



Welsh Government  
Consultation – summary of response

# Living with Persistent Pain in Wales Guidance

April 2019

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.  
This document is also available in Welsh.

## Background

In 2008, the Welsh Government published the *Designed for People with Chronic Conditions, Chronic Non-Malignant Pain (CNMP) Directive*. This Directive committed the NHS in Wales to an evidence-based multi-disciplinary 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 healthcare professionals and service users, highlighting effective ways of helping those living with persistent pain.

The consultation ran from 5 June 2018 to 14 September 2018. The consultation sought views in relation to the following:

- How services can be further developed
- The key areas of pain management healthcare professionals are required to be aware of
- Areas of research and evidence in this area
- Techniques to help treat and manage pain
- What levels and methods of support are required

## Summary of Responses

39 written responses were received as part of the consultation exercises:

The responses were received from groups and individuals:

Health and social care professionals	12
Royal college / societies	8
Third sector organisations	5
Members of the public	5
NHS Committees / Advisory groups	3
Anonymous	3
Trade Union	1
External NHS	2
<b>Total</b>	<b>39</b>

## Scope of Analysis

In addition to the publication of the consultation document, the Welsh Government held a number of consultation events with pain groups throughout Wales. These events occurred during the development of the document and points raised were incorporated as appropriate.

The responses to the consultation document came principally from professionals working in areas of pain management and interest groups, as well as people living with persistent pain.

The Welsh Government made use of digital channels to maximise impact and understanding and to raise publicity for the consultation. In compliance with the Equality Act 2010, officials ensured that braille and easy read versions were available on request.

The consultation attracted broad support. There are differences of opinions regarding which approaches to take and difficulties in providing a relatively short document that remains purposeful for citizens, health boards and health and social care professionals.

## **Summary of Responses**

There was a good response to this consultation from a wide range of parties. Overall the consultation responses noted the importance placed upon the multiple methods of treating persistent pain and provided useful advice for consideration within the document. There were a number of suggestions regarding what factors should be considered and advice on how pain services should be configured.

Some responses did not use the formatted questions provided. Where additional responses were provided outside the scope of the questions posed, they have been included in question 12 as further points of consideration.

### **Q1. How can services be further developed to be more effective?**

30 responses

The majority of responses provided useful suggestions that were largely complementary to each other. The points which received support include:

- A requirement for multidisciplinary needs to be recognised and adopted
- Acknowledgement that pharmacists, occupational therapists and other primary care professionals can play a key role. Also, GPs need access to psychiatrists, physios, occupational therapists and consideration should be given to the work already being undertaken by community health workers.
- Mindfulness is a powerful tool that needs to be utilised effectively
- Waiting times are too long and current services are not always configured to allow people to be seen by the best placed health and social care professional at the right time.
- Correct exercises should be promoted.
- No focus on children and young people within the document.
- The guidance does not consider prevention
- Early triage is required in order to stratify care appropriately.
- Further education for healthcare professionals is required on communication and pain generally
- Bio-psychosocial approach is required

- Individuals/public need to access to information regarding services. Needs wide distribution in a range of formats. Local, regional and national resources need to be available
- Services required on a national basis
- Planners need to understand the current base line to resource properly
- Shared learning is required between health boards, social care and third sector
- When developing service, unpaid carers need consideration. Carers can also provide insight for patients who struggle with their own health or understanding
- Challenging to navigate and identify ideal service model
- Consider guidance in view of the new *A Healthier Wales* strategy
- Pain must not be seen as standalone
- Better understanding of high and low risk procedures and behaviours
- More detail required regarding secondary and tertiary care services
- Attitudes towards persistent pain are unfairly unbalanced against women
- A lack of pathways or a model service makes guidance disjointed

Responses with specific ideas:

- Dedicated pain clinicians rotating at different GP surgeries
- Information days for patients and/or clinicians come together to share experiences
- Pelvic physiotherapy needs more consideration
- More comfortable waiting rooms
- Early positive messaging
- Further focus on Telemedicine
- Highlight the benefits of aids and adaptations

Officials have addressed a number of areas where an answer was required. Certain suggestions were practical and will be considered by a group which is to be formed to consider pain related services and approaches for Wales.

