.5.4 The pathway of care applies to those people with a variety of needs including those who:

- a. Are generally well and able to live fairly independent lives
- b. Have more significant care needs
- c. Have chronic conditions
- d. Need emergency treatment or rapid access to social care
- e. Need elective care
- f. Require social care.

Each chapter of this document addresses the key stages of the strategic pathway providing specific examples and case studies to illustrate the approach and the actions necessary to drive improvements forward.

1.6 Planning and Commissioning Effective Services

1.6.1 Robust planning and commissioning will need to ensure that services are evidence-based, patient-centred, accessible, cost effective and responsive

to the needs of people living in pain. A continual cycle of review and improvement will strengthen service delivery. Long term and sustainable services will be developed using local intelligence acquired as an integral part of the planning and commissioning process. This will inform the development of local services and the *Health, Social Care and Well-Being Strategies* in partnership with service users, their carers and all key stakeholders.

1.6.2 Where evidence is weak or conflicting, robust evaluation of clinical outcomes is essential. Consideration should also be given to what clinical outcomes are relevant and important. Evaluation and audit should be supported by information technology wherever possible, for example the use of READ codes in primary care to accurately record diagnosis.

1.6.3 Local service users are essential in helping to determine how services can best meet their needs. Public and patient involvement will need to be further developed to ensure this is addressed effectively as part of local planning arrangements.

Key Elements of Service Planning and Commissioning	Issues for CNMP
Assessment of service users' needs	Review the epidemiology of pain Audit of current service provision in primary, secondary, tertiary and social care
Preventative action and services	Prevention across primary, secondary and tertiary care
Public and patient engagement	Signposts guidance ²³ Expert Patient Programme
National Standards and Good Practice	Healthcare Quality Improvement Plan ²⁴ National Institute for Clinical Excellence and Health Care (NICE) British Pain Society Welsh Pain Society International Association for the Study of Pain Scottish Intercollegiate Guidelines Network Oxford Pain Site, Bandolier
Development of care pathways	Integrated care pathways ²⁵ Map of Medicine ²⁶ Year of Care ²⁷
Links with related service commissioning, provision and support	Transition from child to adult GP Clusters Integrated commissioning arrangements between LHBs, NHS Trusts, Local Authority Services, Health Commission Wales Support of National Public Health Services and Regional service arrangements
Demonstration of the development of services within all four tiers of the Chronic Conditions Model	Health improvement and primary care prevention Primary care and community based services Network based, more specialised services Complex case managed services
Population stratification	Risk stratification tools such as the Predictive Risk Stratification Model (PRISM) ²⁸
Workforce implications and planning	Designed for Work ²⁹ Agenda for Change ³⁰ Welsh Deanery Timescales for delivery and service change
Monitoring and evaluation of services	Local Action Plans Annual Operating Frameworks Balanced Scorecard

Chapter 2: Prevention - Reducing the Risks

Aim

To prevent or reduce, where possible, the development of CNMP and related disability through appropriate and early management.

2.1 Background

2.1.1 Effective pain management is of the utmost importance to prevent suffering and reduce or avoid resulting CNMP. The majority of acute pain is managed in primary care and is composed mainly of musculoskeletal pain. The *Service Development and Commissioning Directives for Arthritis and Chronic Musculoskeletal Conditions* should be consulted for further information.

2.1.2 Other acute painful conditions are also managed in primary care for instance, pain of cardiac origin and neurological origin where the aim is to ensure patients are assessed, diagnosed (where possible), managed and/or referred for specialist services as appropriate.

2.1.3 The overarching aim is to ensure prompt access to appropriate services and the right professional to initiate appropriate management regimens. This may include the primary care team, the community pharmacist and/or registered complementary therapists where there is strong evidence for the use of complementary therapies^{31 32 33}. Where evidence of good effect exists,

the use of complementary therapies should be considered as part of the health care package for patients in pain.

2.2 Healthy Lifestyles

2.2.1 A healthy, active lifestyle is important in preventing certain painful conditions and also in helping establish and preserve function and reduce disability in people with pain. Maintaining a healthy weight and taking regular exercise^{36 37} can contribute positively to patient outcomes following acute and CNMP.

2.2.2 The Welsh Assembly Government supports the integration of nutrition and physical activity policies and programmes, where appropriate, recognising the fact that the effects of diet and physical activity on health often interact. A number of existing strategies and initiatives recognise the importance of work to improve nutrition and levels of physical activity, particularly among children and young people and it is important that these key messages continue to be built upon.^{38 39}

2.2.3 Many people with CNMP are not aware of the benefits of exercise and often avoid exercise due to the perception that it may cause further harm.³ Evidence shows that quality of life improvements can be gained by people with CNMP through lifestyle changes including safe exercise and other physical activities.³ Evidence also suggests that exercise and muscle strengthening can have

an impact on function by reducing pain and stiffness; improving muscle strength and endurance; maintaining cardiovascular fitness; supporting weight reduction and contributing to an improved sense of well-being⁴⁰.

Case Study:

Active for Life is a physical activity scheme funded by the Big Lottery Fund which aims to reduce the risk of heart disease in the Vale of Glamorgan. The exercise referral scheme is a 12 week programme for people who would like to improve their medical condition and/or general state of health by increasing their activity levels. The scheme involves health professionals referring patients to a team of qualified instructors who operate from four leisure centres in the Vale. These types of programmes exist elsewhere in Wales and with training and education, staff could offer such programmes for patients with CNMP.

2.3 Secondary Care Acute Pain Services

2.3.1 Pain can arise from apparently uncomplicated surgery⁴¹ and on many occasions no structural reason can be found to explain this. Pharmacological, psychological and behavioural methods can be used to effectively manage pain. While these services are traditionally based in secondary care, with the advent of more day case surgery and complex acute pain

management issues in primary care, acute pain services need to provide support to primary care teams where appropriate.

In one study, the incidence of post surgical CNMP was 30-80% in amputation surgery, more than 50% following thoracotomy, 11-57% for scar pain and 13-24% for phantom pain following breast surgery, 3-56% following cholecystectomy and 0-27% for hernia repair.⁴¹

2.3.2 The advent of acute pain services has improved acute pain management^{42 43 44 45 46} and one of the ways that services for patients have improved is through standardising care and simplifying acute pain strategies. It has been shown that implementation of various strategies such as education, pain assessment and the use of regular analgesia through the use of an algorithm improves patient outcomes.^{47 48}

2.3.3 The Acute Pain Management Scientific Evidence⁴⁹ provides a comprehensive review of evidence-based practice in relation to the management of acute pain. The key, effective elements of acute pain services are⁵⁰:

- A collaborative, interdisciplinary approach to pain control including all members of the health care team (acute and chronic pain) and input from the patient and the patient's family when appropriate

- An individualised proactive pain control plan developed preoperatively by patients and practitioners (since pain is easier to prevent than to treat)
- Assessment and frequent reassessment of the patient's pain
- Use of both drug and non-drug therapies to control and/or prevent pain
- A formal institutional approach with clear lines of responsibility

2.3.4 The majority of Trusts within Wales have a formal acute pain service offering support to patients in secondary care and some offer advice to primary and tertiary care centres. This is not consistent across Wales however and further support to all patients would be beneficial.

2.4 Obstacles to Recovery

2.4.1 The transition from acute to chronic pain is not always well defined. It is essential that when professionals assess and triage patients, they understand when to treat and when to refer to other professionals appropriately. There are considerable variations in practice which need to be unified through the design of evidence-based care plans, through education and training and through working in close collaboration with pain experts where appropriate.

2.4.2 A clear example of the transition issues raised in 2.3.1 is when the expected recovery from an acute injury is delayed. For individuals with acute musculoskeletal injury whose progress is slow, it is important to assess them for Red, Yellow, Black and Blue Flags to identify any obstacles to recovery. The biopsychosocial flags are:

- **Red flags** - Signs and symptoms considered indicative of possible serious pathology or of the need for an urgent surgical evaluation
- **Yellow flags** - Psychosocial risk factors that have been shown to be predictive of CNMP associated disability or chronicity e.g. anxiety, depression, catastrophising, fear avoidance, etc. These can predict disability at an early stage, more so than the biological ones
- **Blue flags** - Work features which are generally associated with higher rates of symptoms, ill health and work loss which, in the context of injury, may delay recovery or constitute a major obstacle to it
- **Black flags** - Nationally established policy concerning conditions of employment and sickness policy specific to a particular organisation⁵¹.

2.4.3 The flag system can be used as a predictive tool by any healthcare professional involved in managing pain and can be used across a wide range of settings. It should be used early in the

pain experience in patients who appear to have prolonged episodes of acute pain or in patients who appear to have abnormal pain behaviours. They are not labels to be attributed to patients but helpful predictors to help determine the best management approach such as targeted education⁵² or anxiety and fear reduction⁵³.

2.4.4 Good communication and the availability of relevant, high quality information is essential. This will help individuals identify the need for effective acute pain management, the role of psychosocial factors in disability and recovery, know when to seek professional advice and understand when self management of symptoms is safe and effective. Information on acute and CNMP and its management should be targeted at:

- **The General Public:** Health promotion information and targeted campaigns, such as Welsh Backs, should educate the public and contribute to a better understanding of how to prevent and manage pain. Information should be focused on the whole population (accessible locally) as well as targeted at those at risk of developing CNMP.
- **People at risk of or actually experiencing acute pain:** Good information helps people become informed about their pain and enables them to become active partners in their care. Information is important to help people

manage their pain and inform them of further options in care.

- **The Health Professional:** Ongoing information and education is integral to the professional development of all healthcare providers. Health professionals have an important role to play in helping people understand how to manage pain effectively to reduce the impact of long-term pain and the obstacles to recovery as well as helping to minimise the risks of further complications.

Case Study:

The Welsh Backs Initiative is targeting the public, health professionals and employers in promoting the 'stay active' message in managing acute, simple mechanical low back pain. The Welsh Backs initiative is responsible for disseminating evidence-based guidelines throughout Wales to ensure people with acute, simple mechanical low back pain receive appropriate help and advice and, if appropriate treatment.

2.4.5 The general public, and those people living with CNMP, should be encouraged and supported to access appropriate information and learn about pain as part of self-care and self-management. This can be achieved through informal means and via more formal mechanisms including the Expert Patients Programme⁵⁵.

Sources of Information

The British Pain Society have a website (<http://www.britishpainsociety.org>) where evidence based guidelines are freely downloadable for both patients and professionals. The Welsh Pain Society website (<http://www.welshpainsociety.org.uk/wb/>) is under development but will also contain information for patients and professionals. Information can also be obtained from the newly established Chronic Pain Policy Coalition which consists of patients, professionals and parliamentarians who operate at policy level to develop an improved strategy for the prevention, treatment and management of CNMP. Various charitable organisations have useful information that may not be pain specific but address living with a chronic condition.

