

**Number: WG34935**



Llywodraeth Cymru  
Welsh Government

Welsh Government  
**Consultation Document**

## **Living with Persistent Pain in Wales Guidance**

Date of issue: 5 June 2018

Action required: Responses by 14 September 2018

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

**Overview** We are currently developing guidance to replace the Welsh Government's Service Development and Commissioning Directive for Chronic Non-Malignant Pain which was published in June 2008.

This consultation seeks your views on the proposed direction of the draft guidance.

**How to respond** This consultation will close on 14 September 2018. You may respond by email or post.

**Email**

Please complete the consultation response form and send it to: [MajorHealthConditionsPolicyTeam@gov.wales](mailto:MajorHealthConditionsPolicyTeam@gov.wales)

**Post**

Please complete the consultation response form and send it to:

Major Health Conditions  
Welsh Government  
Cathays Park  
Cardiff  
CF10 3NQ

**Further information and related documents** **Large print, Braille and alternative language versions of this document are available on request.**

**Contact details**

For further information:

Address: Major Health Conditions  
Population Health Directorate  
Welsh Government  
Cathays Park  
Cardiff  
CF10 3NQ

email:

[MajorHealthConditionsPolicyTeam@gov.wales](mailto:MajorHealthConditionsPolicyTeam@gov.wales)

## General Data Protection Regulations

The Welsh Government will be data controller for any personal data you provide as part of your response to the consultation. Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

Names or addresses we redact might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account.

However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

Your data will be kept for no more than three years. Under the data protection legislation, you have the right:

- to access the personal data the Welsh Government holds on you;
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection

The contact details for the Information Commissioner's Office are:

Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Telephone: 01625 545 745 or  
0303 123 1113

Website: [www.ico.gov.uk](http://www.ico.gov.uk)

For further details about the information the Welsh Government holds and its use, or if you want to exercise your rights under the GDPR, please see contact details below:

Data Protection Officer:

Welsh Government  
Cathays Park

CARDIFF  
CF10 3NQ

Email Address:

Data.ProtectionOfficer@gov.wales

## **What are the main issues?**

We are replacing the Welsh Government's Service Development and Commissioning Directive for Chronic Non-Malignant Pain which was published in June 2008.

Working with clinical and academic partners, we are replacing this directive using a co-productive approach. The new guidance includes effective ways of working in the future for health and social care professionals, as well as people living with persistent pain.

Our aim is to move towards a greater focus on support to help people develop skills to enable them to manage persistent pain for themselves, whenever and wherever they need to, and in so doing increasing their ability to stay in work and live the lives they want to live.

## **Where are we now?**

In 2008 the Welsh Government produced Service Development and Commissioning Directives for Chronic Non-Malignant Pain to support the assessment and management of those living with or experiencing persistent pain in Wales.

The document seeks to aid health boards and health professionals as well as the general public, to help raise awareness regarding the different approaches people can undertake to managing and treating their pain.

## **The evidence for change**

As new approaches to health care within Wales have been adopted, namely a strategy known as Prudent Health, we need to revise service provision and issue new guidance.

## **Consultation Response Form**

Your name: **Philippa Ford MBE MCSP**

Organisation (if applicable): **The Chartered Society of  
Physiotherapy (CSP)**

email / telephone number: [fordp@csp.org.uk](mailto:fordp@csp.org.uk)  
029 2038 2429

Your address: **Unite House, 1 Cathedral Road,  
Cardiff, CF11 9SD**

## **Living with persistent pain**

We wish to highlight the reality for those experiencing and living with persistent pain. We also want to consider how services can be best arranged to address a variety of needs; from those who want simple strategies including self-management, to those who have complex needs that require specialist care.

**To this end we have included a number of questions to consider relating to the content of the document:**

## **Living with persistent pain**

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

The CSP suggests that services for people living with persistent pain must be easily accessible and equitable.

Services must be seen as part of wider service provision, not 'stand-alone' so that appropriate links are made with MSK, neurological and other relevant specialities. The consultation document does not make this explicitly clear in Part 1. Close links with a range of clinical speciality areas will contribute to making services more effective.

The document needs to be clearer in its ambition that people living with persistent pain should be able to access interventions earlier in order to prevent established pain behaviour which could be preventable.

The document indicates that it has been produced for patients with persistent pain but it is unclear how it will be distributed to ensure that it actually reaches them.

The CSP notes that, in the diagram at the bottom of page 5, reference is made to outpatient physiotherapy. This is an outdated term. It should reference community physiotherapy as defined by the Welsh Government data dictionary.

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

The CSP supports all the areas highlighted in the consultation as the key areas that health and social care professionals need to be aware of in order to treat and manage persistent pain effectively.

In the section on careful language and sensitive communication the CSP questions the assertion that metaphors should not be used. Sometimes the appropriate use of a metaphor can be useful in helping to clarify/understand concepts and ideas.

The section on Page 7 relating to the work of the RCGP needs context. As set out, it is confusing. When or how did the RCGP provide an opportunity for stories to be heard? The reference is provided but clarity is needed to set the scene for the reason for the constant themes as identified in the paper.

The themes provided by the work of the RCGP are helpful and the CSP suggests it might be useful to put in bold some of the words to indicate the focus of each theme. For example:

- Cultured challenges
- Feeling believed
- Communication of pain
- Listening
- Knock-on effect
- Consistent advice

The CSP notes the diagram on Page 9 in the section on considerations when supporting management of people with long-term conditions. It would be helpful to see a reference for this in the document.