## **Q2. What are the key areas the health and social care professionals need to be aware of to treat and manage persistent pain effectively?**

26 responses

Responses include:

- Disagreement with metaphors being universally unhelpful
- Healthcare professionals require upskilling on topics such as coproduction and shared decision making
- Physical pain needs to be considered with psycho-social problems and the knock-on effects of pain that cause stress e.g. who will walk the dog, etc.
- Conditions of home, state of mind or other health conditions have major consequences
- The major effect socio-economic deprivation plays as well as home and living conditions
- Support services external to the NHS should be quality assured and validated

- Acknowledgement that all cases are different and patients are to be believed
- A need to recognise importance of medical interventions when appropriate
- Front line staff need to be trained on identifying psychological distress and understand what to do when identified
- Questions provided to people living with pain to consider: what are their options, what services or treatments health professionals can provide, how can they help themselves
- More effort is required to overcome challenging attitudes to self-management – health coaches and social prescribing
- Consistency is required from clinicians to avoid repetition
- Education relating to pain is required for patients and clinicians
- More consideration is needed regarding how to refer to social care
- Patients require a clear pathway to understand how and why they are being treated

**Q3 Is there any new research or evidence not included in the document that you are aware of which should be taken into account to better enable people to live with persistent pain?**

22 responses

- NICE guidance should be referred to, highlighting they are reviewed
- Professionals need to utilise current evidence base
- National database needed of all evidence
- Learn from external sources to Wales
- Behavioural approach should be utilised to identify and address cognitive, emotional, coping responses physical and lifestyle factors
- Need to understand and measure the value of interventions
- Pain Management Programmes are not all the same. More detail needed from appropriate evidence-based guidance
- Stress clinic, breathworks
- Compound AT121 – being tested, a painkiller without risk of addiction
- RCP published 2<sup>nd</sup> edition of Complex regional pain syndrome for adults
- Bio-psychosocial approaches
- Need to develop improved data on persistent pain
- Health boards should develop action plans to deal with any shortcomings

**Q4. What further support would provide help to patients and their needs?**

26 responses

- The public wish to feel assured that the actions will be held to account and success measured. An ideal model to benchmark services against
- Improved sign posting
- Communicated in clear language and not just digitally
- Care needs to be patient centred
- Clear assessment and treatment pathways, especially for GPs
- Support to stay in the workforce – proactive occupational health services

- Patient should be queries whether consent should be given to carers regarding persistent pain management
- Replicate the Scottish MSK app to provide advice on pain and where to obtain assistance
- More time for patients to spend with health professionals
- Terminology to move away from patient in all health literature
- Specialist psychological support
- Better support for housing, access to benefits, etc

**Q5. What are the most effective and accessible means of helping people with persistent pain to find information, assistance and advice?**

25 responses

- To avoid assumptions everyone is digitally connected
- Supportive framework providing reliable and evidence based information online
- Self-help groups and easy access to support
- Ensure no gaps in services in localities. All services available to all in society
- DEWIS Cymru to be further developed to be fully populated
- GPs and Pharmacists are key to providing initial pain treatment
- Better awareness of self-referral process to physiotherapy service
- Link health information to correct level of understanding and ask how people like to receive it. Provide clear, easy to read, jargon free information
- Consideration of the role of technology enabled solutions
- Utilise video conferencing to reduce travel
- Apps with timely information and support
- North Wales needs a dedicated information / drop-in centre
- Making Every Contact Count approach
- Signposting tools available to all health professionals
- Signposting only to reliable sources

**Q6. What are the most effective and accessible self management techniques?**

23 responses

- Clarity required regarding EPP and PMP and social prescribing
- Skilled assessment of the conditions
- Hydrotherapy
- Pharmacological support, CBT, patient education and peer support
- Prevention
- Neuro Orthopaedic Institute resources – protectometer
- Hobbies such as photography, writing, painting and walking
- Attendance at support and self-management groups
- Detail needed regarding potential for care plans to support self-management for patients

**Q7. Does the guidance capture all the elements of a good therapeutic relationship and what effective help looks like?**

22 responses

- No mention of alternative therapies
- Does not provide current overview of provisions
- Review services against Faculty of Pain Management standards
- More detail on service design. Faculty of Pain Medicine guidelines and British Pain Society guidelines for PMP for adults provide frameworks for best practice
- Carers overlooked
- Overview of what a patient could expect to access
- More required on shared decision making

**Q8. How can local health boards, local authorities and third sector organisations support people with persistent pain to live as well as possible?**

25 responses

- Work together to ensure people are referred to the correct service
- Refer to Regional Partnership Boards in decision making and service decision
- Short term courses are good but not funded for long
- Ensure range of community based services available
- Adapt dwellings for people with long term pain/mobility problems
- In addition to self-management, focus is needed on physical therapy, evidence-based pain injections and medications. Multi-modal and disciplinary approach important
- Improvement in communication channels between mental and physical health
- Wide range of activities that incorporate arts and creativity. Activity rather than exercise, via social prescribing
- Registry of patients with pain to gain better understanding of numbers and population
- Consistent message across organisations
- Share best practice
- Focus on living well, not symptom management
- Work with employers to improve knowledge of pain
- Simplify access to support

