



Llywodraeth Cymru
Welsh Government

Living with Persistent Pain in Wales

"This guidance aims to provide advice to those experiencing persistent pain and their families, and health and social care professionals."

April 2019



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Ministerial Foreword



Vaughan Gething Minister for Health and Social Services

Persistent pain can take many forms and can result from many conditions but the one thing people who live with it have in common

is the effect it can have on their lives. In some cases people can be unable to work or undertake the day to day activities that most people take for granted. The personal and national cost of persistent pain makes it an important area for improvements in management and care.

The aim of this guidance is to move towards a greater focus on helping people to develop skills to enable them to manage persistent pain for themselves in their daily life, and so increase their ability to stay in work and maximise their physical, mental and economic well-being. The aim of enabling people to live longer, healthier and happier lives, as independently as possible as long as possible is key to *A Healthier Wales*¹.

A Healthier Wales is our first national strategic plan for health and social care. The plan requires service providers to place more emphasis on prevention, which includes helping people to stay well and avoid illness, predicting and detecting illness sooner so that we can offer better, cheaper, earlier treatment, helping people to get better after they have been ill, or to manage their own health if they have a long term condition.

This aim of this document is also very much in line with Welsh Government's National Strategy, *Prosperity for All*² and the principles set out in the Well-being of Future

Generation Act. Our financial climate means it is imperative for the NHS and social care to focus on making the best use of resources to make a real difference. Continuing concentration on prudent healthcare principles and value based healthcare is essential to allow the development and delivery of efficient and effective services.

Prevention was considered as part of this guidance. It was determined work on prevention should remain separate to the guidance to ensure this guidance remains relevant for those already living with pain and methods to avoid pain.

During the consultation process, queries were raised in relation to a number of performance areas such as timescales, performance measures and upskilling of staff. Whilst this guidance is not intended to be used as a framework, Welsh Government recognise that health boards require further support and accountability to ensure work in this area is maintained and improved. An implementation group will be established with representation from each health board area, social care representation and a wide range of stakeholders to ensure continuous improvement is undertaken in this area. This group shall consider local and national issues, ensuring health boards across Wales provide the required levels of services for their population. The group will also consider the current resources and examine where resources could be used to best effect.

In the spirit of partnership working, this guidance has been co-produced in conjunction with clinical leads, academics and service users who formed a steering group to drive forward the work needed to progress it to publication. I would like to extend my thanks to all those who contributed to the process.

I encourage health boards and relevant partner organisations to adopt the guidance and ensure staff are equipped to positively treat and support those living with these conditions.

¹ www.gov.wales/topics/health/publications/healthier-wales/?lang=en

² www.gov.wales/docs/strategies/170919-prosperity-for-all-en.pdf

Executive Summary

In 2008, the Welsh Government published the *Designed for People with Chronic Conditions*³, Chronic Non-Malignant Pain Directive. The Directive committed the NHS in Wales to an evidence-based multidisciplinary service provision, underpinned by national and professional standards, which were required in order to address the needs of the people in pain in the 21st Century.

Following the introduction of new approaches to health care within Wales, the Welsh Government, clinical and academic partners and service users have collaborated to produce guidance relating to persistent pain provisions.

This guidance aims to provide advice to those experiencing persistent pain and their families, and health and social care professionals.

Introduction

In previous documentation, the Welsh Government and NHS in Wales have used the term chronic pain. For the purposes of this guidance, the term chronic pain has been replaced with “persistent pain”, as it believed this terminology will help the public to better understand the condition.

Persistent pain is described as pain that continues for more than twelve weeks⁴. Persistent pain can affect anyone of any age, at any time and is a significant health problem for a substantial proportion of the population. It is estimated that between 11% and 20% of adults are affected⁵, with symptoms ranging from mild discomfort to debilitating pain.

Living with persistent pain can negatively impact on a person’s quality of life and ability to function, not only physically, but also psychologically, socially and economically. It can limit potential well-being, lower self-esteem, increase co-morbidities due to inactivity, have adverse effects on relationships and work, and be associated with feelings of shame and guilt.

This guidance aims to signpost people living with persistent pain and healthcare professionals to relevant provisions and support available, as well as highlight common issues and examples of best practice.

Who is this guidance for?

This guidance is for health and social care professionals. It aims to support the management of services, provide greater understanding of the different approaches available for the management of persistent pain, and optimal approaches health and social care professionals should use when offering care and management to anyone living with persistent pain. It should enable existing services to quality assure their service and develop appropriate management options as needed. The guidance is also

³ www.wales.nhs.uk/documents/Chronic_Conditions_English.pdf

⁴ Useful Definitions and Glossary [online] www.britishpainsociety.org/people-with-pain/useful-definitions-and-glossary/ (accessed on 22 January 2019)

⁵ Parsons, G and others: Chronic Pain Service Provision in Wales: Five years after the launch of Design for Pain. 2014 www.welshpainsociety.org.uk/documents/cpspiw.pdf (accessed on 22 January 2019)

aimed at helping those experiencing persistent pain and their families understand the approach taken by health and social care professionals in Wales. A glossary has been provided at the end of the document to help advise on terminology used throughout the guidance.

What does this guidance do?

This guidance provides general signposting for individuals to help consider the choice of effective approaches and enable them to make informed decisions about their care and support. An overarching aim is to support anyone living with persistent pain to take control of managing their own long term condition where possible, actively engage and choose the approach(es) most effective in the management of their pain. It also provides a focus for Welsh health boards and other authorities to improve the range and quality of services for people living with persistent pain, and signposting to information and the current policies and direction of health and social care in Wales.

Policy context in Wales

*Prosperity for All*⁶ is the Welsh Governments' National Strategy. It sets out the Government's aims and provides clarity about the changes it wants to make in Wales and how it wants government and delivery partners to be part of a new approach to delivering priorities.

The Well-being of Future Generations (WBFG) Act 2015⁷ acknowledges the contribution that everyone can make to the shared goals for Wales and provides a basis for creating a different kind of public service in Wales. The heart of this strategy is a recognition that public services and third sector partners want to work together towards common objectives, to focus on the needs of people, at all stages of their lives and in all parts of Wales.

In September 2017 the Welsh Government published a *Well-being Statement 2017*⁸, setting out in more detail how the Well-being of Future Generations Act will contribute to the seven well-being goals for Wales.

The Parliamentary Review of Health and Social Care in Wales published its report in January 2018. The report recommends actions should be framed around delivering the Quadruple Aim: Improving the health and well-being of the population; improving the experience and quality of care for individuals and their families; improving the well-being and engagement of the workforce; increasing the value achieved from the resources that are invested in services.

In June 2018 Welsh Government provided a response in *A Healthier Wales: our Plan for Health and Social Care*⁹ which called for bold new models of seamless local health and social care at the local and regional level. The plan aims to make it easy for health and social care services to work together, and with other services like education and housing. It also aims to help health and social care services provide more care at home, or as close to home as possible and move some services away from hospital and help people stay well by looking after themselves better.

⁶ www.gov.wales/about/programme-for-government/?lang=en (accessed on 22 January 2019)

⁷ www.gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en (accessed on 22 January 2019)

⁸ www.gov.wales/docs/strategies/170919-wellbeing-statement-en.pdf

⁹ www.gov.wales/topics/health/publications/healthier-wales/?lang=en

Part I: Living with Pain

Persistent pain can affect a person of any age and may be caused or precipitated by a wide range of conditions. Many people affected by persistent pain begin a journey of tests, investigations and surgical or medical interventions. For many this can turn into repeated visits to GPs and various specialists, looking for explanations and a cure, which sometimes can be unattainable. Whilst it is vital to investigate newly presenting pain and exclude causes which require specific treatment such as physical therapy, surgical or medical care, it is equally important to enable a person living with pain, and their health provider/professional, to move on beyond the medical model when investigations have not shown a cause, have excluded sinister processes, or when other interventions have not provided any benefit.

It may be difficult for a person to accept their pain is not 'curable' in the medically modelled sense, but nevertheless they can still move forward. Sometimes a person with persistent pain may become stuck in a routine of repeat interventions, on high doses of pain killers which are ineffective and which give unwanted side effects. A person with persistent pain in any situation can benefit from a pain management approach where he or she can understand more about their pain and strategies that can be helpful in improving quality of life.

The treatment and management of pain can be considered by a wide range of healthcare professionals. Pharmacists, occupational therapists, psychologists and other primary care professionals can play key roles in the support and treatment provided to people living with pain. If people living with pain are directed to the correct service, this will result in the reduction of waiting times and allow specialists to spend the quality time required with people who require their services the most.

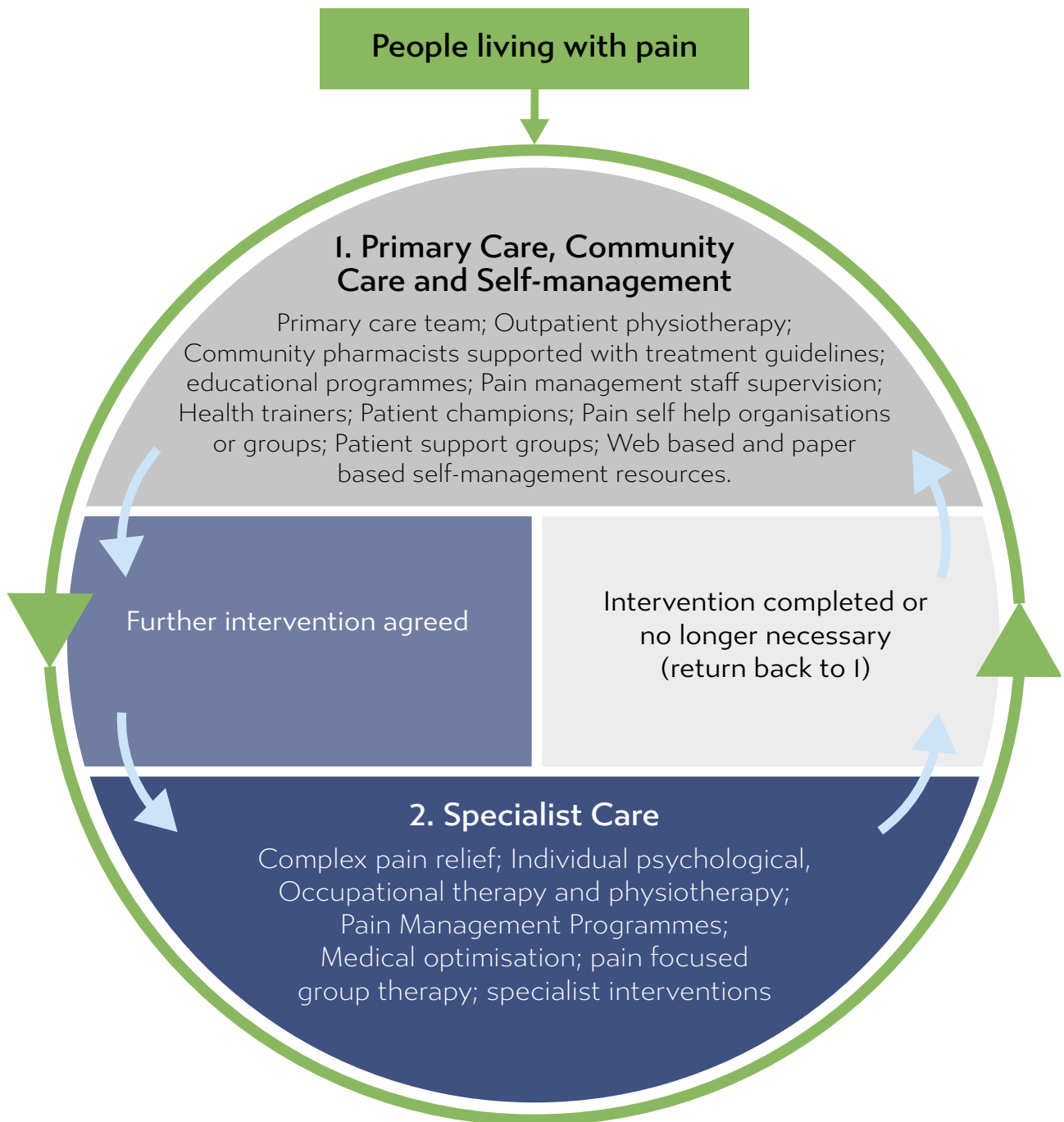
Context of current services

People with persistent pain may require varying levels of care services at different times. The spectrum of pain experienced ranges significantly from low risk, where an individual can deal with their own pain as a manageable condition with continued support, to higher risk individuals who require complex case management programmes.

As a person living with pain I should:

- Understand my pain to know how best to approach my treatment
- Be seen by the healthcare professional with the right skills
- Work with my healthcare professional and tell them what you need them to know

Persistent pain services: Population requirements¹⁰



¹⁰ Developed from Pain Management Services: planning for the future – Guiding clinicians in their engagement with commissioners. Published by The Royal College of General Practitioners – www.rcoa.ac.uk/document-store/pain-management-services-planning-the-future-guiding-clinicians-their-engagement (accessed on 22 January 2019)

Lived experiences

The experience of living with persistent pain is individual to every person.

Consultation Pain group attendee: "I am a 22 year old woman taking 23 pills a day. Some pills simply counteract the side affects caused by the other pills."

Service User via consultation group: "Relationships change when you're diagnosed with pain. It affects families, friends, work and social life."

Reflecting on the experiences of those living with persistent pain is essential to understanding the most effective intervention for that person.

As a person living with pain I should:

- Expect to be listened to
- Only be given appropriate treatment
- Actively discuss issues with healthcare professionals
- Decide together what the next steps should be

Constructive conversations

Health and social care professionals and those living with persistent pain need to engage in constructive conversations to agree expectations, needs and goals.

A bio-psychosocial approach should be undertaken to consider the needs of the whole person, not just the medical ailment. Psychosocial approaches can include thinking about the everyday tasks which can cause an individual concern, such as walking during the day, picking up the children from school and so forth.

The principles of *Making Every Contact Count (MECC)*¹¹ should be applied and adopted in each encounter with people living with pain.