In the section on information and advice, on Page 11, the consultation document highlights resources also available in Wales.

- The original chronic disease self-management programme for people with health conditions
- A course of carers
- An on-line self-management course
- A 3-hour health and wellbeing course

Are these resources available everywhere in Wales? If not, how can people find out details of what is available? Are details on DEWIS for all areas? Can hyper-links for the on-line resources be included in the live, on-line version of this document once it is launched?

The CSP considers this section of the document could be strengthened and the action needs to ensure responsibilities for keeping DEWIS details current for all programmes and services available for people living with persistent pain.

The guidance appears to have a list of approaches that should be used in persistent pain services but it lacks a description of a model service thus the guidance appears confusing.

## **Evidenced based care**

### **3. 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?**

The CSP suggests it would be useful to refer to NICE guidance and highlight that these guidelines are regularly reviewed, as are the recommendations for managing persistent pain. This supports clearly a co-production approach and 'Making Choices Together' allowing clinicians to have difficult conversations about the suitability of treatments such as certain medications, acupuncture or injection therapy which may not be offered.

## The way forward

### 4. What further support would provide help to patients and their needs?

The CSP supports the key actions in this section but notes that there is a further action described in the narrative on Page 14 that:

*'Each health board is encouraged to set out how they provide person centred coordinated care which supports people to make informed decisions, and empowers them to self-manage their chronic conditions in collaboration with health and social care professions. This should be included in their integrated medium term plans'.*

*Any plans for transforming and developing services will need to be featured in health board IMTPs.*

The action needs to feature in the actions section of the document for this chapter and needs to be understandable by patients and the public.

The CSP also suggests that patients, their carers and the public more generally want to know that services are successful. Currently, the consultation does not specify how success of service provision will be measured.

The actions are laudable but how will the public know if they have been achieved?

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

The CSP notes that the answer to this question is heavily influenced by how people choose to access healthcare and support.

Service configuration is changing and primary care is transforming with access to a wider multidisciplinary team in primary care. Self-referral and first contact physiotherapy roles, for example provide better access to clinicians who can support MSK conditions. People are also accessing information in different ways through digital platforms and mobile technology. However, that will not suit everyone and traditional access models will also still be required.

## Supported self-management

### 6. What are the most effective and accessible self-management techniques?

The CSP considers this section will need review. Reference is made in the document to a range of options and concepts such as 'Making Choices Together', 'Expert Patient Programmes' and 'Pain Management Programmes' Clarity is required to ensure there is not confusion about EPP and PMP and there needs to be understanding of the role of social prescribing in signposting to suitable self-management.

The CSP notes there will be a range of techniques used by patients. Physiotherapists will incorporate many of these within their treatment and management approach.

## **Health & Social Care provision**

### **7. Does the guidance capture all the elements of a good therapeutic relationship and what effective help looks like? What else can be recommended?**

The CSP considers that this section of the response provides the top-level policy and legislative context in which services are provided. This section does not provide an over-view of current health and social care provision.

It does, however, note that the faculty of pain medicine undertakes a regular census check for England and Wales which analyses the trends relating to the pain workforce and they publish core standards.

The CSP suggests an action should therefore be added in the document that health boards should regularly review their services for people with persistent pain against the FOPM standards and look to address any shortfall through the IMTP process.

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

The CSP considers there needs to be clear communication between all agencies so that patients and their carers can navigate services seamlessly and receive attention to 'what matters to them'. Systems and processes need to be designed to assist this not hamper it.

The CSP suggests that reference is made to the role of Regional Partnership Boards in providing a framework for communicating and making joint planning decisions, particularly in relation to determinants of health and in the transformation of primary and community care services.

## **Additional questions**

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

The CSP suggests this draft is shared with patient advocates to answer this particular question.

### **10. 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.**

The CSP notes that there is a strategic framework for Welsh in health, social services and social care. Statutory organisations operate under 'More than Just Words ...' and in line with the Welsh language standards (health sector) regulations. These will impact



on how services develop and provide opportunities for people to use Welsh and access services through the medium of Welsh.

**What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?**

**11. 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.**

Please see answer to question 10. The CSP considers these issues will be governed by the response to legislation and standards and any developments required will need to be progressed via the IMTP.

**12. We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:**

**Please enter here:**

- Page 10: The example provided reads as if the service is not up and running. It needs to be reworded as the service is operational. It is a very good example.
- Page 11: Red box Hywel Dda example. The first two red boxes in the publication have been patient quotes, should the example be in a blue box like the example on Page 10?
- The section on evidence base needs something to identify that it will be a living document so wherever the evidence base is stored it needs to be possible for it to be updated with current evidence. Consideration will need to be given to who will do that.
- It would be good to see an additional action related to 'Making Choices Together'. "Health and social care professionals should adopt a 'making choices together' approach to their interactions with patients and carers".

Page 19: The section on medication use in pain management and de-prescribing might need to be a separate chapter. Whilst it is appreciated that medicines management will be an important aspect of supported self-management that is not really clear in the document. It feels like a completely separate section talking about pharmacy management not self-management. It might be because of the case study.

Further information (Page 20) also needs more explanation. Is this more information for self-management or generally more information for the whole spectrum of supporting people with persistent pain? It is in the supported self-management section so it is confusing.

Page 22: The information in the integrated care section will need to be updated since the publication of the long term plan for health and social care.

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here: