



r e p o r t

**Scottish Public Health Network (ScotPHN)**

**Health Care Needs Assessment of Adult Chronic Pain Services in  
Scotland**

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## Contents

Preface.....	4
Acknowledgements.....	5
Table of Figures.....	6
Table of Tables.....	6
Acronyms.....	7
Executive Summary.....	8
Introduction.....	8
Methods.....	8
What we found.....	8
In general.....	8
Level 1 - Self-management.....	8
Level 2 - Primary care.....	9
Level 3 - Secondary care.....	9
Level 4 - Tertiary care.....	9
Recommendations.....	9
General.....	9
Level 1 - Self-management.....	10
Level 2 - Primary care.....	10
Level 3 - Secondary care.....	10
Level 4 - Tertiary care.....	11
1 Background.....	12
1.1 Definition.....	12
1.2 Prevalence of Chronic Pain.....	12
1.3 Scope.....	12
1.4 Recent national history and policy context of chronic pain.....	13
2 Scottish Service Model for Chronic Pain.....	16
2.1 Level 1 – Self-management.....	18
2.2 Level 2 – Primary care.....	18
2.3 Level 3 – Secondary care.....	19
2.4 Level 4 – Tertiary care.....	19
3 Epidemiological Needs Assessment.....	20
3.1 Size of the problem.....	20

Chronic Pain .....	20
Co-morbidity with chronic pain.....	21
3.2 Cost of the problem.....	23
Direct costs.....	23
Indirect costs.....	23
3.3(i) Level 1 - Self-Management.....	24
Chronic pain self-management resources .....	24
Self-management in primary care.....	29
3.3(ii) Level 2 - Primary care.....	30
Prescribing of pain medication.....	30
3.3(iii) Level 3 - Secondary Care Pain Service.....	36
Number of new patients seen at the Pain Clinic by NHS Board .....	36
Waiting times for appointments at chronic pain clinics (in hospital setting).....	37
Pain Psychology .....	39
3.3(iv) Level 4 - Tertiary care .....	39
The Scottish National Residential Pain Management Programme (SNRPMP)..	39
High level procedures .....	42
3.4 Data developments .....	42
In terms of what is recorded in general practice and primary care:.....	42
Secondary care.....	42
Quality Performance Indicators.....	43
3.5 Conclusions of the epidemiological needs assessment .....	43
4 Corporate Needs Assessment.....	46
4.1 Level 1 - Self-management.....	46
Self-management information.....	46
Self-Management groups .....	46
4.2 Level 2 - Primary care .....	47
Physiotherapy .....	47
Pharmacy .....	47
General Practice.....	47
Other professions/services .....	48
Referrals .....	48
Training.....	48

4.3	Level 3 - Secondary care .....	49
	Vetting of patients .....	49
	Ideology of the service .....	49
	Multi-disciplinary make-up of the secondary care team .....	49
	Pain Management Programme (PMP) .....	51
	Enablers and barriers to change in secondary care pain services .....	52
4.4	Level 4 - Tertiary care .....	54
4.5	Conclusions of the corporate needs assessment .....	54
5	Recommendations .....	56
5.1	General .....	56
5.2	Level 1 – Self-management .....	56
	Self-management resources .....	56
	Provision of self-management support .....	56
5.3	Level 2 – Primary care .....	57
	Promote self-management during consultations .....	57
	Improve recording of chronic pain and self-management .....	57
	Prescribing reviews .....	57
	Improve referral to secondary care including development of a standard referral pathway .....	57
	Training for primary care staff .....	58
5.4	Level 3 – Secondary care .....	58
	Specialist Pain Service Provision .....	58
	Improve access to services .....	58
	Intervention guidance .....	58
	Quantify potential future workforce and take action accordingly .....	58
5.5	Level 4 – Tertiary care .....	59
	List of Appendices .....	60
	Appendix 1: Previously used Scottish Service Model for Chronic Pain (2011) .....	61
	References .....	62

## Preface

For most of us, pain is an unpleasant consequence of an acute illness or injury. We know it is evidence of the way in which our body is protecting us from further harm. Perhaps most helpfully, we know that there are tried and tested treatments that can alleviate the pain. For most of us, that is.

For others, however, pain is something that is always there. Sometimes we understand the ways in which the pain is caused, but not always. It is a debilitating condition, affecting the simple day to day activities that most of us take for granted. Such chronic pain can be managed with appropriate care, even if it is not simply alleviated by taking some pain-killers.

But unlike a disease which can be easily identified and for which there is a clear and approach to treatment, chronic pain only becomes recognised over time. Other possibilities have to be considered and then excluded. Treatment is not something that can be simply applied and guaranteed to work. It is a more careful process where the clinician and the patient work with each other to help create a way of managing the pain in a way that works for them.

I am indebted to Ruth Mellor, who has worked with experts in chronic pain management across Scotland, to map out what services are already in place and what needs to be developed further. She has been ably supported by her local colleagues in NHS Lanarkshire, and by a national ScotPHN Steering Group. Without them, this work would not have happened.

Ensuring that there are health care and support services available for people experiencing chronic pain is something to which we are committed in Scotland. Helping make it happen locally is what this document is about.



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## Acknowledgements

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- Other contributors: Cara Richardson, (University of Dundee), Julie Arnot (NHS Health Scotland), Gillian Armour (NHS Health Scotland)
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## Table of Figures

Figure 1: Key national changes and reports around chronic pain .....	13
Figure 2: Chronic Pain Policy Matrix .....	15
Figure 3: Scottish Service Model for Chronic Pain .....	17
Figure 4: Airing pain listens by quarter .....	25
Figure 5: Helpline calls answered and demand.....	25
Figure 6: Step 2 opioids (other than Strong Opioids) DDDs per 1,000 list size per day, April to June 2017, by board.....	32
Figure 7: Step 2 opioids (other than Strong Opioids) DDDs per 1,000 list size per day, by board, by quarter April to June of 2015 to 2017 .....	32
Figure 8: Number of Patients Prescribed Strong Opioids (including Tramadol) long term (>2 years) as percentage of Patients Prescribed Strong Opioids, by board, July 2015 to June 2017 .....	33
Figure 9: Number of Patients Prescribed Strong Opioids (including Tramadol) long term (>2 years) as percentage of Patients Prescribed Strong Opioids, by board, July 2013 – June 2015 to July 2015 - June 2017 .....	34
Figure 10: Gabapentinoid DDDs per 1,000 list size per day, April to June 2017, by board.....	35
Figure 11: Rate of Gabapentinoid DDDs per 1,000 list size per day, by board, by quarter April to June of 2015 to 2017 .....	36
Figure 12: Adjusted* waiting time for new appointments at chronic pain clinics for 2017 Q4, examined against the Scottish Government's treatment standard target, of at least 90% of patients to go from referred to treatment within 18 weeks .....	38
Figure 13: Force Field Analysis: Change within Chronic Pain Services (relevant to other areas also) .....	53

## Table of Tables

Table 1: Level of pain related to estimated affected Scottish population.....	21
Table 2: Number and percentage of individuals with cancer, diabetes, anxiety or depression, that were issued a prescription item used for the management of chronic pain, by board, 2016.....	22
Table 3: NHS board area, no. people attended groups (no. Group locations)*, coloured by who organised the group <sup>Δ</sup> .....	27
Table 4: Number of patients referred and starting Pain Association Scotland course, (percentage of those who were referred who started a course) by NHS board area	28
Table 5: The number of new appointments within the Pain Clinic for financial year 2016/17 (2016 q2, q3,q4 & 2017 q1).....	37
Table 6: The number of new appointments for Pain Psychology for financial year 2016/17 .....	39
Table 7: Clinical activity in 2015/16 and 2016/17 .....	40
Table 8: Referrals for Pain Management to RNHRD, Bath .....	41
Table 9: No. referrals by board between April 2015 and March 2017 .....	41
Table 10: Disciplines included within secondary care pain service, by board .....	50



## Acronyms

AHP	Allied Health Professional
CHI	Community Health Index
CPD	Continuing professional development
CRPS	Complex regional pain syndrome
GDP	Gross Domestic Product
DDD	Defined daily dose
GG&C	Greater Glasgow & Clyde
HIS	Healthcare Improvement Scotland
HNA	Healthcare needs assessment
IASP	International Association for the Study of Pain
ICD	International Classification of Diseases
ISD	Information Services Division
LGOWIT	'Let's get on with it together'
MDT	Multi-disciplinary teams
MSGCP	Ministerial Steering Group on Chronic Pain
MSK	Musculoskeletal
NACCP	National Advisory Committee on Chronic Pain
NCPSG	National Chronic Pain Steering Group
NSS	National Services Scotland
PMP	Pain management programmes
QPI	Quality performance indicators
RNHRD	Royal National Hospital for Rheumatic Diseases
SIGN	Scottish Intercollegiate Guidelines Network
SIGs	Service Improvement Groups
SNRPMP	Scottish National Residential Pain Management Programme
SPIRE	Scottish Primary Care Information Resource

# Executive Summary

## Introduction

Chronic pain is pain that has lasted for three months or more, despite appropriate treatment. In Scotland between 10.4% and 14.3% of people are experiencing moderate to severely disabling chronic pain. Chronic pain is associated with multi-morbidity and can be experienced for a long period of time. Healthcare and wider socioeconomic costs could result in chronic pain costing between 3% and 10% of Gross Domestic Product annually.

## Methods

This health needs assessment includes both an epidemiological needs assessment and a corporate needs assessment. The epidemiological needs assessment examines routinely available data related to service provision. The corporate needs assessment sought the view of key informants to understand service set up and the enablers and barriers to change in relation to secondary care services. The assessments were used to formulate the recommendations.

## What we found

Findings are ordered in relation to the different levels of the Scottish Service Model for Chronic Pain.

### In general

- The current Scottish Service Model for Chronic Pain is holistic to reflect the diversity of developments over time and is not prescriptive in how it should be delivered.
- There are varied service pathways and set ups between boards. This has resulted in different treatment options being available for patients depending on where they live.
- There is a lack of data on chronic pain service provision.

### Level 1 - Self-management

- A diverse range of self-management resources exist both online, in hard copy and through face to face sessions.
- Uptake of some online resources is high.
- Access to third sector or patient run face to face self-management varies both between and within boards. Uptake of courses is relatively low and support groups have varying numbers of members. Attendance often starts when patients are quite far along in their patient journey. However once engaged

course completion is high and members may stay engaged in support groups for a long time.

### **Level 2 - Primary care**

- The only currently available routine primary care data related to chronic pain is on analgesic prescribing.
- Prescribing varies within and between boards, not all of which will be accounted for by difference in board populations demographics, therefore implying there must be some sub optimal use.
- The lack of data on other primary care interventions, for example physiotherapy or access to counselling sessions, could be hiding good practice and / or unmet need.
- Between boards there is different access to primary care professionals who are up-skilled in relation to chronic pain. This has been influenced by different initiatives have been run by boards to increase staff confidence and ability in this area.

### **Level 3 - Secondary care**

- The majority of patients with chronic pain do not need to access secondary care services, managing with support through self-management and primary care.
- The rate of new patients seen within secondary pain clinic varies by board, as does how long they have to wait for their first appointment.
- Secondary care Pain Service teams were made up of different staff disciplines, provided different treatment options and so there is difference in service provision. This variation is particularly stark for remote and rural services.
- Another area of disparity was links with addiction services which is a problem now and will increase even further in importance given the trend of increasing prescribing of addictive analgesics.
- Whilst there has been service improvements, and different services have different challenges, common themes that enabled or prevented change were cited, with having a sustainable workforce being paramount.

### **Level 4 - Tertiary care**

- Tertiary services are provided at a regional or national basis. There is variation in referral to the Scottish National Residential Pain Management Programme, but now all board areas have had one or more patient referred to the service

## **Recommendations**

Ordered in relation to the different levels of the Scottish Service Model for Chronic Pain:

### **General**

- NHS Boards should report on the number of people who have sought and who are accessing NHS services for chronic pain management by type of service.

### **Level 1 - Self-management**

- All providers of Pain Services (Level 1 to 4) must provide quick and easy access to educational material that informs about, and supports self-management of chronic pain.
- Ensuring all resources are available online and provided through a well-regarded and quality assured website such as [NHS Inform](#).
- For NHS Board areas where there are currently no self-management groups, courses or education sessions, one type of face to face support is established. Where there is inequitable or limited access to these groups, that provision expanded for example through broadening digital access.

### **Level 2 - Primary care**

- The majority of patients with chronic pain should be able to manage their pain with support from self-management and primary care. NHS Boards should self-management and support reliable access to other forms of non-pharmacological management of chronic pain, including psychological, talking therapies (online courses including under supervision). Their use should be recorded as part of routine patient records.
- Chronic Pain should be routinely recorded in Primary Care, with staff using the specific Read Code.
- Any patient receiving regular analgesic prescriptions must have these reviewed. NHS Boards should have a review strategy that outlines responsibility for conducting the reviews. A quality performance indicator for reviews should be introduced.
- Improve training for Primary Care staff around pharmacological and non-pharmacological interventions.
- Chronic pain should be covered as part of pre-registration training.
- Clear criteria should be developed to support appropriate referrals to secondary care, and specify what information is required to support that referral.

### **Level 3 - Secondary care**

- Each NHS Board must ensure adequate provision of, or access to, a multi-disciplinary pain service, with sufficient and appropriately trained clinicians representing all the relevant disciplines.
- To enable adequate provision of, or access to, a multidisciplinary team, a range of approaches may need to be considered, including a more distributed models of care across existing NHS boundaries, increasing telehealth options, or service restructuring.
- Similarly, the potential future workforce needs to be quantified and action taken. Alternative methods of creating a broader, clinical workforce trained in pain medicine and management, should be considered. Furthermore professional

development support for Allied Health Professionals (AHP) not formally employed within a Level 3 pain service should be extended.

- Healthcare Improvement Scotland should consider facilitating the development of nationally agreed guidelines for pain relieving, repeated interventions, where there do not yet exist. These should not only include criteria for treatment initiation, but also criteria for successful pain relief and, therefore continuation / discontinuation.

#### **Level 4 - Tertiary care**

- NHS Boards should collaborate to ensure that access to Level 4 services is equitable, irrespective of the Board area where the patient resides or is being managed.

# 1 Background

## 1.1 Definition

Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (1). Chronic pain is pain that has continued past the expected (normal) tissue healing time (2). In practice chronic pain is defined as pain that has lasted for three months or more, despite appropriate treatment (3).

## 1.2 Prevalence of Chronic Pain

In the UK prevalence of chronic pain is 43.5%<sup>1</sup>, ranging from 35.0 to 51.5%. However it is more usual to focus on the clinically relevant 10.4-14.3% of people experiencing moderate to severely disabling chronic pain (Von Korff grade III-IV) (4), and 5.7%<sup>2</sup> with severe chronic pain (Von Korff grade IV), resulting in high disability and severe limitation (5). Chronic pain prevalence increases with age (3)(4), is higher in women and increases with increased deprivation (6). Chronic pain is associated with multimorbidity (7) and can be prolonged, a European survey found 59% of respondents had experienced pain for two to fifteen years, with a further 21% of respondents had experienced pain for 20 years or more (8).

## 1.3 Scope

Chronic pain was pain acknowledged “as a condition in its own right” in 2008 (9). Therefore chronic pain is going to be examined in totality, not in relation to specific underlying conditions. There can be chronic pain which has a known reason, but chronic pain can also exist as a functional illness or ‘medically unexplained symptom’ where there is no known underlying cause. Many of the lessons from chronic pain could be extended to other areas of functional illness.

This work is concentrating on clinically relevant adult pain. Childhood pain is important, but not covered here, please refer to ‘Management of Chronic Pain in Children and Young People’ (Scottish Government Guideline Development Group and Collaborators, 2018).

The Health Need Assessment (HNA) contains: a description on the Scottish Service Model for chronic pain; the recent chronic pain national policy context; an epidemiological needs assessment; and corporate needs assessment; which feed in to the recommendations. Where possible the Scottish Service Model for chronic pain has structured the sections.

This Health Needs Assessment aims to assist NHS Boards and the National Advisory Committee on Chronic Pain (NACCP) by providing analysis to inform further service

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<sup>1</sup> This is a pooled estimate based on 7 studies, from general population samples from locations within the UK, these individual studies had prevalence rates ranging from 35.0%-51.3%.

<sup>2</sup> This population prevalence is based on a single, Scotland based study.

development to meet the current and future needs of adults with chronic pain. Within this the epidemiological needs assessment examines routinely available data related to service provision. The corporate needs assessment sought the view of key informants to understand service set up and the enablers and barriers to change in relation to secondary care services.

#### **1.4 Recent national history and policy context of chronic pain**

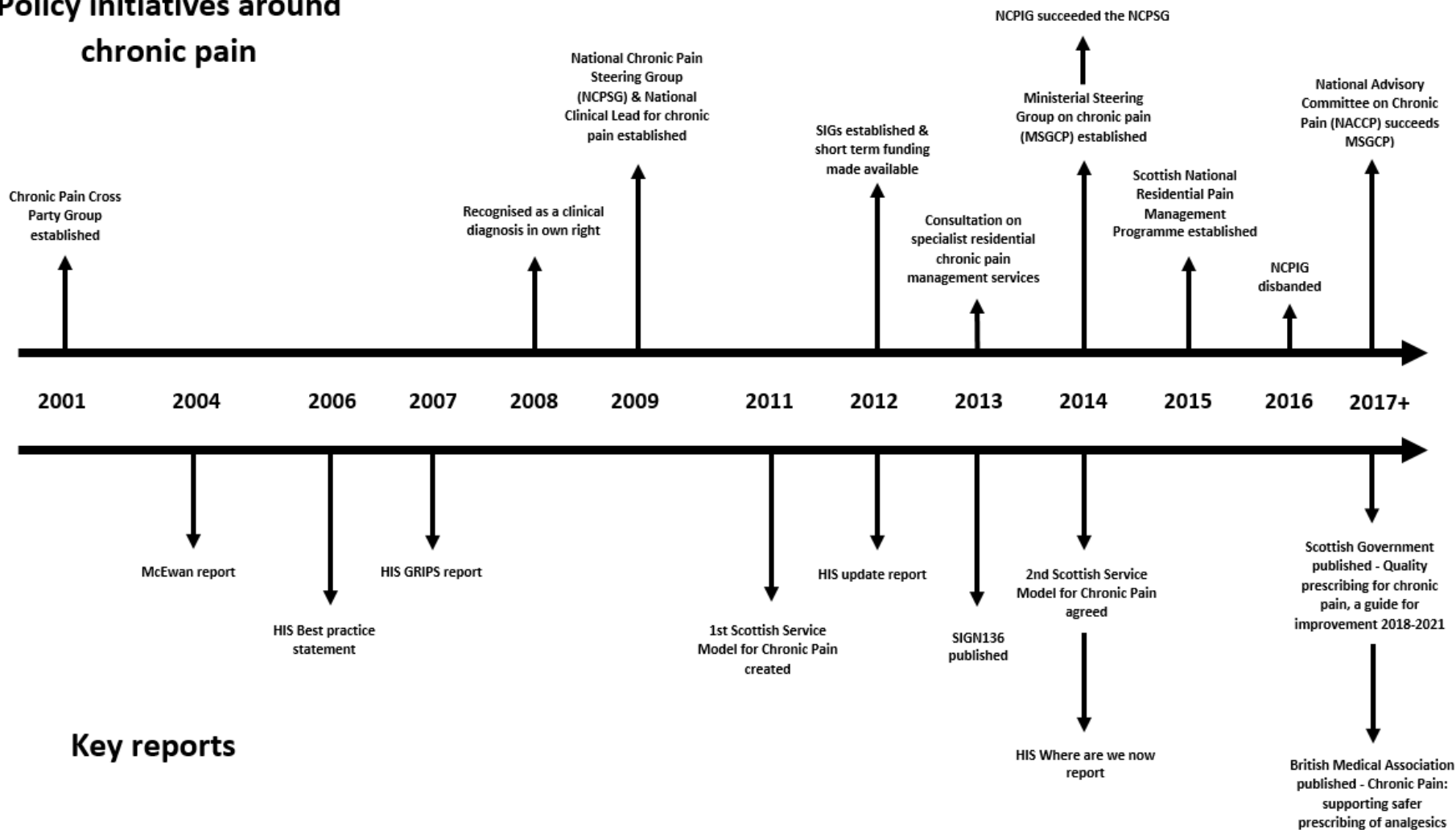
The key national initiatives around chronic pain and the key reports that will have influenced them are shown in [Figure 1](#). The set-up of national leadership has varied over time, with the NACCP and the Chronic Pain Cross Party Group currently having government and / or parliamentary input. With Healthcare Improvement Scotland (HIS) reviewing chronic pain services between 2007 and 2014, there was increased national scrutiny and their reporting highlighted recommendations. During their work, in 2008 chronic pain became recognised as a clinical diagnosis in its own right, service improvement groups (SIGs) were established and the Scottish Government provided short term funding for services. The timing of this report provides an opportunity to see what has happened to services now that the funding is no longer available.

A policy matrix covering health policies from 2012 to 2018, created by Richardson and colleagues (10), is shown in Figure 2. It highlights that the tenets that make good management of chronic pain are shared between many of the policies, with them being exemplified in 'Realising Realistic Medicine' (11). Therefore through the promotion of good chronic pain management these policies would also be promoted.

Furthermore patients with chronic pain can experience indirect costs, for example through impacting an individual's ability to work. Therefore the wider social and economic policy context for example the Welfare Reform Act (12) will influence this patient population.

Figure 1: Key national changes and reports around chronic pain

## Policy initiatives around chronic pain





**Figure 2: Chronic Pain Policy Matrix**

		Health Policies from 2012 to 2018										
		Realising Realistic Medicine (11)	Quality Prescribing for Chronic Pain. A Guide for Improvement. 2017-2020 (13)	eHealth Strategy 2014-2017 (14)	Effective Prescribing (15)	National Clinical Strategy (16)	AHP Delivery Plan (17)	Achieving Excellence in Pharmaceutical Care: A Strategy for Scotland (18)	Improving together: A National Framework for Quality and GP Clusters in Scotland (19)	Allied Health Professions Co-creating Wellbeing with the People of Scotland The Active and Independent Living Programme in Scotland (20)	Health and Social Care Delivery Plan (21)	Targets and Indicators in Health and Social Care in Scotland A Review (22)
Consideration for Good Management of Chronic Pain	Shared decision making	✓		✓					✓	✓	✓	✓
	Reducing harm, waste and variation in care	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓
	Personalised approach to care	✓		✓		✓	✓	✓		✓	✓	
	Early assessment	✓	✓									
	Ongoing review	✓	✓		✓							
	To enhance the availability of appropriate information for relevant parties to inform decisions on service delivery, performance and improvement	✓										
	Demographic changes in our population	✓				✓		✓	✓	✓		✓
	Financial considerations	✓		✓	✓	✓			✓		✓	✓
	Cluster working and collaboration between services	✓		✓			✓	✓	✓	✓	✓	✓

Source: Richardson C, Berlouis K, Smith B, Cameron P, Colvin L. Data and Measurement for Chronic Pain Services. A Pilot Study to Inform National Service Improvement. 2018 (10)

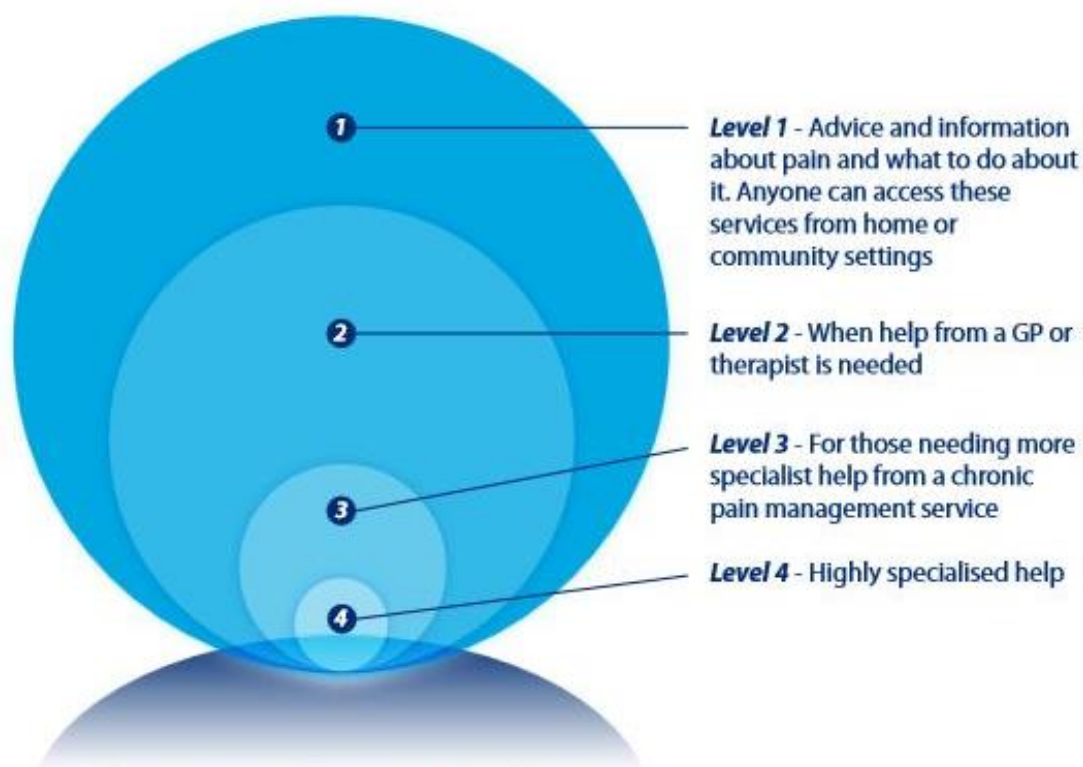
## 2 Scottish Service Model for Chronic Pain

This section outlines the Scottish Service Model for Chronic Pain, and summarises the interventions conducted at that level. There are several key publications that cover the care of patients with chronic pain, for more detailed information please refer to: SIGN 136 (23) which provides guidance on the evidence base for recommendations on the management of chronic pain; the Faculty of Pain Medicine 'Core Standards for Pain Management Services in the UK' (24); and in relation to medicine use, the 'Quality Prescribing for chronic pain a guide to improvement 2018-2021' (13) and 'Chronic Pain: Supporting Safer Prescribing of analgesics (25). Examples of local good practice can be found in [appendix 2](#).

Within Scotland the discussion of chronic pain service provision has been heightened since 2004 and the McEwan Report (26). One of the considerations of such discussions was the creation of a service delivery model. The current service delivery model for chronic pain in Scotland is the 'Scottish Service Model for Chronic Pain' (Figure 3). It was created by the project team within the National Chronic Pain Steering Group (NCPSPG) and was endorsed by the Group in 2014 (27). It was designed to be a simplification of the 2011 model (shown in [appendix 1](#)) to improve ease of use and understanding, in line with feedback from stakeholders (27). A limitation of the model is that due to its simplified nature, it is open to interpretation, allowing for divergent patient pathways.