The simple 3As approach can be used undertaking a brief health chat:

- Ask individuals about their lifestyle and changes they may wish to make, when there is an appropriate opportunity to do so.
- Advise appropriately on the lifestyle issue/s once raised.
- Act by offering information, signposting or referring individuals to the support they need.

¹¹ www.wales.nhs.uk/sitesplus/888/page/65550

Being heard

Individuals living with persistent pain repeatedly highlight a feeling of not being heard by their health professional. Whether perceived or real, this is identified as a major contributor when people with persistent pain report whether or not their management was helpful.

Comprehensive assessment of need and risk

Targeted conversations are imperative during every stage of managing pain to determine the health of the individual, potential risk factors leading to reduced health, as well as any issues with the access to and quality of services to address needs. It is important that health and care professionals listen to what matters to people to ensure they receive the most appropriate care. Clinicians with expertise in pain related instances should be made available to assess people prior to medical intervention. Conservative forms of treatment should be considered first and developed depending on the responses of the individual.

Safely reducing ineffective medication

It is crucial health and social care professionals enable people with persistent pain to plan the process of reducing or stopping medications that are no longer providing a benefit or potentially causing harm whenever applicable.

Careful language and sensitive communication

It is important health providers/professionals are alert to how phrases may be interpreted, and maintain sensitive and non-judgemental language. Being clear on the cause of people's pain and being clear and consistent when operations or interventions are not required will help people better understand their conditions. It is important to be aware how people with persistent pain may interpret phrases such as 'your spine is crumbling' or 'it's full of arthritis', 'you've got a trapped nerve', or 'your discs have gone', and to avoid terms that individuals might find unhelpful, and damaging to their self-identity and feeling of control. Metaphors should be used carefully and avoid unnecessarily creating negative images. Diagnostic tests may identify a cause for persistent pain but not all tests are definitive, for instance many people have prolapsed discs but experience no pain. Clear and consistent information needs to be provided when there is no effective specific medical or surgical intervention to help enable a person with persistent pain to move on and engage with activities that help them manage their own pain.

Consultation Pain group attendee: "It feels brilliant when your doctor believes your pain".

Consultation Pain group attendee: "A better doctor/patient relationship would help a lot. Feeling like no one understands or listens to your pain story is frustrating."

Often the issues raised by people living with persistent pain are complex. The Royal College of General Practitioner's¹² provided evidence¹³ of some constant themes:

- There are certain cultural challenges regarding the general idea of illness, namely an expectation of receiving a medical diagnosis and cure
- Not feeling believed can have an impact on a person's participation in everyday life
- For some individuals, such as those living with dementia or who have learning disabilities, communication of pain may be non verbal and practitioners should use appropriate reasonable adjustments to understand that person's situation
- Listening to a person's story can help to understand the impact of pain
- The consideration of more than one condition, or the knock-on effect a persistent condition can have on a persons' other health factors should be considered
- It is important health professionals provide consistent advice.

Therapeutic Alliance

The relationship between an individual with persistent pain and their health and social care professional has a strong effect, both positively and negatively, on the outcome for the individual. It may not be easy to measure or quantify this relationship. The King's Fund¹⁴ describes numerous ways in which relationships can be measured, including surveys, perception scales and analysis. This paper concludes that the following factors help create a strong relationship between the healthcare professional and the individual.



It is important that people living with pain feel believed. The majority of people with pain wish to live and work as much as their body will allow.

¹² Johnson, M and others: Pain Management Services: Planning for the Future. 2013. [online] www.rcgp.org.uk/-/media/Files/CIRC/Chronic-pain/RCGP-Commissioning-Pain-Management-Services-Jan-14.ashx?la=en (accessed on 22 January 2019)

¹³ www.rcoa.ac.uk/document-store/pain-management-services-planning-the-future-guiding-clinicians-their-engagement

¹⁴ Greenhalgh, T & Heath I. Measuring Quality in a Therapeutic Relationship. 2010 [online] www.kingsfund.org.uk/sites/default/files/field/field_document/quality-therapeutic-relationship-gp-inquiry-discussion-paper-mar11.pdf (accessed on 22 January 2019)

Honesty and realism

It is important for health and social care professionals to be honest with people, even when it involves difficult conversations regarding an unlikely cure and the management of expectations, whilst remaining open-minded about the management of pain through a range of interventions and therapies. Understanding the needs of people with persistent pain is crucial to addressing methods of helping reduce it.

Pain group attendee: "It is vitally important that patients are not just given medications without knowing what they are and they need to understand the effects those medications will or can have on their bodies."

Shared decision making

The Health Foundation research¹⁵ concluded that shared decision making, described as the partnership working regarding treatment and care between people living with pain and health professionals, has a profound effect on people living with pain seeking treatment. Individuals with persistent pain need to be supported in expressing how pain is impacting on their lives and how to manage their pain. Better conversations between people and clinicians, as partners, supported by reliable and relevant information will enable better (shared) decision making for both. The Making Choices Together movement is encouraging those open conversations between people and their clinicians to make decisions together about the right care for the person.

Welsh Language

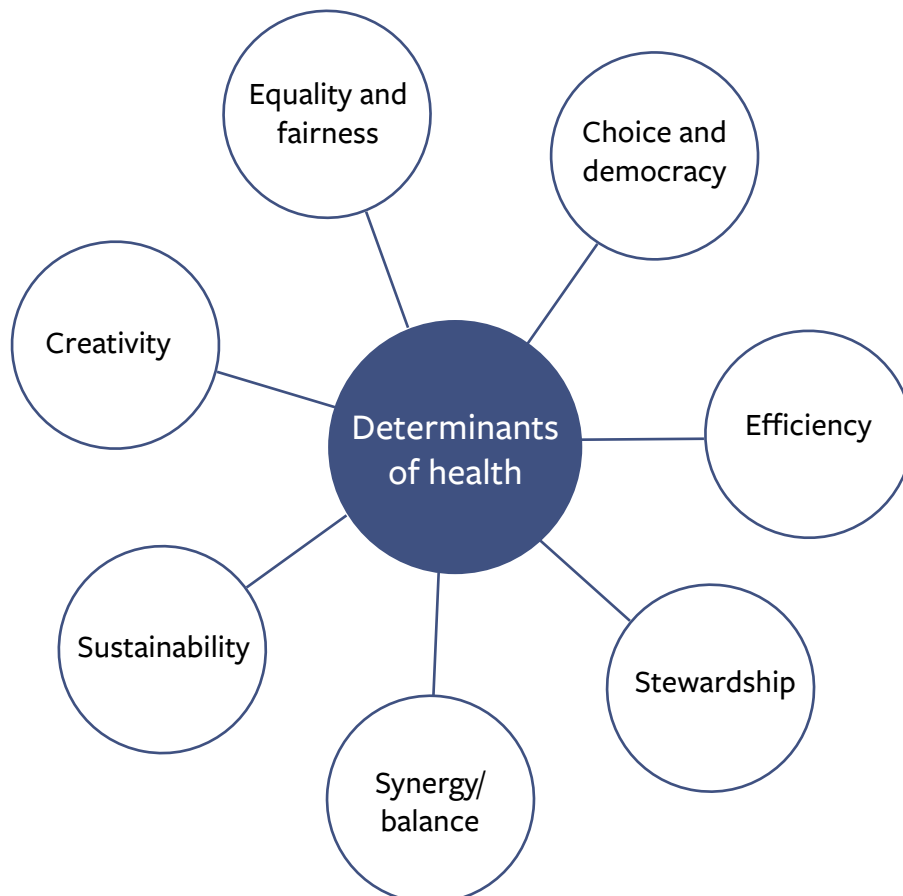
Organisations must consider how they deliver services in the form of an Active Offer which is a key element of the *More than Just Words*¹⁶ strategic framework for Welsh Language services in health, social services and social care. In taking valid consent, health professionals are encouraged to discuss conditions and treatment options in Welsh, British Sign Language (BSL) or other language when this is the person's first language. The health professional must feel sufficiently confident in his or her ability to speak the language when seeking the person's consent to examination or treatment. Health boards and Trusts must also ensure that they comply with the relevant Welsh Language Schemes or Standards.