Prevention: Reducing the Risks

Key Actions	By Who
By September 2009, health planners and commissioners will ensure that patients have access to services in the community that are able to assess, manage and evaluate acute pain and the obstacles to recovery appropriately using best available evidence.	LHBs NPHS Welsh Pain Society NLIAH
By September 2009, evidence-based pathways will be developed and implemented for use across all health care settings to manage acute pain and the obstacles to recovery including valid and reliable assessment and evaluation tools and evidence based care plans.	LHBs NLIAH Welsh Pain Society NHS Trusts
By December 2008, standardised patient information on preventative strategies, self management and over the counter medication and treatment options will be easily accessible to the general public.	LHBs Community Pharmacies Welsh Pain Society Social Services Voluntary Sector Local Authorities NHS Trusts
By March 2010, E-learning educational and training packages, aimed at all levels from carers through to specialists in pain management will be available to support better management of acute pain and reduce associated risks.	Educational Establishments Welsh Deanery Welsh Pain Society NLIAH Voluntary Sector
By September 2009, patients with CNMP will be able to identify and access appropriately trained personnel working in local authority exercise referral schemes and other healthy lifestyle programmes currently available for patients with chronic conditions.	LHBs Local Authorities NPHS

Chapter 3: Assessment and Diagnosis

Aim

To ensure timely assessment and diagnosis of chronic-non malignant pain to minimise physical, psychosocial and economic impact.

3.1 Background

3.1.1 Making the diagnosis of CNMP will help ensure that patients receive appropriate assessment and management. Professionals able to make this diagnosis and subsequently take the lead in managing these patients effectively, are essential. A diagnosis is also important in ruling out underlying pathology. This can help patients accept that a cure is unlikely and can support and enable effective management of the pain. The disease or condition causing the pain may be incurable, irreversible or may have caused changes which, although the condition no longer exists, has set up a cycle in which pain continues to be experienced.⁵⁷

3.1.2 Pain is a personal experience, which makes it difficult to define and measure; there are no objective measures to quantify pain. Pain, which is assessed properly, can be remarkably sensitive and consistent, providing data on the pain experience.¹² Pain assessment is important in establishing a baseline and to evaluate management approaches.

3.1.3 Many individual conditions exist which have disparate signs and symptoms, treatment or management regimens and

outcomes. Individuals may experience nociceptive pain (where normal nerve pathways are followed) or neuropathic pain (where abnormal pathways are followed due to nerve damage). Some people experience a combination of nociceptive and neuropathic pain mechanisms, which can make assessment and management potentially more difficult.

3.2 Holistic Assessment

3.2.1 Pain needs to be assessed using a biopsychosocial approach, use inter-professional and interagency working and needs to be addressed across health and social policy boundaries.⁵⁸ The biopsychosocial model addresses:

- **Biomedical** - This can include for instance, ensuring that the pain has been adequately investigated, that previous treatment regimens are assessed for completeness and efficacy, concurrent major medical or surgical problems should be noted and the impact on the pain experience, any major drug and/or substance abuse should also be investigated and any red flags recorded.
- **Level of Physical Activity** - This can include for instance, level of physical fitness, ability to look after personal care, major co-existing musculoskeletal problems, ability to work and perform activities of daily living.

- **Psychological and Social Features -**

This can include for instance, any co-existing major psychiatric or psychological problems, unresolved grief and previous physical or sexual abuse, major misconceptions, difficulty accepting chronic nature of the condition, willingness to change, as well as the yellow, black and blue flags.

3.3 Early Recognition and Appropriate Referral

3.3.1 The development and use of evidence based care pathways with accompanying education and training, means that the majority of patients with CNMP can be successfully managed in primary care. Referral to pain specialist services is only necessary when regular evaluation fails to show an improvement, as may be seen in the more complicated or difficult cases.

3.3.2 The holistic assessment of the needs of people with CNMP should be supported by the *Unified Assessment Process*. Guidance issued by the Welsh Assembly Government in 2002 has provided steps for the development and implementation of this process. This will enable the effective assessment and management of individual care needs to ensure people can, as far as possible, maintain an independent life.⁶⁰

3.4 Multiprofessional Teams

3.4.1 Early assessment and appropriate diagnosis is facilitated by a multiprofessional team of health and social care professionals which cover services across the care pathway in all care settings. A well organised multiprofessional chronic conditions team will ensure that services meet the holistic needs of individuals across each of the four levels of the *Chronic Conditions Management Model and Framework* and are provided as near to patients' homes as possible. Recommendations on the development of multiprofessional teams are provided in Chapter 4: Management.

Case Study:

The development and re-organisation of the Conwy and Denbighshire Pain Management Service to incorporate multiprofessional team assessment following a biopsychosocial approach has led to positive outcomes.

These include highly positive patient satisfaction with the new service, improved efficiency and access to the service and treatment options, changes in management strategies, which include providing appropriate assessment together with the right treatment, to the right patient at the right time.

Assessment and Diagnosis

Key Actions	By Who
By March 2009, biopsychosocial assessment tools, triage and referral protocols will be designed centrally with flexibility built in for local variation in patient needs.	NLIAH Welsh Pain Society LHBs
By September 2009, planners and commissioners will ensure that assessment tools, triage and referral protocols, are in place and supported by appropriate training across all health care settings to aid early assessment and diagnosis of CNMP.	LHBs NHS Trusts Tertiary and Regional Centres NLIAH Welsh Pain Society Welsh Deanery
By September 2009, robust evaluation mechanisms will be in place identifying areas of good practice (that can be disseminated across Wales) and areas where improvements are needed (that need actions planned).	LHBs NPHS Welsh Pain Society NHS Trusts

Chapter 4: Management of CNMP

Aim

To ensure that all individuals with CNMP receive management that is appropriate, timely and where possible evidence-based and locally accessible.