**Figure 3: Scottish Service Model for Chronic Pain**

*Most people get back to normal after pain that might come on after an injury or operation or for no apparent reason. Sometimes the pain carries on for longer than 12 weeks despite medication or treatment – this is called chronic or persistent pain.*



*Source: Gilbert S, Holdsworth L, Smith B. The Scottish model for chronic pain management services. British Journal of Healthcare Management December 2014;20(12):568-577. (27)*

The Scottish Service Model for Chronic Pain consists of four levels: self-management (possibly linked with the third sector); primary care; secondary care; and more specialist services. Patients should be able to move between levels (both up and down) based on need, however for the majority of patients, good intervention at lower levels should reduce or remove the need to attend higher levels of care.

The structure of the model is going to be used throughout this report, splitting sections into the levels of care. For specific information on how individual NHS Boards provide services, please see [appendix 5](#).

## **2.1 Level 1 – Self-management**

The majority of people with chronic pain are able to manage it themselves, with activity, relaxation, and non-opioid pain killers such as paracetamol or anti-inflammatories. Third sector organisations e.g. the Pain Association Scotland, Pain Concern, can provide information and access to support around managing pain. The Pain Toolkit is a resource that outlines 12 ‘tools’ to managing chronic pain, which include goal setting and pacing (28).

The Scottish Service Model for Chronic Pain shows self-management as overarching, and that it can be linked into by any other level. Scottish Intercollegiate Guidelines Network (SIGN) guidance highlights that healthcare professionals should signpost patients to these resources, as complementary to other therapies, and should be used from early on and throughout the patients’ journey (23).

In terms of activity and exercise, it is safe and beneficial (29). SIGN recommends exercise and exercise therapies for patients with chronic pain (23). From evidence around low back pain, they highlight that advice to stay active alone is insufficient (23).

## **2.2 Level 2 – Primary care**

Primary care, be that a GP, Physiotherapist or Pharmacist can provide help through, assessing pain, providing advice, medication, exercise programmes, linking to self-management support, or alternative therapies such as acupuncture. Counselling services and chaplaincy can help through talk and therapy. Within some NHS Boards some specialist pain services are provided through primary care. Primary care is expected to see the majority of patients with moderate to severe pain. A 2002 study estimated that in the UK, 4.6 million appointments per year are used in the management of chronic pain (30).

Another way to assist in the management of chronic pain is through the use of medication. When considering pharmacological intervention first line treatment is with non-opioid analgesics, paracetamol and / or non-steroidal anti-inflammatory drugs, and if not successful other options can be considered, in terms of opioid prescribing then, ‘starting low and going slow’ is recommended (13). Patients should be advised of potential side effects, and aware that opioids are not effective for everyone and their expectations managed to appreciate that a 30% reduction in pain would be a success (13). If medicines are not providing sufficient relief they should be discontinued, their benefits need to be weighed against their risks, both in relation to side effects and addiction. A significant increase in the number of people affected by opioid misuse has been reported in the US, the total economic burden of which is \$78.5 billion a year (31). Higgins *et al*/systematic review and meta-analysis found a pooled incidence rate of 4.7% of formally diagnosed iatrogenic opioid dependence or abuse, in patients with pain who were exposed to opioid analgesic therapy (32).

SIGN recommends that patients using analgesics should be reviewed at least annually, and sooner if the patient's pain has altered or medication is being changed; the 'Quality prescribing for chronic pain a guide for improvement' (13) recommends (in situations where the patient is receiving substantial relief and is stable in their use) that they be reviewed every six months. Signs of addiction or abuse of opioids should be looked for when reassessing patients using strong opioids, although SIGN found no good evidence for pill counting, prescription monitoring and routine urine testing in detect these problems (23). The BMA recommends that support is required for patients and doctors to discontinue opioid treatment if it is not working (25).

Inappropriate use of analgesics is not only detrimental to the patient, but to the environment too. Between 30-90% of an oral dose of medicine is excreted in urine or faeces (33). Medicines are now found in the watercourse, and have detrimental impacts on aquatic life. Currently little is known about the implications of their presence or bioaccumulation to humans (34). Hence it is important that medicines are used appropriately and their use and effects in individual patients monitored.

### **2.3 Level 3 – Secondary care**

Hospital based pain clinics or services can be referred into by primary care (at least by GPs) or from hospital Consultants working in other disciplines. As pain has biopsychosocial components, pain services usually have a multidisciplinary team (MDT), this can include Consultants trained in chronic pain, Nurses, Physiotherapists, Psychologists, Pharmacists, Occupational Therapists and Psychiatrists. Staffing and services vary by NHS Board. Services can include giving further insight into current treatment, advice from one or more of the disciplines involved, entry into a Pain Management Programme (PMP) (35), or provision of specific interventions ranging from provision of TENS machines, to blocking nerve transmission. Some services have links to or joint clinics with substance misuse teams.

### **2.4 Level 4 – Tertiary care**

Tertiary care includes highly specialised services. Within Scotland intensive PMPs are conducted by the Scottish National Residential Pain Management Programme (SNRPMP), in Glasgow. Specialised interventions such as spinal cord stimulation are provided at specialist centres, within NHS Greater Glasgow and Clyde (GG&C), NHS Grampian and NHS Tayside.

## 3 Epidemiological Needs Assessment

The epidemiological needs assessment covers four areas:

1. The size of the problem;
2. The cost of the problem;
3. Routinely available data related to the four levels of the Scottish Service Model for Chronic Pain; and
4. Current data developments. The methods related to this section can be found in [appendix 3](#).

### 3.1 Size of the problem

#### Chronic Pain

There is no published study reporting the prevalence of chronic pain across Scotland. Perhaps the closest we can get was based in Grampian and published in 1999 (36). Taking the prevalence data from the literature and applying it to the Scottish population (Table 1), there are very large number of people who are experiencing chronic pain, variations in figures reflect differences in case identification and ascertainment, as well as methodological rigour. Chronic pain varies in severity; and for some it will be considered minor and not result in their seeking treatment. Other patients will have sought treatment in the past and be self-managing their condition now. Not everyone, even those with severe pain, seeks medical help (5), however, there will be many people who need to. Regardless of pain severity patients could benefit from self-management. The severity of the pain will influence the intensity or level of care patients need, although it imperfectly correlates with level of expressed need (37). The absence of chronic pain natural history data in the Scottish context means it is not possible to know how many people will need different services at the one time.

**Table 1: Level of pain related to estimated affected Scottish population**

Level of pain	How they fit into the Scottish service model	Percentage of general population reported in literature	Number of people in Scotland*
Any chronic pain	Majority manage themselves or with level 2	35.0-51.3 Fayaz <i>et al</i> (4)	1.9 million to 2.8m million
Moderate to severely disabling chronic pain (CPG III & IV)	Start with level 1, most manage with level 2	10.4-14.3 Fayaz <i>et al</i> (4)	562,000 – 773,000
Severe chronic pain (CPG IV)	Start with level 1, then 2, then referred to level 3, a minority go onto level 4	4.9-6.5 Smith <i>et al</i> (5)	265,000 - 351,000

\*Based on 2016 mid-year Scottish population estimate 5,404,700 (38)

CPG = chronic pain grade

### **Co-morbidity with chronic pain**

Chronic pain may occur in isolation but more usually it occurs in association with other comorbidities (7). In Scotland in 2016, 16.2% of patients with diabetes, 14.8% with cancer, and 19.3% with anxiety or depression, were also being prescribed medication that is used for chronic pain (although the patient may be using this medication for another purpose, e.g. acute pain or epilepsy (Table 2)<sup>3</sup>. However, the proportion of patients who were comorbid for chronic pain with diabetes, cancer, or anxiety or depression varied by NHS Board, with the Borders, Lanarkshire, Tayside and Ayrshire and Arran having consistently higher proportions of co-prescribing. Barnett *et al*'s work would suggest that there is increased co-morbidity in patients from deprived areas (7).

<sup>3</sup> See [Appendix 3](#) for methodology

**Table 2: Number and percentage of individuals with cancer, diabetes, anxiety or depression, that were issued 4 or more prescription items used for the management of chronic pain, by board, 2016<sup>4</sup>**

NHS Board	Cancer		Diabetes		Anxiety or depression	
	Prevalent cases	% issued 4+ prescription items for chronic pain management	Number of patients	% issued 4+ prescription items for chronic pain management	Number of patients	% issued 4+ prescription items for chronic pain management
Ayrshire & Arran	15,600	15.2%	23,489	17.5%	55,858	20.7%
Borders	5,047	15.2%	6,694	19.0%	15,532	20.9%
Dumfries & Galloway	7,000	13.7%	9,412	16.2%	19,383	19.6%
Fife	13,942	14.5%	21,389	16.7%	51,040	18.9%
Forth Valley	11,269	14.5%	16,729	16.6%	40,514	19.7%
Grampian	19,929	13.5%	28,420	14.7%	65,771	17.5%
Greater Glasgow & Clyde	45,110	15.8%	62,874	16.1%	169,013	19.3%
Highland	13,318	12.6%	17,100	13.7%	36,230	18.7%
Lanarkshire	22,415	17.5%	38,671	17.7%	96,560	20.8%
Lothian	30,600	13.3%	40,197	14.7%	101,711	17.4%
Orkney	872	10.2%	1,168	11.9%	2,492	16.9%
Shetland	923	11.6%	1,123	14.7%	2,472	17.1%
Tayside	16,054	15.5%	23,294	17.6%	55,325	20.5%
Western Isles	1,183	12.3%	1,421	12.1%	2,865	18.8%
<b>Scotland</b>	<b>203,262</b>	<b>14.8%</b>	<b>291,981</b>	<b>16.2%</b>	<b>714,766</b>	<b>19.3%</b>

<sup>4</sup> Scottish Burden of Disease project, personal communication (data yet to be published)



### 3.2 Cost of the problem

Gauging the extent of the total costs associated with chronic pain in the UK is problematic.

There is a dearth of current evidence and whilst there are estimates of the costs of subsets of pain e.g. back pain, some of which are now dated, there would appear to be no overarching current estimates of the costs, direct or indirect, of all chronic pain in Scotland or the UK.

However, the available evidence suggests that the socio-economic burden of chronic pain in the UK could be significant. One estimate, based on studies carried out in Ireland, Sweden, Denmark and the United States, indicates that, for European nations, the costs of chronic pain could be somewhere in the range of 3% to 10% of Gross Domestic Product (GDP) (39). For Scotland this would equate to between £4.5billion<sup>5</sup> and £15.1billion.

#### Direct costs

One measure of the cost of chronic pain, although not the sole measure, is associated with the use of prescription medicines. In Scotland between 2010/11 and 2014/15, the number of items dispensed more than doubled: for gabapentin rising from 302,736 to 629,741 items, and for pregabalin rising from 133,985 to 364,111 items (25). Pregabalin currently has the highest gross ingredient cost at £40.74 million of items dispensed by NHS Scotland. These costs have increased from £30.4m in 2014/15 to £35.3m in 2015/16. To see prescribing data split by NHS Board go to [Section 3.3\(ii\) Level 2 – Primary care](#). Within the NHS in Scotland, co-codamol (2.81 million items) and paracetamol (2.6 million items) were the second and third most prescribed medicines during 2016/17. The prescribing of Ibuprofen has also increased, from 325,281 items in 2015/16 to 418,541 items in 2016/17, representing a 29% increase in items and a 27% increase in costs (40).

Opioid prescribing in Scotland, as in the rest of the UK, has increased. Over 50% more morphine was dispensed in 2014/15 than in 2010, up from 280,351 to 440,472 items. Codeine increased by 64% from 89,159 to 146,561 items, tramadol by 12% from 972,922 to 1.09m items, oxycodone by 33% and Fentanyl by 23%. In Scotland the annual cost of this prescribing is around £32 million (25). Examination of prescribing of opioids in 2012 showed that for strong opioids, patients in most deprived areas were 3.5 times more likely than those in least deprived areas to receive them (41).

#### Indirect costs

Chronic pain impacts not only on the direct costs associated with prescriptions, treatment and use of healthcare services (evidence suggests that those with chronic pain access a higher volume of healthcare consultations, driving up costs) (42) but on a wider set of indirect costs, principally workplace absenteeism, reduced levels of

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<sup>5</sup> Based on onshore GPD for the period Oct 2016-Sept 2017 (Scottish Government, 2018).

workplace productivity, increased risk of leaving the labour market *altogether* and the payment of benefits to those unable to work (43).

Establishing the costs associated with this is difficult. Again, there appears to be little current evidence for Scotland or the UK. The Chief Medical Officer annual report for 2008 reported that those with chronic pain are seven times more likely to leave their jobs due to ill health than the general population, 25% eventually lose their jobs, and chronic pain was the second most common reason for claiming incapacity benefit (44).

This impacts on household income and increases wider societal and economic costs in terms of payments of out of work and sickness benefits as well as lost work days. In 2009 Philips estimated that musculoskeletal (MSK) disorders (lower back pain, general chronic pain syndromes) as well as mental health problems were most closely associated with disability benefits, comprising more than 50% of sick certification. MSK complaints accounted for around 20% of benefit recipients in the UK (43). The current UK spend for incapacity, disability and injury benefits is £44bn, for family benefits, income support and tax credits it is £46bn and £2bn for unemployment benefits (45). It has to be assumed that chronic pain contributes to an unknown, but significant proportion of this spend. The combined annual costs of worklessness and sickness absence may amount to around £100bn (46) and some proportion of this must be attributed to the impact of chronic pain.

In addition to this, 31.2 million working days were lost to sickness in the UK in 2016/17. There is no estimate for the proportion of those days lost due to chronic pain. However, MSK disorders accounted for 8.9 million days (47). It may be assumed that many of these individuals will be affected by chronic pain, as are those absent from work for other reasons.

### **3.3(i) Level 1 - Self-Management**

Self-management can be signposted to or provided at any point in the patient journey. Across Scotland a range of different resources are available, from educational leaflet, to online resources, to in-persons sessions run by the third sector, to toolkits that can be used within primary care consultations. This section covers use of Pain Concern's resources and face to face self-management sessions.