¹⁵ Dr Ahmad, N and others. Person-centred Care: From ideas to action. 2014. [online] www.health.org.uk/sites/health/files/PersonCentredCareFromIdeasToAction.pdf (accessed 22 January 2019)

¹⁶ www.gov.wales/topics/health/publications/health/guidance/words/?lang=en

Considerations when supporting management of people with long term conditions

When considering the best path to help people, the factors which effected people earlier in their lives or that a person had little control over, can give pointers to the potential for improvement.



- **Equity and fairness** – inequalities in health, and their links with social factors, make a difference. Being viewed with fairness, although difficult to measure, has potential benefits which should not be underestimated.
- **Choice** – The person living with persistent pain has a right to be part of the discussion regarding their health, social care and support needs.
- **Democracy** – People need to be actively engaged and provided with access to information.
- **Stewardship** – Investment is required in the correct areas to maintain and improve vital public resources.
- **Efficiency** – optimal use of evidence based resources to obtain maximum benefit – discussions are required around the effectiveness of interventions and the priority accorded them.

- **Synergy/Balance** – people living with persistent pain can work collaboratively and differently to improve their health and well-being.
- **Sustainability** – positive life-style changes need to be sustainable and shown to make improvements.
- **Creativity** – exploring the different models of care available to service users.

Trauma informed care¹⁷/Adverse Childhood Experiences

Traumatic events in childhood, including neglect and abuse, interpersonal violence, and bereavement, are associated with a much higher rate of illness in adulthood, including physical illnesses as well as persistent pain and medically unexplained symptoms. Such features should be seen as key aspects of an individual's life story, elicited through sympathetic, systematic enquiry, and considered as a potentially important factor in identifying effective management options.

Example: Low Back Pain Community Education Group

Aneurin Bevan University Health Board has introduced an initiative designed to enhance the management of back pain and sciatica in primary care.

The back pain education groups set out to equip people with the knowledge to make fully informed and appropriate decisions about their own care that relate to their personal context.

The purpose of the group is to provide detailed information about back pain and sciatica, its causes and treatment options, along with self-management strategies. It is not a therapeutic group and is designed as an adjunct, not a replacement, to existing referral pathways.

¹⁷ Mock and Arai 2013 Childhood Trauma and chronic illness in adulthood Front Psychol (www.ncbi.nlm.nih.gov/pmc/articles/PMC3153850/). 2010; 1: 246. Published online 2011 Jan 31. doi: www.frontiersin.org/articles/10.3389/fpsyg.2010.00246/full (accessed 22 January 2019)

Information and advice

As a person living with pain I should:

- Be given advice in a way I can understand
- Be made aware of different areas of support that can be provided

The information and advice provided to people living with persistent pain must ensure the reader has the ability to digest and utilise the information effectively. Health and social care professionals may need to reflect on a person's competency, capacity and literacy when considering why individuals may not be responding or reacting to correspondence or providing information accordingly. Alternative methods of communication should be considered. For example, Welsh Government guidance advises that people within gypsy, Roma and traveller communities may have improved interaction with the health service when contacted face to face, via text message or on the phone, as opposed to receiving a letter¹⁸.

People living with pain and professionals need to be able to find and understand the relevant health information. There is an associated link¹⁹ between those having poor health literacy and acquiring poorer health outcomes.

There are many third sector and local based organisations that can support pain management for those who are in need. Health boards and local authorities are strongly encouraged to make these organisations visible to their populations via their websites and literature.

Education Programmes for Patients (EPP) Cymru²⁰ provides a range of self-management health and well being courses and workshops for people living with a health conditions or for those who care for someone with a health condition. In 2017, Public Health Wales purchased the licence to train EPP trainers across Wales to facilitate the Stanford Pain Management Programme – Chronic Pain: Dealing with long term pain, which is a 6-week lay-person led group.

Example: EPP pain management programme

Hywel Dda University Health Board has included the EPP pain management programme into its pathway as a referral option pre-accessing their service, or post-assessment if it transpires that secondary care is not required, as well as providing patients with the information for being able to self-refer for 'refresher/top up' information after being involved with secondary care specialist services.

¹⁸ www.gov.wales/docs/dhss/publications/150730guidanceen.pdf (accessed 22 January 2019)

¹⁹ Briggs and others. Health literacy and beliefs among a community cohort with and without chronic low back pain [Pain 2010;150:275-283]. [Pain. 2011] www.ncbi.nlm.nih.gov/pubmed/20603025 (accessed 22 January 2019)

²⁰ www.wales.nhs.uk/sites3/home.cfm?orgid=537 (accessed 22 January 2019)

Well-being through Work

Schemes such as the Well-being through work (In-work support service)²¹ provide rapid access to tailored occupational therapy, physiotherapy and psychological therapy services designed to help people to return to work or to manage a health condition in work.

Actions

1. Staff understand prudent health and can communicate this effectively.
2. The principles of *Making Every Contact Count (MECC)*²² should be applied and adopted in each encounter with people living with pain.
3. Individuals receiving communication from health and social care professionals can understand what they have been told.
4. Shared decision-making tools are available in all health boards providing information on which people living with persistent pain can make informed decisions about their care.
5. Information about third sector provision is available and advise how they can support individuals and their families.
6. Each local health authority has an information, advice and assistance service supporting those living with persistent pain, with the majority using DEWIS. Wales²³.

²¹ www.nhsdirect.wales.nhs.uk/localservices/ViewLocalService.aspx?id=7686&s=Health%2C+Wellbeing+&+Support&print=I

²² www.wales.nhs.uk/sitesplus/888/page/65550

²³ www.dewis.wales/ (accessed 22 January 2019)

Part 2: Evidence Base

The aim of this section is to provide health and social care professionals with sources of reliable guidance so they can develop shared decision making tools and provide people living with pain with choice.

It is important that professionals utilise high quality evidence. The following list provides links to high quality guidelines and evidence to inform and commission practice:

- The National Institute for Health and Clinical Excellence (NICE)²⁴ is an agency of the National Health Service charged with promoting clinical excellence in NHS service providers in England and Wales, by developing guidance and recommendations on the effectiveness of treatments and medical procedures.
 - » NICE recommendations are issued in the form of "technology appraisals". These are based on a review of evidence of clinical and cost effectiveness for a particular technology, and give recommendations about whether and in what circumstances the technology should be used in the NHS. The majority of technologies assessed by NICE are drugs, but it has also considered surgical procedures, medical devices and screening technologies.
 - » NICE also produces "clinical guidelines", providing wider guidance on the management of whole diseases or clinical conditions, which usually include several different treatment options.
 - » NICE is also responsible for assessing the safety and efficacy of interventional procedures for diagnosis and treatment.
 - » NICE is tasked with conducting assessments and drawing up guidelines by the Department of Health and the Welsh Government.
- The Faculty of Pain Medicine²⁵ is the professional body responsible for the training, assessment and continuing professional development of specialist doctors in the management of pain in the UK.

As a person living with pain I should:

- Expect my health or social care professional to use evidence based practice when providing treatment or advice

The British Pain Society²⁶ aims to promote education, training, research and development in all fields of pain. It endeavours to increase both professional and public awareness of the prevalence of pain and the facilities that are available for its management.

²⁴ www.nice.org.uk/guidance

²⁵ www.rcoa.ac.uk/faculty-of-pain-medicine/evidence-base/chronic-pain (accessed 22 January 2019)

²⁶ www.britishpainsociety.org (accessed 22 January 2019)

- The Cochrane Library²⁷ is a collection of six databases that contain different types of high-quality, independent evidence to inform healthcare decision-making, and a seventh database that provides information about the Cochrane review groups which provide expert advice on specific conditions.
 - » Cochrane Database of Systematic Reviews (CDSR)
 - » Cochrane Central Register of Controlled Trials (CENTRAL)
 - » Cochrane Methodology Register (CMR)
 - » Database of Abstracts of Reviews of Effects (DARE)
 - » Health Technology Assessment Database (HTA)
 - » NHS Economic Evaluation Database (EED)
 - » About The Cochrane Collaboration
- The International Association for the Study of Pain²⁸ outlines classification of diagnosis for persistent pain.
- Evidence Based Medicine and its relationship to other approaches to decision making in clinical practice, can be found at: Ashcroft (2004)²⁹, Fernandez et al (2015)³⁰, Gilbert et al (2010)³¹, Miles & Loughlin M. (2011)³² and Montori et al (2013)³³.

Actions

Audit and service evaluation should show that all guidelines, shared decision making tools and information leaflets are informed by the strongest evidence available.

Where the evidence of effect is poor, this should be communicated to those living with persistent pain and their carers/family.

Health and Social care professionals need to have an easily accessible repository of executive summaries of all key guidelines produced by reputable and learned bodies and societies.

²⁷ www.cochranelibrary.com/about/about-cochrane-library#ABOUT

²⁸ www.journals.lww.com/pain/pages/articleviewer.aspx?year=2019&issue=01000&article=00004&type=Fulltext

²⁹ www.jme.bmj.com/content/medethics/30/2/131.full.pdf

³⁰ www.ncbi.nlm.nih.gov/pmc/articles/PMC4636779/

³¹ www.ncbi.nlm.nih.gov/pubmed/20920289

³² www.researchgate.net/publication/51525692_Models_in_the_balance_evidence-based_medicine_versus_evidence-informed_individualized_care_INTRODUCTION

³³ www.jamanetwork.com/journals/jama/fullarticle/1763247

Part 3 – The way forward

Excellent quality will always be a priority for those accessing and providing health and social care systems. The Wales Audit Office³⁴ concluded that whilst the plan for persistent conditions is clear at a national level, improvement is required at local levels. People in Wales need to receive excellent care in every area of the country.

Health boards in Wales have adopted a multiprofessional approach which they have found to be beneficial in improving provision in their areas. There is evidence of the added value of undertaking a multiprofessional approach and this is being demonstrated in health boards across Wales. Health and social care professionals are encouraged to give further consideration to this approach and to consider multimodal approaches to pain management which encourages effective self-management alongside surgical and other options where appropriate. The Core Standards for Pain Management services in the UK³⁵ published by the Faculty of Pain Medicine provides further guidance relating to the approaches required by multi-discipline and multi-speciality teams.

As a person living with pain I should:

- Expect the different professionals considering my care to work together to develop the best approach
- Be included in discussions on what is best for me

Specialist services provide treatment modalities not available to GPs, but also inform the treatment of people experiencing pain who are looked after in the community. This includes better mechanisms to use medication rationally and reduce variation in treatment.

Closer links between pain management programmes within specialist services and primary care projects such as the EPP may enable improved self-management depending on the level of personal/individual support required.

Health boards are encouraged to avoid duplication by bringing together practitioners working with people living with pain under one umbrella. Linkage with other secondary services such as musculoskeletal disorders, spinal and palliative care will improve understanding amongst the differing professions; reduce referrals and consultations between services and lead to a consistent approach to persistent pain in Wales.

Each health board is encouraged to set out how they provide person centred co-ordinated care which supports people to make informed decisions, and empowers them to self-manage their chronic conditions in collaboration with health and social care professionals. This should be included in their Integrated Medium Term Plans.

³⁴ Auditor General for Wales, The Management of Chronic Conditions in Wales – An Update 2014 [online] www.audit.wales/system/files/publications/chronic-conditions-2014-english.pdf (accessed 22 January 2019)

³⁵ www.rcoa.ac.uk/system/files/FPM-CSPMS-UK2015.pdf (accessed 22 January 2019)

Healthcare professionals need training to fully embrace the principles of self-management, co-production and shared decision making. People living with pain should be provided clear, easy to understand advice in a format the individual can take in.

There are many examples of good practice and examples from across Wales, which produce novel and effective models of working in partnership with people living with pain in the future.

Co-Production³⁶

A key factor to enabling the people of Wales to receive care in the optimum way is via co-production. This is when service users and health and social care professionals work together in equal partnership to access the right support for the right person. It requires building relationships and focusing on the best possible outcomes for the service user.

The key principles of co-production relating to health services:

- All participants are valued as assets and their strengths built upon.
- Develop dynamic peer-support networks.
- Build relationships of equality.
- Create transformative change through share power and shared responsibility.

A co-production interactive catalogue³⁷ has been produced by Public Health Wales and Co-Production Wales and includes case studies, resources and further information.

Actions

Pain management services must adopt a multiprofessional approach and be informed by the Core Standards for Pain Management Services³⁸. (Note: are currently being updated).

Health boards need to review pathways that people living with persistent pain take to establish actions that reduce multiple referrals, for instance, one point triage services.

Key signposting of co-production information and relevant pain related support should be visible across settings that people living with persistent pain are supported/treated/managed.

³⁶ www.allinthisogetherwales.wordpress.com/

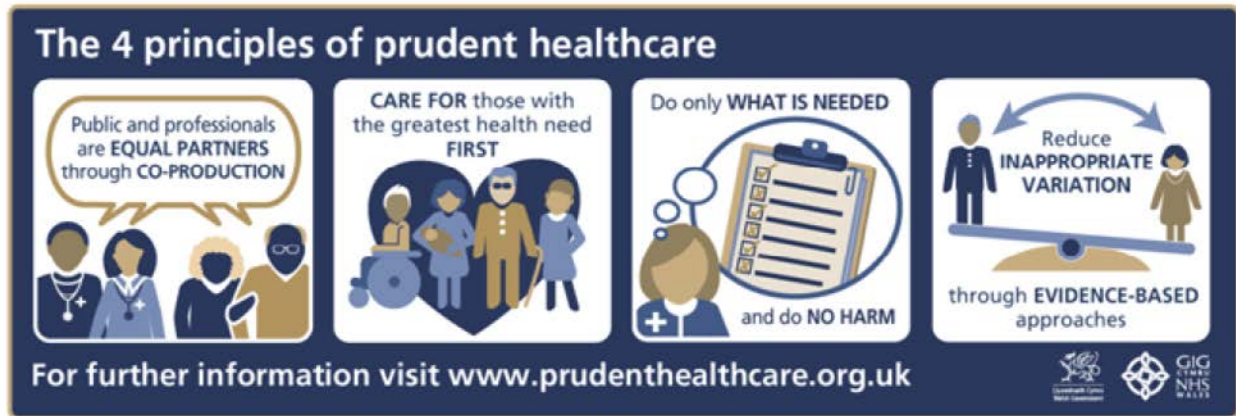
³⁷ www.goodpractice.wales/co-production-catalogue-from-wales

³⁸ www.rcoa.ac.uk/system/files/FPM-CSPMS-UK2015.pdf

Part 4 – Prudent Value Based Healthcare

Prudent healthcare is a philosophy for the whole healthcare system, giving permission to health professionals to develop and deliver services in a way which better aligns with individual need and experience. It has attracted strong international support and is something to build on in Wales.

Prudent Healthcare provides principles adopted by the NHS in Wales. It aims to empower people in their own healthcare and help improve outcomes for the NHS.



As a person living with pain I should:

- Expect healthcare professionals to only do what they need to
- Expect healthcare professionals to base decisions on evidence
- Be given choices of treatment and the potential pros and cons clearly explained

Since the introduction of prudent healthcare in 2014, the NHS in Wales has applied the principles to decision making. When prudent healthcare principles are fully embraced by those designing, managing, delivering and using healthcare services, organisations will:

- work in partnership with others around a common goal of improving health and well-being;
- be fully aligned with their quality strategy;
- provide services to those people in greatest need first and ensure, when people receive those services, they are provided by staff with the appropriate skills and expertise to meet their needs and in locations appropriate to the level of need;

- work in partnership with the public and people living with pain, ensuring the services that are offered stand the greatest chance of improving quality of life;
- ensure services and treatments will never do harm;
- ensure care will always be based on the evidence of what works and the results published openly and honestly;
- strive towards the reduction of variability.

See www.prudenthealthcare.org.uk for more details.

Value based healthcare is emerging as a measurable approach to prudent healthcare – to ensure the best outcomes for money invested. Work is underway to ensure value remains a key aim for a prudent healthcare based system, by identifying and eradicating low value work and reducing unwarranted clinical variations in the first instance.

Making Choices Together

Embracing similar principles to prudent and value based healthcare, *Making Choices Together*³⁹ is a movement to encourage open conversations between people and their clinicians to make decisions together about the right care for people. It is informed by good evidence and responsive to the needs and wishes of the person living with pain.

Making Choices Together seeks to encourage a change in attitudes and culture whereby professionals find out what is important to people, offer choice as to management or support of problems and explain options leading to shared decisions whilst also identifying interventions of low value and reducing their use.

A key principle is that it is a clinician led movement, taken on by practitioners alongside service users with a view to creating and fostering a culture change to the way in which medicine is measured and considered, moving away from the notion that more is always better.

The Making Choices Together movement suggests service users asks three questions when considering tests or treatments:

- What are my options?
- What are the benefits and harms?
- What can I do myself?

Similarly, health and social care professionals are encouraged to use the following to guide their opening questions to the people they are helping:

- “What matters to you?” rather than “What is the matter with you?”
- “How can we decide together how to improve things?” rather than “How can I help you?”

³⁹ www.1000livesplus.wales.nhs.uk/making-choices-together

Medication use in pain management and de-prescribing/optimal prescribing

Prescription of medicines forms the basis of the majority of people's pain management experience. Some people will find medicines useful. However, de-prescribing relates to the planned process of reducing or stopping medications that are no longer providing a benefit or which may be potentially causing harm.

People with persistent pain may remain on medications for significant periods of time. Often, medications will be continued despite little evidence of benefit, in terms of pain reduction or functional and quality of life improvements.

A number of organisations have developed resources to support practitioners, generally in primary care, to review and rationalise medications. Guidance tends to be focused on particular groups – frail, older people have been a target due to frequent polypharmacy; and particular medications e.g. proton pump inhibitors or benzodiazepines.

Part 5 – Supported Self-management

Most people living with persistent pain manage their symptoms or pain (as you have said, for some there is no 'condition: no diagnosis) themselves with support and advice from health and social care professionals only when needed. Supported self-management is an essential part of persistent pain management and it works best when the individual is able to take the lead in deciding how they want to live their life and are supported in finding ways of reducing persistent pain.

As a person living with pain I should:

- Be given pros and cons of all the options
- Be supported to a self-management plan
- Be given information in clear, easy to understand language
- Be signposted to a range of areas that could provide support

It is important that the support and advice is available in a timely and accessible manner. The type of support required will change at different stages of an individual's journey. When persistent pain is first diagnosed a person, and the people relevant in their lives, need to understand what management options are available and what the pros and cons of each option entail. For some people, it is best if this information is presented face to face, for others written information allows them to discuss the options with their families prior to an appointment and often a combination of both communicates most effectively.

Elements of self-management include improving physical functioning, psychological (and spiritual) well-being and social connectedness. It includes a range of techniques which have been demonstrated through research to be effective such as activity management, mindfulness, graded exercise and mood management. Self-management plans can be developed by individuals to include a tool kit of techniques which are tailored to their own unique situation. Ideally, techniques included in the tool kit are free and available to be used whenever and wherever the individual needs it. A comprehensive plan for dealing with situations such as flare-ups in symptoms as well as maximising well-being on a day to day basis is useful. Key self-management strategies should enable people to continue to live their normal lives, remain in work and socialise as they would wish and to manage variations in symptoms as they happen.

In consultations, a collaborative agenda setting approach facilitates the establishment of a relationship with professionals which values the abilities of each participant. In order to support people with pain to develop self-management skills, a health coaching approach is needed by professionals who build on the individual's existing skills and resources and has a clear focus on what matters to the individual. The use of language that is understandable to both parties is key and prevents people feeling out of control. The end goal is an effective management plan co-produced by the person with pain and the health and social care professional.

Pain Management Programmes	Education Programmes for Patients
<p>A key way for people to gain self-management skills is through attending pain management programmes. Strongly grounded in psychological principles. These can be delivered in a variety of ways from weekly courses to residential programmes and also online but they all include the development of key condition management approaches. People should be free to choose from a range of programmes which enable them to fit them into their existing lifestyle as much as possible. Effective self-management is also important for preventing secondary problems such as a depression and anxiety.</p>	<p>Self management courses have been provided for over 10 years in Wales under the brand of EPP Cymru. Courses aim to support individuals with a chronic condition to develop skills to help them to manage their health and well-being. Additionally, courses aim to give participants the confidence to take responsibility for their own care and make better use of health services, whilst also encouraging them to work in partnership with health and social care professionals. This in turn should improve the quality of life of individuals with a chronic condition and reduce pressure on NHS services. EPP Cymru has developed a Chronic Pain Self Management course for people who have a primary or secondary diagnosis of chronic pain. The Chronic Pain Self Management Programme does not conflict with existing programmes or treatment. It has been designed to enhance regular treatment. The programme provides participants the skills to coordinate all the things needed to manage their health, as well as to help them keep active in their lives.</p>

In summary, self-management means the person living with persistent pain having the knowledge, skills and motivation to manage their own health and well-being with the support of easily accessible, high quality information and appropriately skilled professionals as and when required.

Social Prescribing

Social prescribing is a mechanism that acts to systematically link people to community-based well-being services. It has become an umbrella term to describe methods of linking individuals to sources of community-based, non-medical support. This mechanism recognises numerous factors affect people's health. These factors include social, economic and environmental issues. Social prescribing helps to enable primary and community care professionals to direct people to a range of local, non-clinical support.

Sources of non-clinical care and support in local communities have a vital role to play alongside clinical care or even as an alternative in improving someone's individual health and well-being outcomes. Sources such as Book Prescriptions, Green Gyms or welfare support can play an important part in meeting an individual's health and well-being needs. Such schemes are often provided by the third sector and professionals are not always aware of them or of their potential benefits.

Providing people with the skills and tools they need to improve their health allows health and social care professionals the ability to explore different approaches to treatment and recovery, complementing the clinical support that is available in both primary and secondary care.

At its core, social prescribing is about prevention. It is a way of treating the causes not just the symptoms. By dealing with the root causes, it encourages action which can prevent problems from arising or escalating.

Identifying appropriate well-being services can provide long term solutions and improved outcomes where people thrive and expand their opportunities to reach their potential.

The Welsh NHS Confederation has provided information and a definition of social prescribing and its link to the NHS in Wales.⁴⁰

As a person living with pain I should:

- Have my health and social care needs considered together
- Be informed of non medical support in the local area and beyond

⁴⁰ The Welsh NHS Confederation, Social Prescribing and health and well-being, 2017. www.nhsconfed.org/~media/Confederation/Files/Wales%20Confed/Social%20Prescribing%20E.pdf (accessed 22 January 2019)

Example of the multi-disciplinary approach in primary care

The person seeking treatment had a 10 year history of low back pain with sciatica on polypharmacy, including two muscle relaxants. They had been seen by GP and Pharmacist and demonstrated limited function and depressed mood due to pain and co-morbidities. Analgesics were found to be ineffective so the pharmacist discussed making a change to a low-dose, slow-release opioid. The pros and cons were explained and an exit plan agreed before prescribing.

Once stabilized, the individual was referred to community-based physiotherapy for support and provided advice around graded increases in activity. The plan was made with the individual, GP and Pharmacist to slowly reduce muscle relaxants in line with exercise programme. After 18 months, the individual was undertaking daily stretching routine, increased function and single muscle relaxant, prescribed on 3 days per week with plans to make further reductions. Reductions were also made in hypnotic prescribing and anti-depressant as sleep and mood improved with increased activity.

Actions

Service evaluation should illustrate that people living with persistent pain have self-management plans which are reviewed annually.

For those individuals who have opioids or gabapentanoids prescribed, all should have a medication review, annually informed by expert guidelines (e.g. www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware).

Further information

Please be advised this guidance contains links to websites owned and operated by third parties. The Welsh Government is not responsible for their content or availability.

Community Connectedness

5 ways to well-being Recommendations for individuals to build into their daily lives: Connect with people; Be active; Take Notice; Keep Learning and Give.

www.wales.nhs.uk/sitesplus/888/page/61011

Telehealth

Powys Teaching Health Board run Invest in your Health, a course designed for people who live with a health condition. The course includes facilitation and sessions are focused on acceptance, setting a weekly commitment, follow up & solution finding, mindfulness, focusing on the positive, communication, healthy eating, hydration and weight management, first aid for low mood and activity & movement.

www.powysthb.wales.nhs.uk/invest

The British Pain Society

The British Pain Society developed five pledges to help people living with persistent pain state that everyone should have:

Active involvement in the management of their pain; Time assessment of their pain; Access to appropriate management and support; Relevant information; Access to adequate resources and facilities.

www.britishpainsociety.org/

Pain Toolkit

The Pain Toolkit website (available in 60 languages) is to help and support individuals living with pain and healthcare professionals to make pain self-management, their first choice and not the last resort. This document provides an overview of the Pain Toolkit and further resources for both people living with pain and health and social care professionals.

www.pain toolkit.org/

www.wales.nhs.uk/sitesplus/documents/863/pain%20tool%20kit%20%28CPAT%29.pdf

Further Reading

Supporting self-management: A guide to enabling behaviour change for health and well-being using person- and community-centred approaches

www.health.org.uk/sites/default/files/SupportingSelfManagement.pdf

RCGP – Pain Management Services: Planning for the Future

www.rcoa.ac.uk/system/files/FPM-Pain-Management-Services.pdf

The Health Foundation – Shared decision making

www.health.org.uk/improvement-projects/enabling-people-to-self-manage-musculoskeletal-pain

Faculty of pain medicine

www.rcoa.ac.uk/faculty-of-pain-medicine

Part 6 – Health & Social Care Provision

This section provides overarching models and practice examples to support the development of pain services which are aligned to the needs of those living with persistent pain, supporting resilience and mindful of future challenges.

Social Services and Well-being (Wales) Act 2014

The Social Services and Well-being (SSWB) Act provides the Welsh Government's statutory framework for improving the well-being outcomes for people who require care and support. Under the 2014 Act local authorities have a duty to assess an individual's eligible needs for care and support and what those care and support needs might be. Any assessment must focus on the outcomes an individual wishes to achieve in their daily life and the extent to which the provision of care and support, preventative services or the provision of information, advice and assistance could contribute to the achievement of their outcomes. Both the NHS and Social Services must work together with the individual requiring care and support to ensure their eligible needs and agreed outcomes are met.

Integrated care

The Welsh Government is committed to integrated, safe, sustainable and effective people-centred services aimed at improving well-being. For people needing care and support, care should be planned with the individual in mind and allow the person control over the outcomes.

An example of how to achieve this is set out in the *Framework for Delivering Integrated Health and Social Care for Older People with Complex Needs*⁴¹.

The Intermediate care fund was initially established to support older people to maintain independence and to improve partnership between social services, health, housing and the third and independent sectors. The fund was expanded in 2016-17 to support development of integrated care and support services for other groups of people, including people with learning disabilities, autism, and children with complex needs. From 1 April 2017 it was rebranded as the Integrated Care Fund (ICF) to better reflect an expanded scope. The ICF support a range of innovative services and has been used to develop innovative models of integrated working. These include preventative, therapeutic, rehabilitation, Recovery and reablement solutions, single points of access, housing and telecare interventions, rapid response teams, dementia care and seven-day social work support.