**Q9. Are there any terms or phrases in the document you feel would benefit from further explanation in a glossary?**

14 responses

- Easy read version for patients, with shorter sentences, plain English, pictures and colour
- Words that required simplifying or explanation including: Polypharmacy, multidisciplinary, proton pump inhibitors and Benzodiazepine
- Outpatient physiotherapy should be community physiotherapy
- Co-Production, Health literacy, Collaborative agenda setting
- Unpaid carers should be added through the document and defined
- Trauma informed care should be changed to Adverse Childhood Experiences
- De-prescribing would be better described as optimal prescribing, medicine optimisation or balanced prescribing

- Self-management
- Medical model

**Q10. We would like to know your views on the effects that persistent pain management guidance would have on the Welsh language, specifically on:**

- i) opportunities for people to use Welsh and**
- ii) on treating the Welsh language no less favourably than English.**

16 Responses

- Documents should be bilingual
- Important for vulnerable and those with dementia to have first language choice
- Should adhere to legal requirements
- Video conferencing enable patient choice of language

**Q11. Please also explain how you believe the proposed policy could be formulated or changed so as to have:**

- i) positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and**
- ii) no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.**

9 responses

- Repeat of answers provided in question 10

**Q12. We have asked a number of specific questions. Additional points**

21 Responses

- NHS in Wales not current geared towards persistent pain treatment
- Current focus on secondary care and escalation, not prevention
- Stronger primary care sector would help preventative care
- Information required on education and prevention of conditions. Should link to other relevant strategies e.g. planning, housing, etc.
- Needs more information beyond tier 1
- The “Back in Action” programme in C&V could be used an example of best practice
- Self-management in specialist care needs consideration
- Separate section needed for de-prescribing and medication
- Sub-heading to align title with NICE approach
- Lacking detail to make it a commissioning directive



- No mention of nurse led pain clinics
- Healthcare professionals need to understand the wide range of specialities to consider before moving on from medical intervention
- Guidance requires implementation plan and funding – audit tool, resource implication assessment and timeline
- Symptoms should form diagnosis, as often persistent pain not diagnosed
- Structure of the document not easy to follow

### **Specific comments**

- Not currently guidance for people living with pain. More as background for people.
- Can be harmful to continually investigate when serious pathology is excluded
- Schematic unclear and lacks context
- Specialist care box needs more detail: PMP, medication optimisation, pain focused group therapy, specialist interventions
- Add definition of 'pain management approach
- Quotes – actual or from evidence based?
- Reference for diagram
- Are resources available across Wales? Can hyperlinks be included? Is DEWIS working for all?
- Include another action to offer all those with persistent pain a developed and agreed action plan
- Should include more detail on types of services provided for patients
- Explain Making Choices Together much wider than just pain
- Social prescribing being about prevention = needs heavy qualifying
- Narrative on Integrated Care very generic

### **Conclusion and Recommendations**

The document has been developed by clinicians, experts and people living with pain. The Welsh Government is grateful to all those who responded to this guidance or attended any of the meetings.

The task and finish group responsible for initially developed the document met twice following the conclusion of the consultation process to discuss the responses and advised upon further changes. Changes were made to the document as deemed appropriate.

Numerous consultation responses were made which were felt to be beyond the remit of the group to accept. These points included 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 is to be established with representation from each health board and a range of stakeholders to ensure continuous improvement is undertaken.

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. The group will review the responses to the consultation to consider any areas not included in the document.

For further information please contact: [PopulationHealthcare@gov.wales](mailto:PopulationHealthcare@gov.wales)

## Appendix 1

### List of Contributors (excluding those who did not agree to share their details)

#### 6 responses requested to remain anonymous

1.	Community Pharmacy Wales
2.	Dr Joanne Griffiths
3.	Royal College of GPs Wales
4.	Involvement Network – Conwy Participation Group
5.	Chartered Society of Physiotherapy
6.	Hywel Dda University Health Board
7.	Welsh Pain Society
8.	Andrew Colwill
9.	Carers Wales
10.	All Wales Directors of Therapies and Health Sciences
11.	British Pain Society
12.	Faculty of Pain Medicine
13.	Faculty of Pain Medicine of the Royal College of Anaesthetists
14.	The College of Podiatry
15.	Royal Pharmaceutical Society in Wales
16.	Fair Treatment for the Women of Wales
17.	BMA Cymru/Wales
18.	James Needham
19.	Ian Williams
20.	Dr M Phipps
21.	Brian Stapley
22.	Kerry Williams
23.	Caro
24.	Debbie Davies
25.	Anne Lauppe-Dunbar
26.	Jo Haupson
27.	Professor Blair H. Smith
28.	Owen Hughes
29.	Jan Underwood
30.	Joanne Griffin, Occupational Therapy Advisory Forum for Wales
31.	British Society for Rheumatology & Rheumatology SAG Wales
32.	Versus Arthritis
33.	Welsh Association of ME and CFS Support