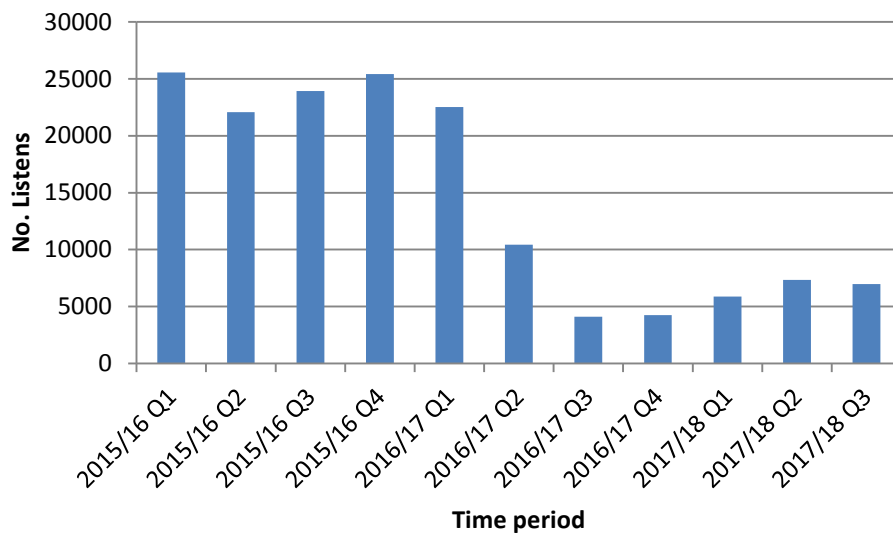
#### **Chronic pain self-management resources**

People can also learn from and get support through online resources. Pain Concern, a third sector organisation, hosts links to a range of resources on their website (<http://painconcern.org.uk/>), including: videos and leaflets; a radio programme (Airing Pain); a helpline; and a forum. The access statistics for these are reported in turn, and highlights the varying reach of these resources. Data has been provided by Pain Concern.

In 2016/17 the Pain Concern website had 262,194 new users worldwide: 19,182 were located in Scotland; 161,917 in England; 7,739 in Wales; and 4,720 in Northern Ireland.

Airing Pain, which has been broadcasting since 2010, has 101 episodes (as of 17 April 2018), and is available as a podcast. It has had varying number of listens over time, from over 25,000 in Quarter 1 of 2015/16 to just over 4,000 in quarter 3 of 2016/17 (Figure 4), with a drop off being apparent during the financial year 2016/17, attributed to a change in dissemination strategy. It is not possible to differentiate location of listener.

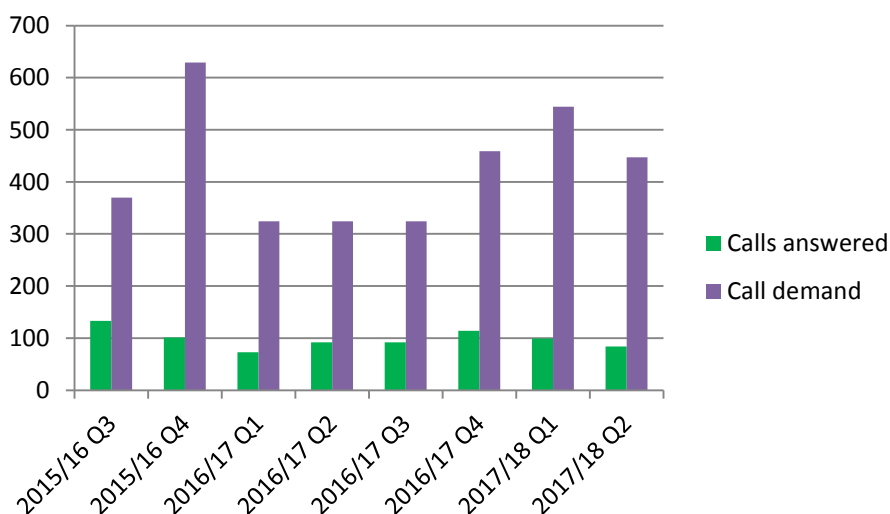
**Figure 4: Airing pain listens by quarter**



Source: created from Pain Concern data

The helpline receives calls from across the UK and the calls are answered by volunteers (Figure 5). In 2016/17, 380 calls were answered but this met 21.9% of call demand (although some people could have rung multiple times). In 2017/18, there were 2,754 members of the Health Unlocked forum, of which Pain Concern estimate 220 are located in Scotland.

**Figure 5: Helpline calls answered and demand**



Source: created from Pain Concern data

### ***Chronic pain self-management support groups, courses or education classes***

Face to face self-management sessions are split into three categories: rolling session support groups; multi-session intensive courses; and one-off education classes. Their structure dictates the kind of services they can facilitate and this can potentially influence the relevance to people at different points in their pain journey. For example, education classes may be beneficial to those who have not come across self-management processes for pain, whereas a support group could provide the peer support that someone who has decided to pursue self-management could benefit from.

Individual health board areas have different provision of sessions, which are mainly provided by the third sector, and NHS staff may be linked into, or involved with them to varying extents.

### ***Self-management groups***

Self-management support groups are run by different organisations. The Pain Association Scotland, a third sector organisation, is the most frequent provider of chronic pain specific sessions, providing both a monthly support group and intensive courses; in 2017 they had a service level agreement with 8 of 14 NHS Boards. Two individual NHS Boards support board-specific groups: in Grampian there are the patient led Affa Sair and Grampian Pain support groups; in Highland people with chronic pain are linked into a long term conditions support group 'Let's get on with it together' (LGOWIT). Some NHS Board areas have other condition specific groups such as Arthritis Scotland Living Well groups, or fibromyalgia groups.

NHS Board areas have different set ups for self-management session provision.

Table 3 shows the provision of groups. Within some NHS Board areas this has been constant over the five year period, but other NHS Board areas have had varying provision. The number of participants vary by group, with some having relatively few participants. In terms of the rolling group, from the Pain Association Scotland data it is clear that some individuals continue attending over multiple years. The number of group locations also varied and was highlighted as a concern for NHS Board areas which are geographically large.

**Table 3: NHS board area, no. people attended groups (no. Group locations)<sup>‡</sup>, coloured by who organised the group<sup>Δ</sup>**

Year	Ayrshire & Arran	Borders	Dumfries & Galloway	Fife	Forth Valley	Grampian	Greater Glasgow & Clyde	North Highland	Argyll & Bute	Lanarkshire	Lothian	Orkney	Shetland	Tayside	Western Isles
2013	45 (1)		47 (2)	98 (5)	66 (2)	28 (1)	67 (6)	23 (1)	10 (1)	73 (3)	7 (1)			145 (5)	24 (1)
2014	61 (2)		66 (2)	97 (5)	58 (2)	14 <sup>^</sup> (2)	35 (5)	18 (1) (1)	9 (1)	54 (3)				132 (5)	22 (2)
2015	57 (2)	52 (2)	65 (2)	88 (4)	65 (2)	20 <sup>^</sup> (2) (1) *		16 (1) (4)	7 (1)	74 (3)				137 (4)	34 (2)
2016	43 (2)	62 (2)	67 (2)	91 (4)	76 (2)	23 <sup>^</sup> (2) (1) *		17 (1) (7)	6 (1)	116 (3)				149 (4)	44 (2)
2017	62 (2)	75 (2)	56 (2)	81 (4)	88 (2)	23 <sup>^</sup> (2) (1) 12 (1)		(17)	6 (1)	113 (3)				158 (4)	36 (3 <sup>€</sup> )
Total no. attending PA group between 2013-17 (or shorter period)	187	142	212	254	224	NA	84	49	24	320	7			491	93

<sup>‡</sup>Note the topics covered in the group are rolling, and people are welcome to attend into the group at different years

<sup>€</sup>The new group in the Western Isles is delivered via TeleHealth

<sup>Δ</sup>Group: purple=Pain Association Scotland, green = Grampian Pain Support Group, yellow = Affa Sair, orange= 'Let's get on with it together' (LGOWIT) 'Better Together' support group for people with long term condition

<sup>^</sup>Average attendance at the main monthly meeting, rather than for both groups or the membership for that year, and therefore a comparative underestimate in comparison to how other figures were calculated, for example in 2017 the average attendance was 27, but the membership was 67.

\*Average weekly attendance not known, however between 2015-2017 online membership increased from 84 to 370 people

NA: non-applicable, PA: Pain Association Scotland

@covers period April to December 2017

Source: data acquired from different third sector organisations

### Self-management courses

The Pain Association Scotland ran a 5 week (2.5 hours per week)<sup>6</sup> self-management course in four NHS Boards between 2013 and 2017 (Table 4). Patients have to be referred to the course by a health care professional. For more information on the course see [appendix 2](#).

**Table 4: Number of patients referred and starting Pain Association Scotland course, (percentage of those who were referred who started a course) by NHS Board area**

Year	Dumfries & Galloway	Forth Valley	Tayside	Western Isles
2013/14	97, <u>36</u> , (37.1%)	237, <u>62</u> , (26.1%)	496, <u>159</u> , (32.1%)	31, <u>7</u> , (22.6%)
2014/15	154, <u>53</u> , (34.4%)	190, <u>46</u> , (24.2%)	452, <u>145</u> , (32.1%)	50, <u>21</u> , (42.0%)
2015/16	89, <u>22</u> , (24.7%)	215, <u>63</u> , (29.3%)	391, <u>151</u> , (38.6%)	50, <u>26</u> , (52.0%)
2016/17	66, <u>18</u> , (27.3%)	249, <u>81</u> , (32.5%)	332, <u>133</u> , (40.1%)	63, <u>29</u> , (46.0%)

Source: extracted from Pain Association Scotland data

Between 22.6% and 52.0% of patients referred, went on to start a course (Table 4). Attendance to the course may have been influenced by the level of encouragement patients were given to attend, e.g. if they were handed information with other information versus, the merits and contents being discussed in the consultation with the clinician. Otherwise they might have been practical barriers for their attendance: not yet ready to engage with self-management; still looking for a clinical diagnosis; feeling like being referred to the course is an unwelcome discharge as they would still like more intervention; or maybe not like a group setting. Similarly some patients were unable to attend the course, in which case they were given the opportunity to attend the next course. However, of those who started the course in 2017, 94% went on to complete the course (attend at least 3 of 5 sessions). Within the 2017 Scottish and Welsh cohort, a range of questionnaires were completed pre and post course: the mean group had a 40% improvement in perceived self-efficacy; 33% reduction in anxiety scores; 29% reduction in depression scores; and 22% improvement in positive outlook score (48). Participants also reported higher scores in relation to skills gained, but impact on health service use was not captured.

In the Highlands, LGOWIT also run self-management courses; 13 were scheduled in the Highlands in 2017 see [appendix 2](#). There are other organisations such as Arthritis

<sup>6</sup> With the exception of the Western Isles, where the course is run over two consecutive days – taking into account the island element of this location.

Care and the Lorn and Oban Health Options who provide community based interventions not exclusively for chronic pain patients, but which they could participate in.

### ***Self-management education classes***

Education sessions about self-management for chronic pain have also been run in some boards. They have been delivered: by patients to those in the general community; by staff to identified patients; and as part of the patient pathway in health boards for those referred to the pain clinic (see [appendix 5](#) on individual board services).

In GG&C Pain Trainers, who are patients living with pain, are delivering two hour workshops open to anyone. The number of people who have attended is in 2015, 84 people (69.4% of those who booked), 2016, 160 people (71.7% of those who booked) and in 2017, 139 people (65.6% of those who booked<sup>7</sup>)<sup>8</sup>. Of the 198 participants who completed an evaluation, they reported the topics discussed to be useful or very useful (49). It is not known what the longer term behaviour change impacts of the one off session would be. For more details see the example in the [appendix 2](#).

Argyll and Bute piloted Pain Toolkit half day workshops, using the Pain Toolkit (28). These workshops were delivered by trained Volunteer self-management coaches. In 2016 they ran 15 workshops which included 103 participants, including patients, carers, and interested professionals (50).

### **Self-management in primary care**

Self-management could be incorporated to primary care consultations. It is not known how frequently or successfully primary care clinicians refer to self-management resources, this is not something that would come under a Read code. Barriers to incorporating self-management highlighted by patients, carers and health care professionals in Scotland as reported by Gordon K, Rice H (51) are: patient perceived readiness to self-manage; negative patient attitudes, for example being a way to “plug a gap in health care system”; self-management not in line with the current medicalised culture; mixed messages from professionals; mixed perceptions by professionals of third sector self-management support groups. In addition to practical difficulties of short appointments and long waiting times for other services; self-management more holistic, but pain issue could be dealt with in silos.

Pain Concern is also developing a consultation tool, see [appendix 2](#) for further information. In Argyll and Bute some Physiotherapists and other AHP staff were trained to deliver the pain toolkit within a one to one consultation setting and hard copy toolkits were purchased for use in consultations and workshops. To assist continuity of use, a further refresher workshop was hosted in 2017. Their delivery models are

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<sup>7</sup> Data available for April to December 2017.

<sup>8</sup> Personal communication

being evaluated to ensure that a sustainable self-management programme can be delivered and embedded in each locality in Argyll & Bute.

### ***Summary of face to face self-management session provision***

The patterns of face to face self-management session provision vary. Four board areas having regular rolling support group meetings and intensive courses available. Two of those areas do not have local PMPs, and this could have influenced their desire to have the intensive course. Six board areas have a rolling support group. The remaining four board areas currently having no community based chronic pain self-management support group. Within those four, both NHS Lothian and NHS GG&C runs frequent PMPs, NHS GG&C have Pain Trainer one off education workshops, and post-PMP NHS Lothian provide patients with a local resource list. The other two boards without community based chronic pain without support sessions, are Orkney and Shetland. Although within the Orkney region there is a fibromyalgia Facebook group, an Arthritis Care support group, and Tai Chi for Arthritis sessions. Shetland had a Pain Association Scotland group in the past but does not now.

The integration of self-management into primary care is being examined in some boards.

### **3.3(ii) Level 2 - Primary care**

Within primary care there are lots of different treatment options delivered by a range of professionals (See Background Section). However, the only nationally available data is around prescribing. In the future with Scottish Primary Care Information Resource (SPIRE) it would be possible to see more about chronic pain from GP records. This data is not currently accessible, out with individual practices ([see section 3.4](#)).

#### **Prescribing of pain medication**

Information on the number of people being prescribed analgesics for chronic pain is not straightforward. Prescribing data does not provide information on the condition for which the medicine is prescribed, therefore it is not possible to differentiate whether the prescription is for a patient with chronic pain, or if the medicine is being prescribed for another reason. Some medicines that can be used to treat chronic pain are used frequently for other reasons e.g. paracetamol to lower temperature, therefore presenting data on them would be misleading. For more information and guidance on chronic pain prescribing in Scotland please refer to the 'Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021' (13).

Three areas of pain related prescribing are step 2 opioids (codeine phosphate, dihydrocodeine tartrate, meptazinol), strong opioids, and gabapentinoids (includes both pregabalin and gabapentin). Recent prescribing information related to them is presented below (see Box 1 for instructions on reading the graphs).



### Box 1: How to read the prescribing graphs

There follows a series of Board level data charts relating to prescribing for chronic pain. Within the data, the boxplot charts should be interpreted as follows:

- median GP practices in NHS Board– dark grey bar;
- interquartile range or middle 50% of GP practices in NHS Board – blue box;
- maximum and minimum – whiskers, unless greater than 1.5 of interquartile range;
- outliers – (○) GP practice value greater than 1.5 but less than 3.0 of interquartile range;
- extreme outliers – (•) GP practice value greater than 3.0 of interquartile range.

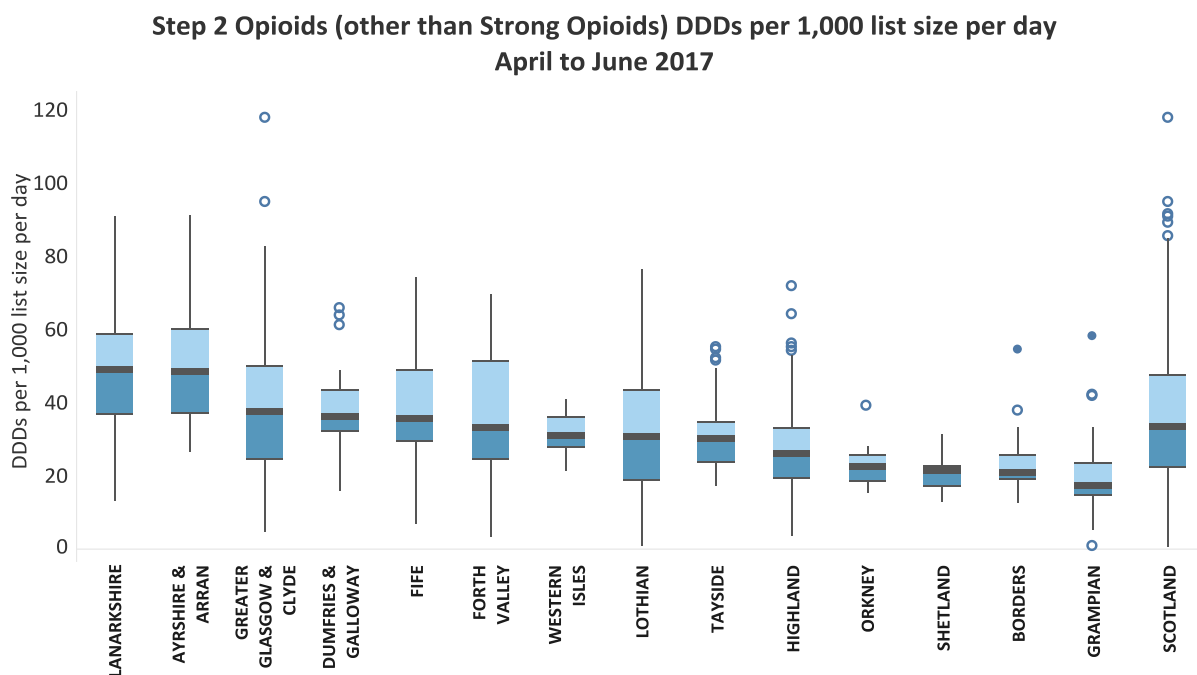
The three year charts utilise the mean position of the Board, each year.

The data provided must be considered within the context of local populations and local healthcare arrangements, and provides an indicator of clinical practice. Due to the complex nature of the prescribing being analysed it is not possible to provide advice on *what good looks like*.

*Source: Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021. Scottish Government (13)*

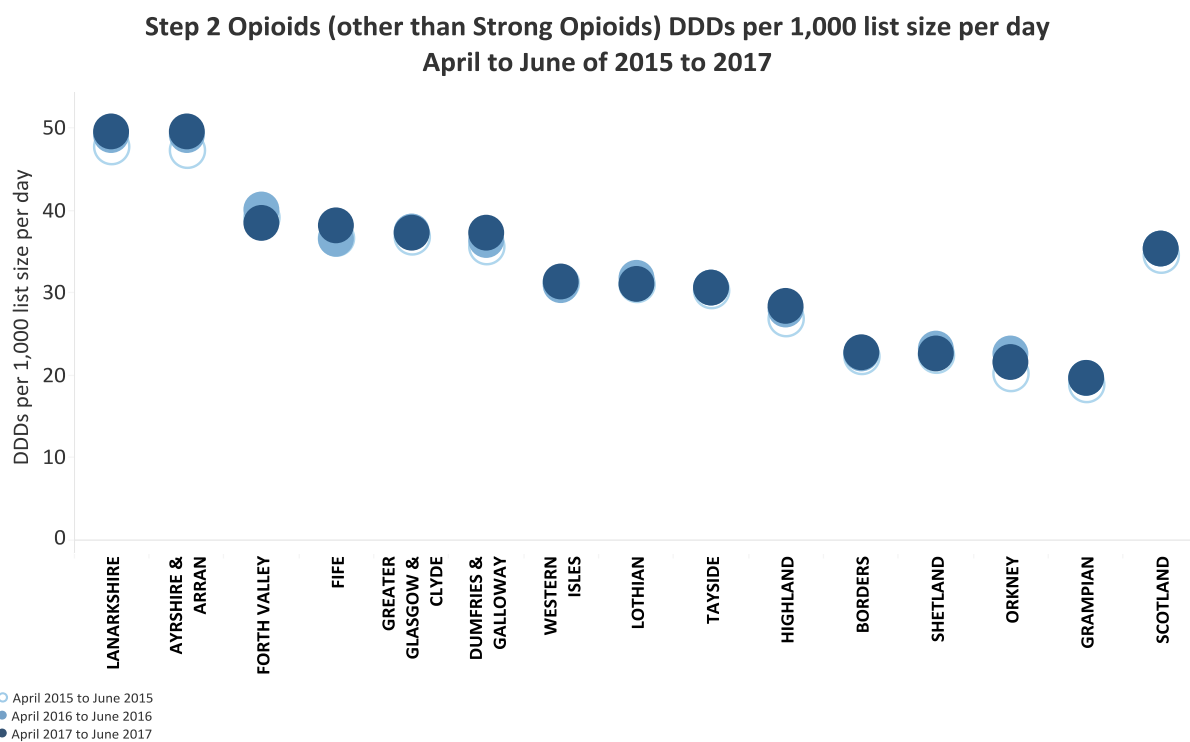
In Scotland the median defined daily dose (DDD) of step 2 opioids (other than strong opioids) per 1000 list size per day is 33.20 (interquartile range 22.13-47.34). Figure 6 highlights that this varies by NHS Board, but Figure 7 shows that this has remained constant overall between 2015 to 2017, with some NHS Boards increasing and some decreasing, when examining one quarter of the year.

**Figure 6: Step 2 opioids (other than Strong Opioids) DDDs per 1,000 list size per day, April to June 2017, by board**



Source: Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021. Scottish Government (13)

**Figure 7: Step 2 opioids (other than Strong Opioids) DDDs per 1,000 list size per day, by board, by quarter April to June of 2015 to 2017**

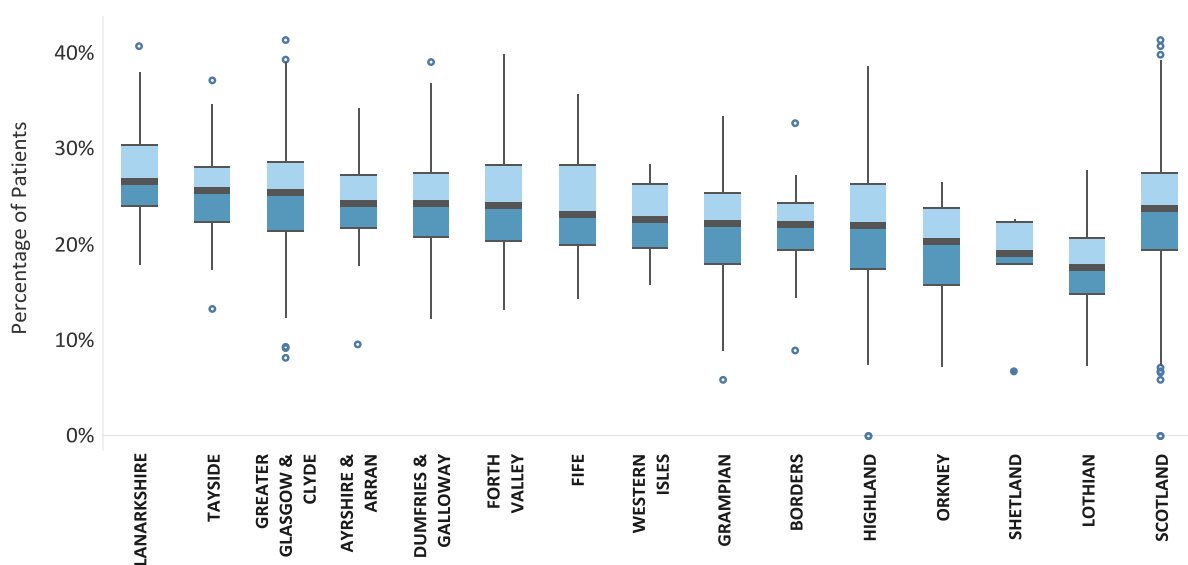


Source: Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021. Scottish Government (13)

In Scotland 23.64% (median) (interquartile range 19.29%-27.34%) of patients prescribed strong opioids, were prescribed them long term (over 2 years) (Figure 8); this proportion of patients has increased over the period 2015 to 2017 (Figure 9).

Between April to June 2015 and April to June 2017 the number of patients on long term strong opioids has increased from 81,956 to 86,677. However the number of people prescribed strong opioids between April to June 2015 and April to June 2017 has dropped from 357,395 to 335,754<sup>9</sup>. Suggesting fewer patients are being started on them, but those what are already on them continue to use them for a long time.

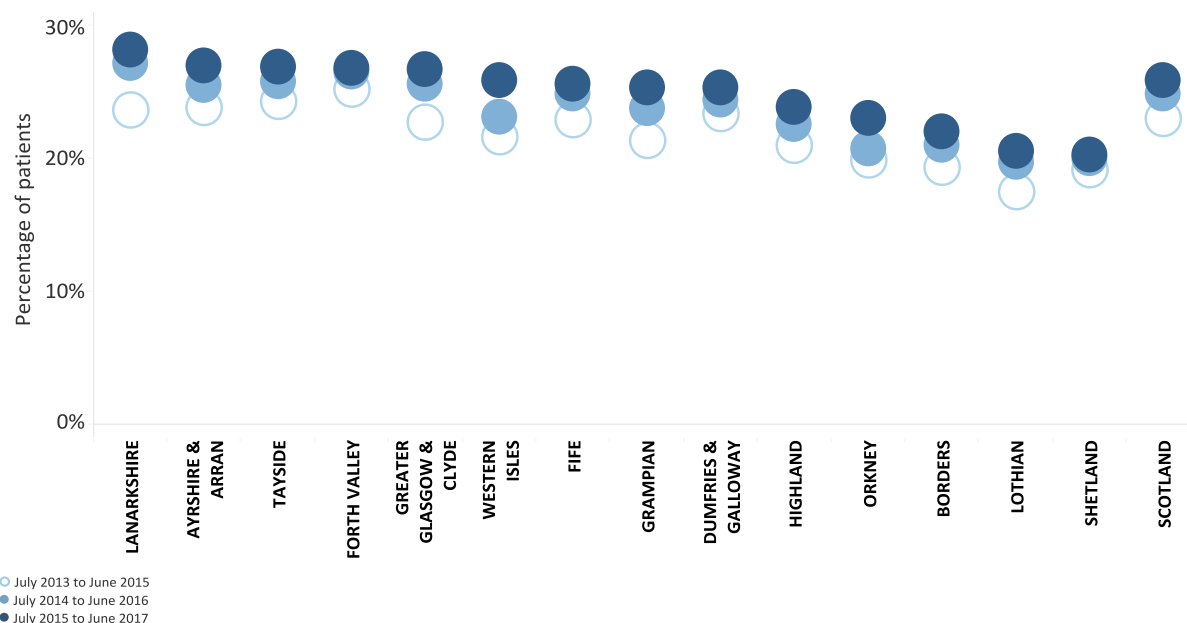
**Figure 8: Number of Patients Prescribed Strong Opioids (including Tramadol) long term (>2 years) as percentage of Patients Prescribed Strong Opioids, by board, July 2015 to June 2017**



Source: *Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021*. Scottish Government (13)

<sup>9</sup> Personal communication

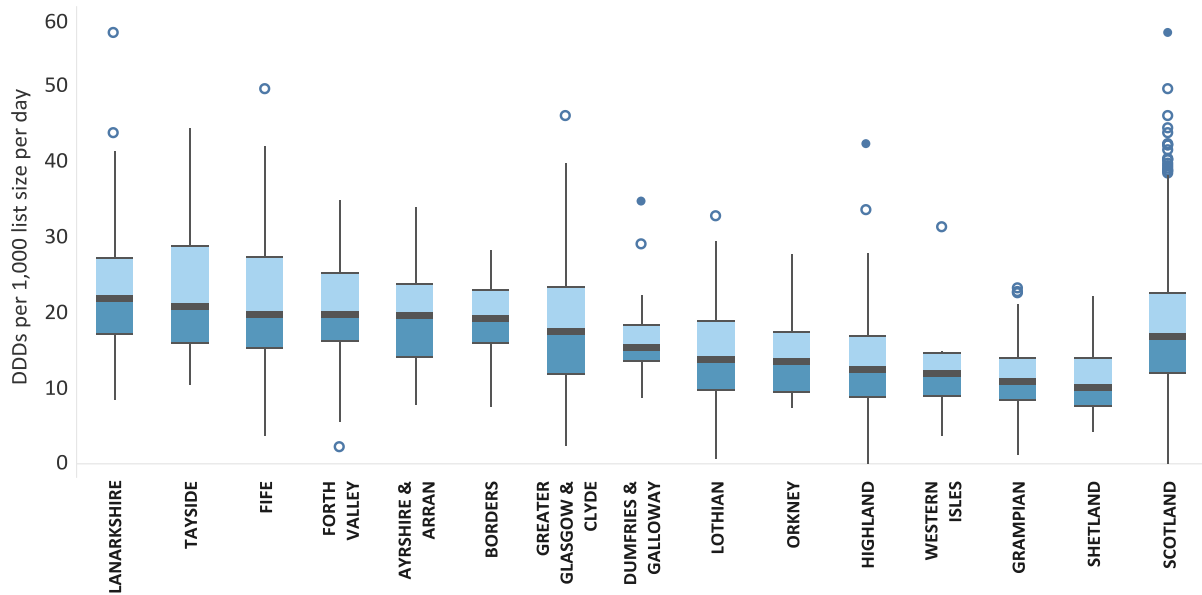
**Figure 9: Number of Patients Prescribed Strong Opioids (including Tramadol) long term (>2 years) as percentage of Patients Prescribed Strong Opioids, by board, July 2013 – June 2015 to July 2015 - June 2017**



Source: *Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021. Scottish Government (13)*

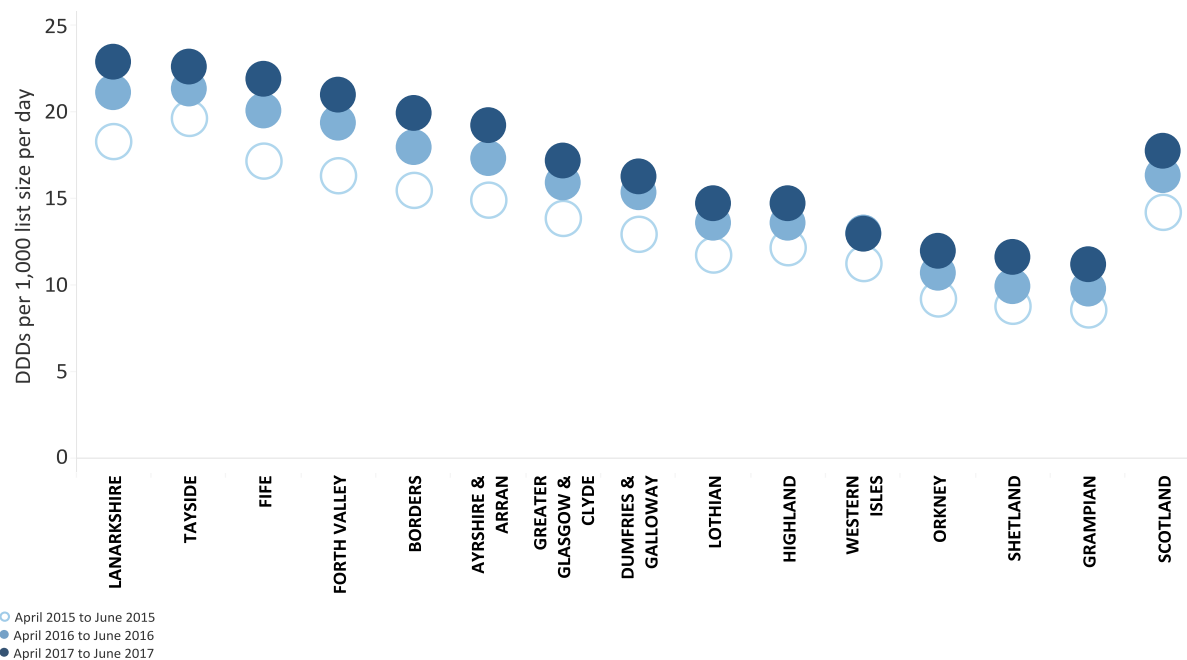
In Scotland the median gabapentinoid defined daily dose (DDD) per 1000 list size per day is 16.80 (interquartile range 11.93-22.38). Figure 10 highlights that this varies by NHS Board and Figure 11 shows that this has continued to increase each year between 2015 to 2017, when examining in the one quarter of the year. This increase could be due to increased doses, prescribed quantities, volume of patients or a combination. More research is therefore needed to explain the increase.

**Figure 10: Gabapentinoid DDDs per 1,000 list size per day, April to June 2017, by board**



Source: *Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021*. Scottish Government (13)

**Figure 11: Rate of Gabapentinoid DDDs per 1,000 list size per day, by board, by quarter April to June of 2015 to 2017**



Source: *Quality Prescribing in Chronic Pain: A Guide for Improvement, 2018-2021. Scottish Government* (13)

### 3.3(iii) Level 3 - Secondary Care Pain Service

As with primary care data, limited information is routinely collected. This section will cover the number of new patients seen in Pain Clinics and waiting times for these appointments. The minimal data that has been collected for pain psychology services will also be reported. There is no routinely collected data for physiotherapy appointments or participation in PMPs, or number of nursing or medical interventions conducted.

#### Number of new patients seen at the Pain Clinic by NHS Board

Within the financial year 2016-17 NHS Boards saw between from 53 to 3,394 people as new patients in the Pain Clinic, taking into account population size of the board this is from 1.34 to 5.55 new patients per 1000 population (Table 5). The number of appointments available will be influenced not only by patient demand, but also clinic capacity, variation could be influenced by changes in service e.g. absent or departed staff. This data is based on waiting time data submissions, no data was available during this period for the Highlands or Western Isles. Data is limited to new appointments, return appointments are not included.

**Table 5: The number of new appointments within the Pain Clinic for financial year 2016/17 (2016 q2, q3,q4 & 2017 q1)**

Health board	No. new patients seen in the Pain Clinic 2016/17 <sup>^</sup>	Crude rate per 1000 population <sup>‡</sup>
Ayrshire & Arran	779	2.10
Borders	236	2.05
Dumfries & Galloway	406	2.72
Fife	497	1.34
Forth Valley	979	3.20
Grampian	1240	2.11
Greater Glasgow & Clyde	3394	2.90
Highlands	No data	No data
Lanarkshire	1127	1.71
Lothian	1952	2.19
Orkney	53	2.41
Shetland	128	5.55
Tayside	1157	2.78
Western Isles	No data	No data

<sup>‡</sup> based on the estimated population for each board for 30 June 2017 (38), this is unadjusted for the age and sex distribution of the population

<sup>^</sup> There was considerable variation between quarters in the year, in some boards.

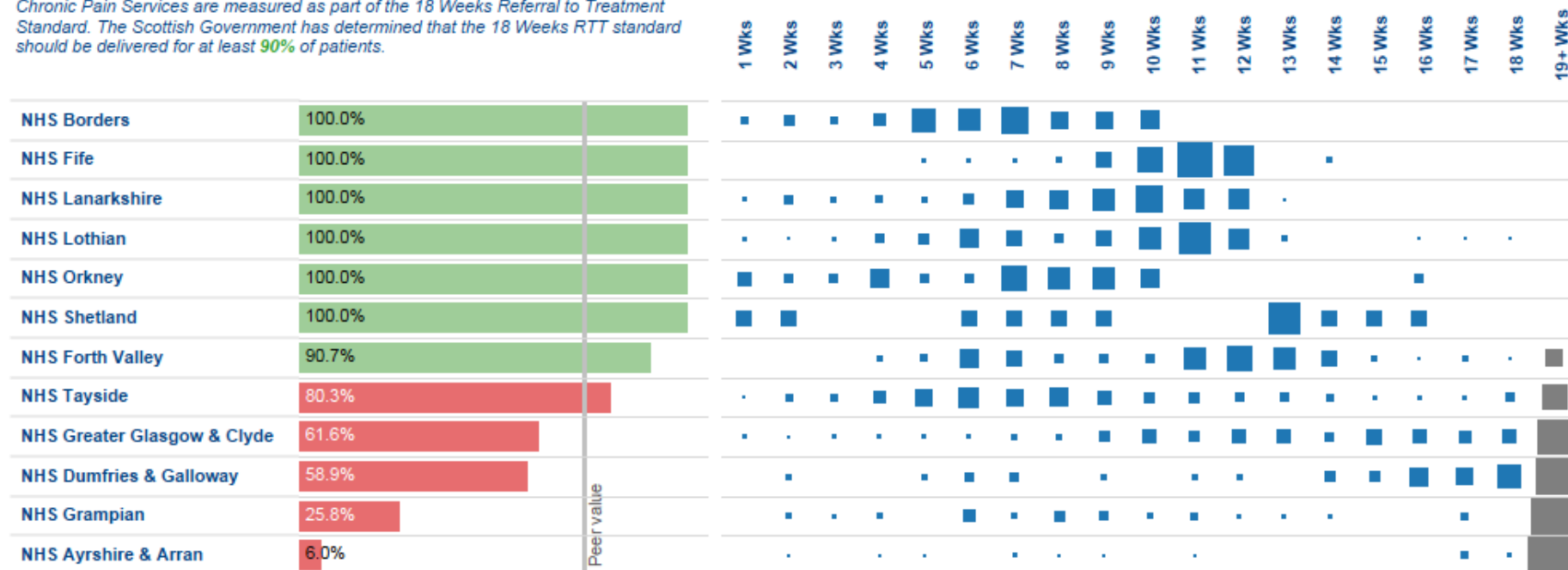
Source: NHS National Services Scotland. NSS Discovery, Chronic Pain Adjusted/Unadjusted Waiting Times (52)

### **Waiting times for appointments at chronic pain clinics (in hospital setting)**

The Scottish Government recommend that at least 90% patients should be able to commence treatment at a chronic pain clinic within 18 weeks of referral (21). Figure 12 shows that for quarter 4 of 2017 7 of 14 boards (in green) met this standard. The blue squares represent the percentage of patients attending within so many weeks of their appointment, the patterns of when patients attend varied by board. Some boards data suggest that the majority of patients seen after the 18 week period – however this dataset is considered ‘developmental’ by Information Services Division (ISD) and boards are working with ISD to improve completeness of data collection (52). Furthermore patients may have had chronic pain for a long time prior to referral to secondary care; 89% of new referrals had symptoms for over a year at time of first appointment (53).

**Figure 12: Adjusted\* waiting time for new appointments at chronic pain clinics for 2017 Q4, examined against the Scottish Government's treatment standard target, of at least 90% of patients to go from referred to treatment within 18 weeks**

Chronic Pain Services are measured as part of the 18 Weeks Referral to Treatment Standard. The Scottish Government has determined that the 18 Weeks RTT standard should be delivered for at least 90% of patients.



\* The waiting times were adjusted to take into account any period the patient was unavailable e.g. on holiday, or any appointments rearranged or missed

Source: NHS National Services Scotland. NSS Discovery, Chronic Pain Adjusted/Unadjusted Waiting Times (52), note newer date is available on the [ISD website](#)



## Pain Psychology

During the financial year 2016/17 six boards had at least one quarters worth of data recording new appointments for pain psychology (Table 6). Along with the pain clinic waiting time data this is an area that ISD and the Scottish Government are working with boards to make this information more complete and consistent (52).

**Table 6: The number of new appointments for Pain Psychology for financial year 2016/17**

Health board	No. new appointments for pain psychology, for 2016/17
Ayrshire & Arran	83
Borders	21
Forth Valley	117
Grampian <sup>^</sup>	6
Lanarkshire <sup>^</sup>	20
Lothian	808

<sup>^</sup> data only recorded for 1 of 4 quarters

Source: NHS National Services Scotland. NSS Discovery, Chronic Pain Adjusted/Unadjusted Waiting Times (52)

### 3.3(iv) Level 4 - Tertiary care

Tertiary services include highly specialised care. A major change in provision of chronic pain services in Scotland has been the opening of the SNRPMP, which assessed its first patients in 2015, its clinical activity is reported below. There is no routinely available data on other highly specialised services.

#### **The Scottish National Residential Pain Management Programme (SNRPMP)**

The SNRPMP concentrates on the development of self-management skills to improve patients' quality of life (54). It is a residential programme that provides a block of three weeks treatment, which is then consolidated at home, with a follow up telephone review and later a follow up in person group review (55). The Programme assessed its first patients in January 2015 and the first patient group was in November 2015(55).