Integrated Care as an approach has been supported by numerous expert organisations. The Kingsfund⁴² and the International Foundation for Integrated Care⁴³ have both produced short videos to help explain integrated care. There are also many examples of models of care⁴⁴ provided for professionals across Wales to consider.

⁴¹ www.gov.wales/docs/dhss/publications/140319integrationen.pdf

⁴² www.kingsfund.org.uk/audio-video/joined-care-sams-story

⁴³ www.integratedcarefoundation.org/resource/understanding-integrated-care-webinar-by-dr-nick-goodwin

⁴⁴ www.kingsfund.org.uk/audio-video/integrated-care-map

Workforce

With an increasing ageing population, it is likely that demand will increase for more pain specialists in certain areas of Wales. The Welsh Government does not routinely keep information regarding vacancies relating to pain management, but works with health boards and trusts via Integrated Medium Term Plans⁴⁵ to understand and respond to areas where demand is required. However, ensuring adequate provision for services is ultimately a matter for health boards.

The Faculty of Pain Medicine undertakes a regular census check for England and Wales⁴⁶ which analyses the trends relating to the pain workforce. The Faculty of Pain Medicine also published non-mandatory core standards⁴⁷ as a guide to numbers of staffing and what services should be available. Health and social care professionals providing persistent pain services are encouraged to review these standards and adhere to as many as services will allow.

Actions

All health boards need to provide community based social prescribing programmes and models of integrated care that relate to the population that they serve. They should also ensure that through efficient workforce planning they have sufficient resources to meet the needs of the people under their care, now and in the future.

45 www.gov.wales/topics/health/nhswales/organisations/planning/?lang=en

46 Faculty of Pain Medicine, Workforce www.fpm.ac.uk/faculty-of-pain-medicine/workforce (accessed on 22 January 2019)

47 www.rcoa.ac.uk/node/21140

Glossary

Activity Management	A way for people to manage their symptoms by learning to analyse and plan activities so that they can achieve more at home, at work and at leisure.
Bio-psychosocial	Taking into account all relevant determinants of health and considers the biological, psychological and social factors in the assessment, prevention and treatment of conditions.
Collaborative agenda setting	Deciding together what needs to be considered important.
Graded exercise	An approach for managing pain that involves planned increases in activity or exercise, working towards goals that are important for the person.
Health and social care professional	Any registered qualified person working within health or social care services.
Health literacy	Skill level of people in understanding healthcare.
Integrated care	Care that considers every part of a person's physical, mental, social and emotional health and well-being.
Interventions	An act performed for a person or population whose purpose is to assess or improve health conditions.
Mindfulness	Concentrating the mind to focus on only what is happening at that exact moment.
Modality	Types of treatment.
Mood management	Ways in which individuals select media as a means of affecting or "managing" their moods. This theory generally predicts that individuals' media selections reflect, at least in part, motivations to intensify or prolong positive moods and to reduce or diminish negative moods.
Multimodal	Treatment that combines more than one method.

Multi-professional	A group of professionals from one or more areas or professions (doctors, nurses, Allied Health professionals pharmacists, social workers etc.) who together discuss decisions regarding recommended treatment of individuals.
Polypharmacy	Usually considered as the use of at least four or five medicines.
Shared Decision Making	Shared Decision Making involves patients and health and social care professional working together in partnership to make healthcare decisions. It involves sharing evidence based information and considering individual needs and preferences. It involves doing what is needed, no more, no less.
Stratified care	Matching of subgroups of patients to specific treatments.

Annex I: Stories from those living with pain

This document was developed with contributions from people living in pain throughout Wales. This annex provides examples from those people relating to the realities of living with pain, the different experiences they faced and why access to services and diagnosis is so important:

Story I: Successful approach of Pain Management

Person B recently completed the worthwhile and effective bio-psychosocial Pain Management Programme. She describes the course as extremely beneficially not only to her, but to family and friends too.

For the past 6 years Person B has been on a cocktail of medication. She had become unsociable, depressed and lacked control over her pain. With medication she felt disengaged and without it the pain increased.

It is thought that she had either prolapsed the L4 and L5 discs during/after labour or possibly had Sacro Iliac Joint Dysfunction from falling off the hospital bed just after giving birth. MRI's and X rays failed to show that there is anything remarkable that would need to be operated on. The approach has been to undertake epidural, injections, physiotherapy, chiropody and various 'self-help' methods such as massage and acupuncture. These methods only provided temporary relief if any. The advice usually resulted in increasing or changing the pain medication.

Since taking part in the programme, Person B learnt various aspects about her pain, its effects and how to manage it more effectively. She learned her experiences were normal in comparison to others in the group. Talking to others with persistent pain made a huge difference to how she viewed her own conditions, realising that she has been unrealistic, wished for quick answers and didn't correctly look after her physical and mental health.

The health care professionals communicated the course in a clear and professional manner and were approachable from the beginning. They answered questions honestly and did not present any pre-conceived ideas. Person B learnt to avoid assumptions regarding what others are thinking or feeling or assuming what will happen in the future.

This has resulted in Person B being able to do more of the things that she enjoys whilst significantly reducing medication. Communication between family and friends has improved significantly now that she is being more open and honest. Person B is able to refuse things, explain why and not feel guilt. Person B is coping with pain and putting her life before it. She advises she is slowly becoming sociable again and is enjoying doing more activities.

Story 2: Lack of shared decision making and therapeutic alliance

Person A spent many years being referred between medical professionals with persistent pain. He attended a Persistent Pain Clinic and attended a twelve week pain management course.

Unfortunately his pain continued to worsen. Having recently undertaken the meditation, breathing exercises, mindfulness and positive thinking, he was able to re-evaluate the issue. Although the pain was not relieved, his understanding of his own pain was extremely beneficial.

Throughout the process of seeking help, prior to his consultation at the pain clinic, a huge amount of time and effort was duplicated repeatedly. Person A felt everyone appeared to be working in isolation. Tests were repeated and he left appointments feeling medical professionals did not believe him and his debilitating pain was never addressed in any meaningful way. It was impressed upon him that there was a need for acceptance that NHS could not aid him any further and he would just need to learn to live with his pain.

Although this is an account of Person A's pain, he was also suffering from many other symptoms and was generally very unwell. He was convinced through his own research that although undiagnosed through normal tests, an immune system malfunction was the underlying problem. Because the pain management course had emboldened him with a new understanding of his pain; he approached his doctor feeling newly empowered and was pleasantly surprised to find his doctor, taking the time to re-evaluate the evidence, agreed with him.

New medication was prescribed and this, coupled with self management techniques, resulted in a major reduction of pain. Many of the other debilitating manifestations of his condition were reduced or eliminated. Now with the correct medication and the aid of the techniques learned on the pain course, person A leads a nearly normal life.

Person A believes if instead of just repeating tests, a clear pain management path had been discussed coupled with a clinical approach to diagnosis, years of wasted NHS resources and unnecessary pain could have been avoided. The many years person A spent in pain and seeking help had eroded his confidence completely and he attributes his reinvigorated determination to be heard once again to the lessons learned on the pain management course.