4.1 Background

4.1.1 This chapter focuses on the management of CNMP and highlights the importance of a holistic approach to help people with symptoms of pain cope with the physical, psychosocial and economic dimensions of the pain experience. The overarching aim is to ensure that patients can see the right professional, in the right place, at the right time, and receive appropriate evidence-based treatment and advice on ongoing management across all four levels of the Chronic Conditions Management Model. Management should be patient-centred as evidence indicates that this can have a favourable impact on CNMP⁶¹.

4.1.2 Individual needs will vary and access to services appropriate to need should be secured and care co-ordinated across all four levels of the Chronic Conditions Management Model. Not all patients will require specialist services but those who have complex pain problems may require more expert management. Consistently delivered chronic pain services with access to specific pain management programmes are needed throughout Wales. When a patient presents to secondary care for pain management intervention or to

a pain management programme following a period of living with chronic pain, their beliefs, attitudes and behaviours are usually well entrenched⁶². Lack of attention to evaluating and managing these with education and psychological therapies has been one of the major limitations in care⁶³.

4.2 The Organisation of Care

4.2.1 The principles and actions of the *Model and Framework for Chronic Conditions Management* should underpin the organisation of care for CNMP. This will ensure the delivery of co-ordinated, comprehensive and consistent management for these conditions supported by care pathways as an integral part of mainstream service with appropriate shifts being made to ensure care is delivered effectively and safely in community settings and as close to people's homes as possible. It is important that care is well co-ordinated, ensuring timely and appropriate access to the right services in the right place. Locality Care Service Co-ordinators will play an increasingly important role in this respect.

4.2.3 Integrating services more effectively is crucial to the future of health and social care in Wales. The Community Services Framework⁶⁴ outlines some key approaches which can help to ensure that services are effective and meet all value for money challenges:

- The local development of primary care networks or clusters can ensure that specialist, diagnostic and therapeutic services are available locally
- Specifically tailored arrangements for service co-ordination, such as local networks for patients with CNMP, can promote more effective service collaboration around the user. Improved joint planning and utilising the provisions of the *Health Act Flexibilities* can improve co-ordination and allow secondary care specialists, primary care clinicians and social services to work as a single team within a defined area
- Opportunities to use shared service locations such as a Resource Centre or an existing or redeveloped Community Hospital site should also be explored by commissioners as a way of bringing together a number of services.

4.2.4 Establishing Care Pathways for CNMP is an essential part of improving the local management and co-ordination of care for individuals living with these chronic conditions. The Welsh Pain Society, supported by the Welsh Advisory Board will develop centralised care pathways building on the work driven by the National Leadership and Innovation Agency for Healthcare (NLIAH). These centralised pathways can be modified to meet local needs. They will also develop a range of patient and health professional

information, protocols and guidelines that can be customised to meet local needs.

4.2.5 Older people, disadvantaged groups, those with end-of-life needs, those with cognitive impairment, mental health problems, those confined to home and substances mis-users all may find it more difficult to get access to appropriate services or may require very specialised support. In planning services, these vulnerable groups need to be considered with specialised help made available, for instance, home visits, use of telehealth/telecare, good communications with psychiatric services and strong links with voluntary organisations. The Welsh Assembly Government will continue to support public services in Wales to improve access for people with disabilities as outlined by the *Disability Discrimination Act*.⁶⁵

Case Study:

The North Gwent pain team consists of a multi-professional team. Both the Consultant Anaesthetist and the Clinical Specialist Physiotherapist are present at new patient clinics and are both involved in the patient assessment. Treatment plans are formulated which may include physiotherapy, pharmacology, psychology, and a range of complementary services including acupuncture and trans-electrical nerve stimulation. Treatment strategies are carried out by the appropriate discipline and patients are reviewed by

the consultant, discharged by the nurses or can be seen in a multi-professional clinic where all disciplines are present. Referral pathways exist between disciplines within the team and outside, these can be made by any discipline.

4.3 Integrating Primary and Secondary Care Services

4.3.1 Health care interventions traditionally begin with a primary care team.

The majority of people living with CNMP can be appropriately managed within primary care, by informal and formal health professional, specialist and voluntary care support. Some individuals will require more specialist management in more complex cases for example, in-patient programmes and interventional techniques.

4.3.2 Pain services can be organised in a variety of different ways:

- **Pain Treatment Facility** - Describes all forms of pain treatment facilities without regard to personnel involved or types of patients served.
- **Multiprofessional Pain Centre** - An organisation of health care professionals and basic scientists which includes research, teaching and patient care related to acute and chronic pain. Inpatient and outpatient programs can be offered in such a facility, providing multi-professional and integrated healthcare services.

- **Multiprofessional Pain Clinic** - A healthcare delivery facility staffed by clinicians of different specialties and other non-clinical health care providers who specialise in the diagnosis and management of patients with chronic pain. This type of facility differs from a multiprofessional pain centre because it does not include research and teaching activities in its regular programs. A multiprofessional pain clinic may have diagnostic and treatment facilities which are in nature outpatient, inpatient or both.