Table 7 shows the number of patients referred to the service and then attending groups by financial year. There are inclusion and exclusion criteria to ensure that those who enrol are those who would most benefit from this intensive care, at this point in their patient journey. There is now also a preparatory clinic which helps patients consider whether this programme is for them and works with them to address any needs that would enable them to attend the programme.

**Table 7: Clinical activity in 2015/16 and 2016/17**

<b>Activity</b>	<b>2015/16</b>	<b>2016/17</b>
No. patient referrals	71	77
No. patient assessments	54	64
No. patients started group	17	21
No. Patients completed a group	14	19
No. Groups held (can have up to 10 patients)	2	3

Source: *Scottish National Residential Pain Management Programme. Annual Report 2015-16. : NHS Scotland; 2016 and Scottish National Residential Pain Management Programme. Annual Report 2016-17. : NHS Scotland; 2016 (55)(56)*<sup>10</sup>

Up to 10 patients can attend a group. As a new service two groups were held in 2015/16, then three in 2016/17 and four will have run in 2017-18. In 2015-16 both groups were booked to capacity, of those booked, 17 participants started, and 14 completed the three week block. In 2016-17 28 patients were booked onto the three programmes, with 21 starting and 19 completing.

Reasons for not making it from referral to group include: not fitting the inclusion criteria or meeting the exclusion criteria; having other health or personal issues unrelated to pain that would need to be overcome prior to participation; having pain related needs that would be more appropriately met by local services; the patient not feeling ready for a self-management approach yet; or may not be able to commit to a self-catered three week intensive course.

Furthermore, not all those offered places are able to take them up, due to other reasons closer to the time e.g. illness or family issues: Unfortunately due to the intensive nature of the programme it can be difficult to fill spaces on the programme at short notice, despite the service's best efforts to do so.

Patients in Scotland can still be referred to the Bath Centre for Pain Services, located at the Royal National Hospital for Rheumatic Diseases (RNHRD), which run other specific programmes, e.g. a four weeks intensive hospital based programme, a young person's programme and a complex regional pain syndrome (CRPS) specific programme. Number of approved referrals to the RNHRD for pain management has reduced since 2014-15 (Table 8).

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<sup>10</sup> Personal communication

**Table 8: Referrals for Pain Management to RNHRD, Bath**

Financial Years	Number of Approved Referrals
2013-2014	18
2014-2015	15
2015-2016	9
2016-2017	7
2017-2018 (from 1/4/17 - 09/02/18)	7
<b>TOTAL</b>	<b>56</b>

Source: National Services Scotland<sup>11</sup>

Table 9 shows referrals by health board over the two year period April 2015 to March 2017. Frequency of referring may be influenced by the size of their patient population, variation in the local secondary care service model and service provision, knowledge of what the residential service offers, and having had positive reviews from returning patients. At the end of March 2017 two board areas had not had any residents referred to the service, but as of January 2018, all board areas have had one or more residents referred to the service. The Highlands had a disproportionately high number of referrals, the majority coming from Argyll and Bute due to limited multi-disciplinary service provision locally, alongside the issue of remote and rural geography.

**Table 9: No. referrals by board between April 2015 and March 2017**

Board	No. referrals April 2015 - March 2017
Ayrshire and Arran	*
Borders	*
Dumfries & Galloway	6
Fife	*
Forth Valley	5
Grampian	19
GGC	17
Highland <sup>1</sup>	53
Lanarkshire	9
Lothian	8
Orkney	*
Shetland	6
Tayside	14
Western Isles	6
<b>Total referrals</b>	<b>145</b>

Source: Scottish National Residential Pain Management Programme. Annual Report 2015-16. : NHS Scotland; 2016 and Scottish National Residential Pain Management Programme. Annual Report 2016-17. : NHS Scotland; 2016 (55)(56)

\*fewer than 5 referrals

<sup>1</sup>Highlands - of the 53 referrals received from Highland, 38 were from Argyll and Bute.

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<sup>11</sup> Personal communication

### **High level procedures**

NHS GG&C, NHS Grampian, and NHS Tayside can provide neuromodulation, such as spinal cord stimulation, for both their own residents and patients resident in other boards. The Beatson, the West of Scotland Cancer Centre based in Glasgow, and NHS Grampian and NHS Tayside can provide cancer pain treatments such as percutaneous cordotomy, both to their own residents and act as a regional centre for patients living in other boards.

### **3.4 Data developments**

Chronic pain relevant health data that is collected routinely is limited to overall prescribing patterns and waiting times for first appointments at pain clinics. The absence of more diverse routinely collected data highlights gaps in our knowledge around chronic pain service provision in primary and secondary care, and success of interventions. Current work to improve this situation in primary and secondary care is highlighted below, along with proposed Quality Performance Indicators (QPIs).

#### **In terms of what is recorded in general practice and primary care:**

General practices in Scotland currently use Read Codes, there are Read Codes for individual regional pains e.g. pain in the arm, and one on general aches and pains (57), and in 2015 a specific read code for chronic pain (1M52) was introduced (58). The Primary Care Team, of Public Health and Intelligence (PHI) have created an algorithm to identify patient records with chronic pain, in the interim whilst the Read Code is normalised into practice. The algorithm involves: patient having either the Read Code, or four or more analgesic prescriptions in the last year, or four or more anti-epileptic prescriptions in the last year and without a Read code for epilepsy – they outline which analgesics and anti-epileptics should be used (59). It is worth noting that the definition of chronic pain is being reviewed and may change.

The Scottish Primary Care Information Resource (SPIRE) service coming into primary care can provide individual practices with their own data in a user friendly format and/or extract data from practices in a secure, flexible and consistent way to support cluster working, payments, linkage and research. In the context of chronic pain, the algorithm forms the basis of a SPIRE local report, and can be used to highlight chronic pain records, which could be examined to see if the patients' medication is due for review. If data are to be extracted the data would be encrypted before leaving the practice and securely stored in National Services Scotland with patient identifiers held separately to anonymise it. Practice participation in SPIRE is optional and the individual practice would have to consent for the data to be extracted. Furthermore individual patients can opt out of having their patient identifiable data extracted (60). Any such algorithm will need to be validated for its positive and negative predictive values.

#### **Secondary care**

International Classification of Diseases version 10 (ICD-10) codes are used, in secondary care. ICD-10 "includes some diagnostic codes for chronic pain conditions, but these diagnoses do not reflect the actual epidemiology of chronic pain, nor are

they categorized in a systematic manner” (61). The International Association for the Study of Pain (IASP) Task Force, in partnership with the World Health Organization, has created a classification of chronic pain for the 11<sup>th</sup> revision of the ICD (61).

To improve understanding of patient demographics and effectiveness of service provision for individuals, the Scottish Government have commissioned a core minimum dataset (along with components of a suggested optimum dataset) to be used in all Pain Services in secondary care. The core minimum dataset includes Community Health Index (CHI) identifier, demographic characteristics, pain sites, pain severity, pain duration, underlying diagnosis, emotional impact, functional impact, and health related quality of life. It should be collected at baseline and at later consultations to allow comparison of outcomes (10).

### ***Waiting time data***

In October 2017 ISD consultation highlighted a desire to have waiting times on return appointments, ISD investigated this, but currently only two boards have systems in place to capture this information, ISD has committed to undertaking a review into the collection of return appointment data (62). The variety in patient pathways would make this information hard to measure and assess value. Patients may be directed to one of a number of professionals and/or interventions, and the speed with which it is appropriate to access these varies. A lone statistic on waiting times for an individual service component could not convey that complexity or provide sufficient insight. Instead Richardson and colleagues (10) propose a set of five QPIs to measure and monitor chronic pain service provision.

### **Quality Performance Indicators**

The QPIs that Richardson and colleagues (10) recommend are around: pain education; outcome measures; pharmacy review; service evaluation and audit; and exercise and activity therapies. The indicators aim to allow benchmarking of individual Pain Services against a set of evidence based standards for provision of good quality service; they aim to recognise good quality and to drive improvement in services where these standards are not currently met, through identification of gaps and reporting of these gaps on an annual basis. They have considered them in relation to the Scottish Service Model for chronic pain and evidenced by SIGN 136 (23) and ‘Quality Prescribing for chronic pain’ (13). For more information please see Richardson *et al* (10).

## **3.5 Conclusions of the epidemiological needs assessment**

Based on available evidence, the estimated number of people with moderate to severe chronic pain in Scotland is between 562,000 and 773,000. How many people access services is unknown and needs to be evaluated. A diverse range of self-management resources exist both online, in hard copy and through face to face sessions. Uptake of some online resources is high, access to third sector or patient run face to face self-

management varies both between and within boards. Uptake of courses is relatively low and support groups have varying numbers of members, and attendance starts often when patients are quite far along in their patient journey. However once engaged course completion is high and members may stay engaged for a long time. Keeping in mind that patients live within family and community settings and their engagement with self-management will be influenced by the sympathetic and supportive nature of these environments.

A range of self-management resources should continue to be available and health care professionals should regularly signpost patients to these, so that they can engage with them as soon on the patient pathway as possible. If patients are not able to access support systems, there needs to be innovation e.g. through further utilisation of technology, maximising the use of the range of long term condition groups. Greater encouragement is needed among some professionals to enable them to be comfortable and confident introducing self-management into primary care consultations. This helps improve shared decision making in consultations, in line with Realistic Medicine.

The only currently available routine primary care data related to chronic pain is on analgesic prescribing. This will improve when the chronic pain Read code is regularly utilised and SPIRE is in place. Prescribing varies within and between boards, not all of which will be accounted for by difference in board populations demographics, therefore implying there must be some sub optimal use. Suggesting that there is room for improvement in the frequency of medication reviews, in line with SIGN guidance. Furthermore with the high levels of comorbidity among the population, along with the high cost of analgesic prescribing, an emphasis on the consideration of polypharmacy and effective prescribing is needed. The lack of data on other primary care interventions, for example physiotherapy or access to counselling sessions, could be hiding good practice and / or unmet need.

The majority of patients with chronic pain do not need to access secondary care services, managing with support through self-management and primary care. The rate of new patients seen within secondary pain clinic varies by board, as does how long they have to wait for their first appointment. This is influenced by the patient pathways in the board and the capacity and configuration of secondary care services, resulting in a postcode lottery for patients. Currently boards do not routinely report waiting times for their return appointments, however within secondary care services patients can access different types of care from different professionals appropriate to their needs. Whilst it would not be possible to capture this complexity in a single statistic, a clearer general understanding of service pathways open to patients would highlight inequalities in provision, for example that some boards are able to provide pain psychology clinics and others are not, the corporate needs assessment and appendices look at this further. The QPIs suggested by Richardson and colleagues (10) would cover several dimensions of service provision.

Tertiary services are provided at a regional or national basis. There is variation in referral to the new SNRPMP, but now all board areas have had one or more patient referred to the service.

## 4 Corporate Needs Assessment

The methodology for the corporate needs assessment can be found in [appendix 4](#). It consisted of key informant interviews with a representative from each NHS Board. The results are structured around the Scottish Service Model for Chronic Pain, highlighting service provision and set up at each level and within level 3, secondary care, enablers and barriers to change are discussed. Individual records of chronic pain service provision for each board can be seen in [appendix 5](#).

The corporate needs assessment could have included interviews with patients also. The lack of direct patient involvement is a limitation of this study. However with such a large patient group, with such diverse experiences of chronic pain, it would not have been possible to get representative perspective. Instead engagement with third sector organisations in relation to their data, and other key pieces of work involving patient representatives, has been drawn upon. We encourage locally that there be engagement through existing mechanisms which will guide /support local needs assessments.

### 4.1 Level 1 - Self-management

#### **Self-management information**

There are a range of information resources available, from relevant texts in libraries, to third sector websites, to health service created information leaflets. NHS GGC has a dedicated pain website with information for patients and clinicians. Individual clinicians may have more or less knowledge of what is available nationally and locally. There had been a national website that included self-management support and information ([chronicpainscotland.org](http://chronicpainscotland.org)) but this is no longer functioning.

#### **Self-Management groups**

As shown in the Epidemiological Needs Assessment ([section 3.3\(i\)](#)), different boards have different service provision of self-management groups. Boards also had different levels of interaction with self-management groups: from running them themselves; to giving presentations at patient organised sessions; to referring patients to a Third Sector Organisation, who they may or may not have a service level agreement with, who organised and led the groups. Positive relations or perspectives of the groups encouraged clinicians to refer patients to the service.

Secondary care clinicians mentioned patients being more willing to attend self-management groups if they actively promote them. Although the hope would be that patients were familiar with them and ideally engaging in them prior to getting to secondary care. Some felt that the influence of peers was far greater than their input as to whether a patient would attend a self-management group.



NHS boards can cover very large geographical distances, or be set on multiple islands, or even for smaller boards require some patients to have convoluted journeys utilising multiple buses or trains to get to the hospital setting. These journeys could be made even more difficult by the patient having chronic pain. Therefore the location of self-management groups was key, and having several different locations improved access. For example NHS north Highland chronic pain patients are now directed towards the long term conditions (not specifically chronic pain) groups which are available in multiple locations. Similarly timings of groups will influence who is able to attend. There was some discussion of the value of more generic long term condition approach to self-management and that it did not need to be specific to chronic pain, as that could be a component within the remit.

## **4.2 Level 2 - Primary care**

The interviews were conducted with staff mainly based in secondary care therefore insights into primary care are limited and from the vantage point of secondary care. During the period of government funding boards had SIGs, which in general would have had representation from both primary and secondary care. For the majority of boards SIGs have now disbanded.

In most boards there was a separation between level 2 and 3 services, with the exception of Fife, which has an interlinked primary and secondary care service.

It is recognised that it is difficult to deal with chronic pain in individual short consultations, and that different professionals can have different roles in helping patients.

### **Physiotherapy**

Within the community setting, several boards reported the work of MSK Physiotherapists in relation to treating persistent pain. Within Fife those Physiotherapists provide a patient education programme.