- **Pain Clinic** - A healthcare delivery facility focussing upon the diagnosis and management of patients with chronic pain. The absence of interdisciplinary assessment and management distinguishes this type of facility from a multiprofessional pain centre or clinic. Pain clinics can carry out research but it is not a required characteristic of this type of facility.

- **Modality-oriented Clinic** - A health care facility which offers a specific type of treatment and does not provide comprehensive assessment or management. Examples include nerve block clinic, transcutaneous nerve stimulation clinic, acupuncture clinic and biofeedback clinic.⁶⁶

4.3.3 The management of complex pain problems requires intensive specialist input. Referral to specialist care may be required for individuals who:

- Are not responding to appropriate pharmacological regimens
- Have requested a referral, as is the patients' rights under NHS regulations
- Are experiencing problematic side effects
- Have red flags on assessment (urgent referral)
- Have yellow, black and/or blue flags
- Are expressing suicide ideation
- Require a pain management programme
- Require pain interventions
- Have not experienced the best methods at an early stage and so chronicity is established.

4.3.4 Pain specialists are essential for interventional therapy, pain management programmes, complex pharmacological therapy and dealing with complex psychosocial issues. Pain specialists also have a key role to play in managing patient care when a person is admitted to hospital. Beds should be available for people requiring in-patient pain management programmes or interventions requiring careful post-intervention assessment.

4.3.5 Providing specialist care in the community should be considered as part of shifting care appropriately into community settings. A specialist member of the secondary care team for example

could be commissioned to provide specialist pain services in the community and to cluster GPs across LHB areas. An example of a GP with a special interest approach (GPwSI) is being explored in the Swansea area and this could prove a useful pilot. It is envisaged that the GP and secondary care providers will work closely in primary care assessing and managing pain using evidence-based care pathways.

4.3.6 Community outreach pain services could play an important role in education and patient management when based around GP clusters. A GPwSI in pain management could support this model and also manage a case load of patients in pain who do not require secondary care services. The model of practice will depend on the needs identified by people with CNMP and commissioners and planners of services. Recommendations on the competencies required for GPwSI in Pain Management is being taken forward by the Royal College of General Practitioners in consultation with the British Pain Society and Royal College of Anaesthetists and is forthcoming. Progress on this development can be accessed at <http://www.rcgp.org.uk>. The 'Pain Management Service Development Programme'⁶⁷ may be useful in planning cost effective primary care pain services.

4.3.7 Primary care can play an increasingly important role in the early identification and management of red and yellow

flags. A primary care clinic for acute back pain provides a good example of this. These clinics could be run by appropriately trained doctors, nurses, physiotherapists, osteopaths and chiropractors, providing assessment, simple advice and treatment according to evidence based guidelines. They could operate on a 6 treatment basis in liaison with the GP who could then seek other treatment avenues, should ongoing treatment be required. This would support the guidelines suggested by Welsh Backs’.

4.3.8 The model of care chosen will depend upon local and regional planning decisions and essentially must ensure that services are in place to assess CNMP and deliver care appropriate to the pain experience. Guidance is available for the composition and role of specialist pain services and these can be obtained through The British Pain Society (*Recommended Guidelines for Pain Management Programmes for Adults, A Practical Guide to the Provision of Chronic Pain Services for Adults in Primary Care*) and the International Association for the Study of Pain (*Guidelines for Desirable Characteristics for Pain Treatment Facilities*).

Case Study:

The residential Pain Management Programme in Bronllys provides an example of an effective interprofessional approach. Psychologists, physiotherapists, occupational therapists, nurses and doctors work together with the

programme participants to improve quality of life through reducing disability and improving the approach that individuals with CNMP and Chronic Fatigue Syndrome take to their condition. Participants learn about their condition, develop coping strategies and receive intensive rehabilitation to address condition related disability through a cognitive behavioural programme.

4.4 Care Planning

4.4.1 Treatment and management interventions for CNMP should be underpinned by evidence-based care pathways and protocols. Multi-professional teams should work to agreed goals across care pathways to ensure the delivery of co-ordinated and consistent care services.

Case Study:

As a result of current challenges in the management of neuropathic pain an integrated care pathway has been developed by a multi-professional group of pain specialists for patients initially managed in primary care. The challenges include variations in practice and inappropriate referrals, need to improve patient outcomes, need to lift prioritisation of neuropathic pain in primary care, lack of national standards, inadequate patient monitoring, poor knowledge base and patients remaining on inappropriate treatment for too long. The care pathway is presented as

a template of best practice reflecting the views of a multi-professional advisory group from the NHS and from academia. The pathway structures patient assessment, treatment and follow-up and suggests treatment options according to the evidence and best practice guidelines.

4.4.2 A number of tools have been developed to help structure care pathways including the concept of the ‘Year of Care’⁶⁸ and the ‘Map of Medicine’⁶⁹. The ‘Year of Care’ is a planned, comprehensive approach to assisting people with long term conditions to self-manage their care, the goal being to maximising wellbeing, quality of life, and the efficient use of healthcare resources. It is used to systematise the design, commissioning and delivery of services to people with long term conditions. The ‘Map of Medicine’ is a web-based visual representation of evidence-based patient care journeys. As healthcare provision becomes much more specialised, the need to plan and then benchmark clinical practice against national standards whilst incorporating local intricacies is key. Opportunities should be explored locally to explore the use of these tools in managing CNMP.

4.5 Adherence to National Guidelines/Evidence Base

4.5.1 The delivery of effective services must be underpinned by national and professional guidance. There are

a wide-range of nationally recognised clinical guidelines and research which provide evidence of good practice and recommendations on service delivery for people with CNMP. A good example of this is the Algorithm for neuropathic pain treatment⁷⁰. Consideration should be given to any future NICE guidelines. Audit of these guidelines should be a regular feature of clinical practice as appropriate for clinical practice within Wales.

4.5.2 The British Pain Society⁷¹ have a wide range of guidelines available including recommendations/information for the use of opioids in CNMP and other pharmacological methods, spinal cord stimulators, and pain management programmes. The National Institute for Health and Clinical Excellence (NICE)⁷² offer interventional procedure guidance on a number of pain interventions. Similarly, the systematic reviews of pain related topics undertaken by the NHS Health Technology Assessment Programme,⁷³ and evidence-based care presented by Bandolier,⁷⁴ provide ‘the bottom line’ to advise practitioners on treatment options.

4.6 Workforce Planning

4.6.1 The development of new and the enhancement of existing multi-professional teams with shared care arrangements, will allow some complex conditions to be managed effectively through community and outreach arrangements. Guidelines are available on the composition of

specialist multiprofessional teams including those developed by the British Pain Society.

Evidence indicates that managed care which is co-ordinated by a range of disciplines provide positive outcomes for individuals while helping to reduce demands on secondary care service.⁷⁵

4.6.2 Modernising service delivery will call for innovation in developing new roles, optimising existing roles, the development and expansion of skills and competencies and working across or breaking down traditional organisational and professional boundaries. Planners and commissioners of services will need to work in partnership with the Welsh Assembly Government, NLIAH, the Workforce Development Education and Contracting Unit and the Welsh Deanery to take this forward within the context of Designed to Work: A workforce strategy to deliver Designed for Life⁷⁶.

4.6.3 Services for people with CNMP in Wales can benefit from clinical specialists, extended scope practitioners, independent prescribers and consultant therapists, as well as a greater variety of skilled administrative and clinical support worker roles. Non-medical health professionals, including case managers, can be trained to take greater responsibility for managing people's chronic pain within a multiprofessional team and the voluntary sector is an important part of the workforce supporting patients in pain. Extended scope

practitioners in primary and secondary care can help to reduce demands on consultant time in clinics and help to reduce waiting times for clinic appointments.

4.6.4 Community pharmacists are important in providing advice to individuals with pain on the safe and effective use of medicines, providing educational materials, and can assist in patients' self management in recommending appropriate over the counter medication. They can also advise on general health related activities and undertake medicine use reviews.

4.6.5 Many older adults live in residential or nursing homes. Staff caring for these older adults need to be supported in ensuring pain is assessed, effectively managed and regularly evaluated. This will need to be achieved through education and training and good links with pain specialists.

4.7 Education & Professional Development

4.7.1 Formal and informal education and training of all health professionals involved in the diagnosis and management of CNMP is needed. This will support approaches to care that are professionally integrated and multiprofessional in nature and support workforce planning needs. Given the large body of evidence relating to the role of psychosocial factors in the development, maintenance and recovery from CNMP, education programmes should have expert input from professionals

with a sophisticated understanding of these factors.

4.7.2 Evidence-based continuing professional development e-learning programmes can help to improve current practice and the management of patients with CNMP. The different approaches to psychological training that could be undertaken include teaching psychological concepts, enhancing patient centred attitudes, and developing communication skills to facilitate change and promote independence^{78 79}. Including service users in training programmes where possible could help to enhance effectiveness, enabling the development of more collaborative conversations about managing health.

4.7.3 For health professionals with a specialist interest in CNMP, there should be optional opportunities for the completion of formal qualifications where available as part of Continuing Professional Development (CPD).

4.8 Regional Planning and Service Delivery Arrangements

4.8.1 Arrangements to provide services for CNMP can be made at local and regional levels. Each Local Health Board area in Wales is well placed to work with their local partner organisations which include NHS Trusts, Local Authorities, and the voluntary sector, to provide services which help to meet local needs.

4.8.2 In some cases a regional approach may be more appropriate in terms of planning and funding. Specialist services may only cater for small numbers of patients but these tend to be the extremely complex cases. A regional approach would be beneficial to ensure equity of service provision across Wales. Regionally based services could be organised by collaborative arrangements with the full support and involvement of the relevant service providers and health professionals. Local Service Boards will have an important role in this context. The commissioning of services should take into account the *NHS Commissioning Guidance published in 2007* (WHC(2007)023).

Case Study:

The University Hospital of Wales offers a regional centre for neurosurgical interventions for pain management. Cases referred to this service are complex and usually originate from tertiary referrals from pain clinics and neurosurgery departments across Wales and England. Patients have typically been in pain for several years with key pharmacological and operative interventions not helping significantly. Practice is cumulative due to the nature of chronic pain and is labour intensive but success rates are high for a number of conditions and have proven to be cost effective.

Management of CNMP

Key Actions	By Who
By December 2008, plans to develop the workforce to support the implementation of these Commissioning Directives will be integrated into local workforce and training plans.	Welsh Assembly Government LHBs NHS Trusts NLIAH Welsh Deanery Local Authorities
By March 2009, planners and commissioners will ensure that plans to reconfigure existing secondary care pain specialist services based on assessment of local patient needs are established to ensure patients with complex CNMP are triaged and referred appropriately using evidence-based care pathways.	LHBs NHS Trusts Welsh Assembly Welsh Pain Society NPHS
By July 2009, planners and commissioners will ensure that secondary care pain specialists hold out-reach community based CNMP clinics based around GP clusters and the assessment of local needs.	LHBs NHS Trusts Welsh Pain Society NPHS
By March 2009, planners and commissioners will ensure effective acute pain services are available in all NHS Trusts and that these services support complex acute pain problems in community settings where clinically safe and appropriate.	LHBs NHS Trusts
By October 2009, planners and commissioners will consider existing evidence and the proposed NICE guidelines (due May 2009) on the treatment of chronic non specific back pain and commission appropriate services according to this evidence which may include professionally registered and regulated complementary therapists, including osteopaths and chiropractors.	LHBs NHS Trusts Professional Regulatory Bodies Welsh Pain Society
By April 2009, structured signposting on CNMP management will be developed to address a range of learning needs from carers through to CNMP specialists.	LHBs NHS Trusts Social Services NLIAH Welsh Deanery Welsh Pain Society

Key Actions	By Who
By December 2009, evidence based care pathways for the biopsychosocial management of CNMP across care settings will be designed centrally with flexibility built in for local variation in patient needs	LHBs NLIAH Welsh Pain Society
By December 2009, planners and commissioners will ensure that integrated primary care services for managing people with CNMP are established across Wales driven by evidence-based care pathways.	LHBs NHS Trusts Healthcare Inspectorate Wales Welsh Assembly Government NLIAH HCW Social Services Welsh Pain Society
By December 2009, patients with CNMP will have individual care plans in place, written in partnership between patients and health care professionals, and informed by care pathways.	LHBs NHS Trusts
By March 2009, regular periodic monitoring of medicines for CNMP will be undertaken and guidance and support given on the prescribing and use of medicines for the management of CNMP.	LHBs NHS Trusts NPHS All Wales Medicines Strategy Group (AWMSG)
By March 2009, planners and commissioners will ensure that appropriate in-patient and day case facilities are provided for patients with CNMP.	LHBs NHS Trusts Healthcare Inspectorate Wales Welsh Assembly Government
By September 2009, planners and commissioners will develop mechanisms to identify and share good practice for CNMP across all four levels of the Chronic Conditions Management Model.	LHBs NPHS NLIAH Welsh Pain Society NHS Trusts

Chapter 5: Facilitating and Managing Independence

Aim

To ensure that people with CNMP become partners in their care to support self-management and maximise their independence.

5.1 Background

5.1.1 A key role for health and social care services, in partnership with voluntary sector organisations and others, is to help people with CNMP to maximise their independence. Approaches should support self-management, building on the resources and knowledge individuals and their carers have. They should also include the support offered by the Expert Patients Programme. Not all patients are ready or able to self-manage and/or assume the role of a partner in their care so strategies need to support attaining these.

Case Study:

The Case Manager in level 4 of the Chronic Conditions Management Model and Framework will be a cornerstone in providing co-ordinated care for individuals with highly complex needs including the management of pain.

The Case Manager will be responsible for individual care needs and will be a key one point of contact throughout the care journey for each individual. They will need to have appropriate training and skills in pain management to deliver this care and support.

5.2 Social Model of Disability

5.2.1 The Welsh Assembly Government has adopted the Social Model of Disability as the basis for all its work on disability. The Social Model recognises that disadvantage and social exclusion often stem from the barriers disabled people face rather than from an individual's impairments. All service commissioners and planners should understand and implement the Model when planning their services. Service planners and commissioners should be aware that people with CNMP often have impairments that may be hidden from view (including fatigue) and that the severity of symptoms of the condition may fluctuate significantly from one day to the next.

5.3 Improving Quality of Life

5.3.1 Although it is unlikely that individuals with CNMP will be cured, much can be done to improve quality of life and maximise independence by ensuring:

- Flexible, accessible and responsive services that are multi-disciplinary and seamless
- Training, information and advice on positive lifestyle options and self-management strategies
- Training, education and support for behavioural and cognitive change

- Accessible employment or appropriate social security support, training and education
- Fully accessible buildings, transport, housing, leisure facilities and pursuits
- Clear roles between all appropriate agencies offering advice and support to enable people to fulfil their potential

5.4 Access to Information/ Signposting

5.4.1 People with CNMP can experience a great deal of uncertainty and anxiety regarding their future. A wide range of expertise is needed to support people during this period, being sensitive to their concerns and providing advice, relevant links and information resources. Health care professionals and supporting agencies need to be made aware of such resources to achieve such goals.

5.4.2 Local services such as ‘user led information points’, signposting by health professionals to help-lines, patient support groups and other sources of information can help to support people during assessment and following diagnosis. The Expert Patients Programme can also play an important role in helping people with CNMP by raising levels of confidence and improving self management skills.

5.5 Self Management

5.5.1 Supporting people to self manage helps make the best use of health and social care resources. To be effective, self-management should be woven throughout care pathways and be based upon partnerships between the individual and professionals at all stages of the spectrum of care.

Recent research suggests that self-management can help in reducing some of the symptoms associated with pain but may or may not affect the actual level of pain.⁸⁰

5.5.2 Accurate information and advice on the safe and effective management of pain is essential to allow self-management to take place, supporting independent living. Advice and guidance should focus on how pain should be managed and when health professional advice should be sought. The accessibility of information in public places including internet, pharmacies, libraries, and social care environments for example, is important to help educate people about managing their pain.

5.5.3 Lay-led self management training including the Expert Patients Programme are playing an increasingly important role in supporting people who are living with chronic conditions. These programmes provide appropriate training to help people

learn new skills to manage their conditions more effectively and confidently.

5.5.4 Self-help groups also provide people with CNMP with the opportunity to discuss their concerns, experiences and day to day symptom management with other people with similar experiences. Such groups can help to reduce isolation for some individuals with CNMP and can be a source of reassurance, support and information. They can also develop their own activities that reinforce positive self-management strategies and lifestyle choices such as exercise.

Case Study:

Patient support groups such as the charity Coping and Living in Pain established through the Velindre Pain Management Programme, Cardiff, can contribute to the maintenance of coping behaviours for those who have completed pain management programmes.

5.6 Public and Patient Involvement

5.6.1 Involving service users is crucial to developing services that meet patients' needs and is a key recommendation of the *Review of Health and Social Care in Wales* and Sir Jeremy Beecham's *Review of Local Service Delivery*. Developing user involvement is also a key principle within *Designed for Life* and the *Public and Patient Involvement Signposts Framework*. Health

and social care planning should take account of this guidance to ensure that people with CNMP are fully engaged in contributing to service design and implementation of the services they utilise.

5.7 Personal Assistance and Social Care

5.7.1 For people who need personal assistance, services should be responsive and flexible to take into account the fluctuating and unpredictable nature of their pain. It is important for service users to have control over the care and assistance they receive so these can be tailored to fit individual daily needs.

5.7.2 'Direct Payments' by Social Services offer improved quality of life for disabled people. While the Direct Payment option may not be suitable for all service users, it is important that support and guidance are available to enable people with CNMP who may decide to take up this option if they chose to do so.

5.7.3 Some individuals may require certain aids and adaptations made to both their home settings and places of work. Timely assessment and subsequent adaptations can have a major impact on independence for a person with CNMP. Services and information are provided by health and social services as well as voluntary sector organisations such as the Red Cross. Provision of such, needs to be undertaken in a co-ordinated

way. The Welsh Assembly Government has made funds available to NHS trusts and local authorities to facilitate the development of integrated equipment stores to ensure a more responsive, cost effective and consistent provision.

5.7.4 Consideration of home care, day care and personal assistance should be built into joint and unified assessments of needs for people with CNMP.

5.8 Informal Carers

5.8.1 Many people living with pain are supported by informal carers. CNMP can create a profound sense of helplessness, resulting in feelings of frustration which can manifest as irritability, and sometimes anger, directed at members of the family and other carers⁸¹. Informal carers experience many social disadvantages including loss of income and work opportunities, isolation, stress and fatigue. It is essential that unpaid carers have access to support and information if their contribution to the effective rehabilitation and management of people living with pain is to be maximised. Carers often need choices about whether or not they wish to take on a caring role and if so, be offered appropriate support, information and courses that can help them learn how to cope, manage their own health and well being and keep on caring. A number of voluntary sector organisations provide free information and support to carers. The Expert Patients Programme also offers the 'Looking After Me' course which

helps carers to manage their own lives whilst being a carer.

5.8.2 Assessments for care services under the Unified Assessment Process include a section on the role of any carer who provides or intends to provide 'regular and substantial' care. This should trigger the requirement of the Carers Equal Opportunities Act 2006 that carers should be informed of their right to a separate assessment of their needs.

5.9 Social Inclusion

5.9.1 CNMP has an impact on an individual's access to a wide range of opportunities including employment, housing, benefits, and pensions. In terms of employment, significant barriers to finding or returning to work exist for people with CNMP. There are a number of factors which make the return to work a risk, including the loss of benefits and crucial social support and care⁸². Limitations in transport, location and physical access to places of work can also reduce the options for individuals seeking employment⁸³. Retention in work and back to work programmes are important in securing a future for people with CNMP. Improving liaison with occupational health services is needed to ensure opportunities to refer patients to occupational health specialists are provided, especially for individuals living with CNMP who return to employment.

5.9.2 The Department for Work and Pensions has produced a green paper *A New Deal for Welfare: Empowering People to Work*.⁸⁴ This document proposes a new gateway to benefits for people with illness and disabilities and includes the provision of in-work support to ensure people continue working. Recent proposals for welfare reform express the intention to roll out the Pathways to Work initiative across the UK by the end of 2008.⁸⁵

This endorses the condition-management approach piloted in the Pathways areas, supports the biopsychosocial model to ensure that people off work, because of illnesses or disabilities, can be helped in the pathways to recovery and to return to work by providing the right opportunities, support and encouragement; by helping people to understand and manage their health condition; and by using cognitive behavioural therapy principles and related interventions.

Facilitating and Managing Independence

Key Actions	By Who
By December 2009, individual patient care plans will include a category for self management, for access to rehabilitation and the Expert Patients Programme.	LHBs NHS Trusts Expert Patients Programmes Voluntary Sector Local Authorities
By March 2009, appropriate information and support on CNMP will be widely available, signposting services provided by health care providers, the voluntary sector and local user-led self-help groups.	LHBs NHS Trusts NPHS Voluntary Sectors Local Authorities Welsh Pain Society Expert Patient Programme
By March 2009, opportunities for respite for carers of people in pain will be provided in line with existing guidance.	LHBs Social Services Voluntary Sector
By March 2009, unpaid carers will be actively involved in joint care planning arrangements to help them look after themselves and the person living with pain.	LHBs Social Services Voluntary Sector

Appendix 1: Acknowledgements

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