### **Pharmacy**

There was varying degrees of involvement with community pharmacy, from minimal to educating a small group of pharmacists through the 'teach and treat' which emphasises reducing opioid use and increase awareness of self-management, to NHS Fife who has pharmacy as part of their integrated primary and secondary care pain service.

### **General Practice**

Similarly with general practice there has been an emphasis on voluntary education through continuing professional development (CPD) sessions, but in some boards a few GPs or practices have expressed a special interest in chronic pain and have been upskilled, to act as champions or hold clinics. Within NHS Highlands one practice runs its own PMP in conjunction with a Physiotherapist.

### **Other professions/services**

No board mentioned community Occupational Health in relation to pain management. One board reported having mindfulness classes available in the community, for more information see [appendix 2](#), and another mentioned links to weight management classes.

### **Referrals**

From primary care typically GPs and in some boards MSK Physiotherapists can refer into secondary care chronic pain services, and this referral is through SCI-gateway. SCI-gateway has the ability to have specific questions asked within it, or links to relevant documentation or guidance. The extent to which this is utilised varies by and within boards. Some boards have blank referral forms within SCI gateway, others are more structured with specific questions. It has the potential to highlight other interventions/referrals to other services that patients might benefit from prior to/instead of referring to secondary care. GPs may have access to referral criteria on another platform. However when questions are provided GPs may / may not be able to complete this information. One board, after initial resistance, has instigated GPs getting patients to complete a questionnaire and include it with the referral. However from a primary care perspective having different forms for different services could be challenging to complete in practice, under time stretched conditions.

Secondary care can also receive referrals from other medical specialities, typically this is just through a letter, which may or may not have sufficient information to assess the patient.

### **Training**

Secondary care report provision of training and resources to certain staff, to up-skill them. This will have required time and commitment from both the primary and secondary care staff. The provision of tailored information or consultation structuring resources may be welcomed, however they need to be normalised into use in practice, and if these are hard copy resources then they need to be distributed/printed off and kept up to date.

There are links between secondary care services with specific interested individuals/practices, most of whom will have gained some additional training. However this has the implication that there is variation in service provision within the boards. Although for the populations that those individuals serve fewer may need to access secondary care as their needs are being met in the community. Linking into existing primary care networks, either virtual or physical may expand the scope of the interventions.

Recognise that chronic pain is one of many competing priorities and individuals may not have capacity to attend chronic pain related sessions, or be able to attend evening sessions. Frequently GPs require locum cover to attend education sessions / service

improvement meetings, this can be difficult to cover and can have a cost attached which might not be able to be met.

### **4.3 Level 3 - Secondary care**

#### **Vetting of patients**

Different services have different vetting and triage processes. From individual Senior Nurse or Anaesthetic Consultants reviewing referrals and deciding whether they should be seen and which professional group they should be initially seen by, to the MDT examining them together and making a joint decision. As mentioned before depending on the referral process the clinicians will have varying amounts of information to base their decisions upon. However the reality may be that the majority of new patients are seen by the medical consultant in the first instance anyway.

Another area of variation in the process is whether patients are asked to fill in a questionnaire prior to an appointment. Some services do not require a questionnaire to be completed, others request they bring a complete questionnaire to the appointment, or ask them to complete it in the waiting room, and others require a questionnaire to be completed to enable a patient to have an appointment. Questionnaire content and length is variable. Having questionnaire data early on can assist with the vetting process and provide information for the initial consultation.

Some boards are able to provide (some of) their services in multiple locations, to improve access.

#### **Ideology of the service**

It was clear when speaking to different services that there was a variety of perspectives around pain treatment and management. These were from medical models with an emphasis on medical interventions, to mixed models that have the opportunity for both medical interventions and PMPs, to more bio-psycho-social models where self-management was emphasised.

#### **Multi-disciplinary make-up of the secondary care team**

The perspective of the service is inevitably influenced by and influences the composition of the secondary care team. Make up of service staff was not uniform (Table 10). With the exception of the Western Isles who are accessing Chronic Pain Specialist Consultants via NHS Grampian, all boards had a medical consultant in the team. The majority of boards had a Physiotherapist, the majority had access to a Psychologist and most had a Nurse. However pharmacy input was variable, as were links to addiction services, only two boards reported an Occupational Therapist on the team. Number and diversity of staff discipline was in part influenced by board size. Staffing was the biggest concern for most boards (see Table 10).

**Table 10: Disciplines included within secondary care pain service, by board**

	NHS Ayrshire & Arran	NHS Borders	NHS Dumfries & Galloway	NHS Fife	NHS Forth Valley	NHS Grampian	NHS Greater Glasgow & Clyde	NHS Highland (North)	NHS Highland (Argyll & Bute)	NHS Lanarkshire	NHS Lothian	NHS Orkney	NHS Shetland	NHS Tayside	NHS Western Isles
Medical Consultant Anaesthetist/Doctor	x	X	X	X	X	X	X	X	X	X	x	X	X	X	
Physiotherapist	x	X	X	X	X	X	X	X	*	X	X	*	*	X	X
Psychologist	x	X	X	X	X	X	X	X		X	X	*	*	X	
Nurse	x	x		X	X	X	X	X	X		X	*		X	
Occupational Therapist		X		X					*						
Pharmacist	*	*		X	X	*	X/*		*				*	X	
Psychiatrist		*			X	X		X			X/*				
Addiction team	*	*			x		*	X			X(Psychiatrist above)			*	
Other	Associate specialist			Nursing assistant	Health care assistants	Pain Fellow, health care assistant, others specialty doctors*									GP with Special Interest, non-chronic pain Anaesthetist*

X= member of team, \*assists on ad hoc basis/informal links

Source: Interviews

## **Pain Management Programme (PMP)**

The services the team were able to provide are summarised in the individual board service tables in [appendix 5](#). However there has been a move to increase access to PMP. Currently PMPs are run in 10 of 14 boards, with the island boards, one smaller board not having one, and provision in only North Highlands. Courses vary in their length, with a half day over 7 to 12 weeks, and location (either hospital or community), but always had physiotherapy and psychology input, and sometimes pharmacy and/or nursing. PMPs can have a standard programme, or can vary, being tailored to certain groups/needs. Potential participants are assessed for suitability prior to starting, with the exception of NHS Borders who invite a range of patients and enable them to self-select their attendance through coming to an information session first and then deciding if they want to sign up to the PMP([appendix 5](#)). Patients can be entered into a PMP early in their contact with the pain service e.g. in NHS Borders it is an 'intervention of first resort', too much later when other avenues have been pursued and dismissed.

A couple of boards have non-group pain management options, for example NHS Highland has telephone support for a workbook based intervention. Four boards, including two of those without a PMP have access to Pain Association Scotland intensive courses (see Epidemiological Needs Assessment [\(section 3.3\(i\)\)](#)).

A barrier to uptake can be patients not (at that point) being accepting of a self-management approach, rather wanting to be 'fixed'. Patient expectations were viewed to be influenced by the patients' personality, experiences of friends and family. This can also be compounded by other health care professionals sending patients to the Pain Clinic 'to be sorted out'. It was reported that once patients had accepted their pain was chronic, it was then easier to move forwards with managing the pain.

### ***Medical and nursing interventions***

Services were able to offer different procedures / treatments in line with the staffs' professional skillset. Some upskilled AHPs enabled this provision to expand (see examples in [appendix 2](#)).

### ***Patients' expectations of the service***

Different boards do different things to inform patients what to expect of the service prior to their first appointment. Some boards provide educational sessions prior to the initial appointment (Epidemiological Needs Assessment [\(section 3.3\(i\)\)](#)), other boards provide information leaflets, and another assess expectations through initial telephone triage appointments.

### ***Links to addiction services***

There was disparity between boards as to what was available in relation to chronic pain and substance misuse. Some secondary care services had joint chronic pain and substance misuse clinics in secondary care, others had informal links to addictions

teams, or had greater pharmacy input in the community, and in some boards there was less emphasis on this area.

One interviewee discussed when considering medication being specific about trialling the therapy for a set period of time, with active markers of success and discontinuing the medication if these were not met. The importance of a strategy for withdrawal was also emphasised, recognising that this can be difficult, the patient will require support and this could be time consuming for primary care.

### **Enablers and barriers to change in secondary care pain services**

The main enablers and barriers to service change that staff within pain services reported are summarised in Figure 13 the forcefield analysis<sup>12</sup>. The most consistently cited enabler and barrier was staffing. Boards reported having difficulty filling staff vacancies, which puts pressure on existing staff and reduces the resilience, sustainability and continuity of the service. Difficulties recruiting staff was thought to be influenced by chronic pain not appealing to anaesthetist trainees, and AHPs not having specific training schemes related to chronic pain. However, the flexibility of staff was a great enabler of service change, for example, a number of boards mentioned nurse or physiotherapy staff becoming prescribers and that opening up opportunities (see [appendix 5](#) (NHS Shetland & A&A examples)). Or when a vacancy becomes available use it as an opportunity to restructure the workforce, e.g. replacing an anaesthetist with an AHP.

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<sup>12</sup> Based on Kurt Lewin's Force-Field Analysis Change Model

Figure 13: Force Field Analysis: Change within Chronic Pain Services (relevant to other areas also)

### Enablers (driving forces)

Staff enthusiasm and willingness to change

Flexibility of staff role

Good communication with whole system

Funding: creativity & cutting where can

IT/data literacy

Government targets

Knowledge of and control over tools

Service  
change  
in  
Chronic  
Pain  
services

### Barriers (restraining forces)

Limited time/ change fatigue

Limited trained or in-training workforce

Lack of buy-in from other services/staff

Funding – lack of/delay

Data – unusable/not collected

Government targets

Practicalities e.g. suitability of clinic location

#### **4.4 Level 4 - Tertiary care**

NHS boards are able to refer patients to the SNRPMP in Glasgow ([see section 2.4](#)). Their motivation to do this will be influenced by whether they provide their own in house PMP and feel that it covers what the national programme would cover, whether individual patients are better able to access a residential course, and whether they see the value in a PMP/it is something they consider for patient care.

NHS GG&C, NHS Grampian, and NHS Tayside all have specific specialist services ([see section 2.4](#)), their availability to other regions is variable. NHS Lothian gave the example of pelvic pain specialist service, however this is not open to other boards.

#### **4.5 Conclusions of the corporate needs assessment**

The current Scottish Service Model for Chronic Pain is holistic to reflect the diversity of developments over time and is not prescriptive in how it should be delivered. There are varied service pathways and set ups between boards. This has resulted in different treatment options being available for patients depending on where they live.

There was variation in whether self-management information tailored to the local area was available. Resources should be available in a range of accessible formats and languages. An easily accessible unified website presenting these resources to patients and professionals would be helpful.

Patients with chronic pain are likely to access primary care, however between and within boards there was different access to professionals who are up-skilled in relation to chronic pain. Different initiatives have been run by boards to increase staff confidence and ability in this area, such pilots that have evaluated well should be expanded upon. With the creation of SIGs will have enhanced relations between primary and secondary care, but now that most boards have disbanded SIGs that link is likely to have weakened. Embedding primary and secondary cross working as part of long term conditions would be valuable.

Secondary care Pain Service teams were made up of different staff disciplines, provided different treatment options and so had difference in service provision. Each team should have timely access to appropriately trained staff from all the disciplines outlined in the minimum standards recommended by the Faculty of Pain Medicine. Variation in service provision was particularly stark for remote and rural services, who could benefit from connection between themselves or with other larger services, to access the full breadth of the MDT, as achieved through the linking of the Western Isles and NHS Grampian. Another area of disparity was links with addiction services which is a problem now and will increase even further in importance given the trend of increasing prescribing of addictive analgesics.

Since the 2004 McEwan report there has been calls to improve chronic pain services. Whilst there has been changes, there is still room for improvement. Whilst different



services have different challenges, common themes that enabled or prevented change were cited, with having a sustainable workforce being paramount. Improving recruitment into existing training schemes, providing training opportunities to upskill AHPs, as well as examining alternative models e.g. enabling other medical disciplines into chronic pain, is needed to ensure there are sufficient appropriately trained staff from all disciplines, so that services can continue to operate and provide a multidisciplinary service.

## 5 Recommendations

The recommendations presented here are organised within the context of the tiered model of service described above.

### 5.1 General

Making rapid progress in developing and improving service provision across Scotland presumes that service commissioners and providers have access to accurate baseline information. As this report shows, such data is not currently available. It is recommended that Scottish Government require NHS Boards to report on the number of people who have sought and who are accessing NHS services for chronic pain management by type of service. Increased utilisation of the chronic pain Read Code in primary care will help with this. Such data should also assess associated measures of health and/or outcome. As far as possible, such data collection should be based on the use of routine health data, rather than relying on special data collection exercises.

### 5.2 Level 1 – Self-management

#### Self-management resources

In developing local self-management resources, NHS Boards and their Integration Joint Boards should draw on the existing wealth of self-management / long term conditions resources already in existence. Not only will this facilitate rapid progress whilst also allowing account to be taken of factors such as other co-morbid conditions and symptoms that require management.

All providers of Pain Services (Level 1 to 4) must provide quick and easy access to educational material that informs about, and supports self-management of chronic pain. This may include leaflets, posters, library books and pointers to recommended online resources. These should be developed on a “Once for Scotland” basis.

Ensuring all resources are available online and provided through a well-regarded and quality assured website such as NHS Inform. Such a development should take into account the recommendations of the Digital Health and Care Strategy for Scotland.

#### Provision of self-management support

It is recommended that in NHS Board areas where:

- there are currently no self-management groups, courses or education sessions, one type of face to face support is established;
- there is inequitable or limited access to these groups, that provision expanded using a range of approaches. This could include broadening digital access, especially in remote geographical areas; and
- there are a range of groups and differing approaches to service provision, that care is taken to ensure that the service(s) meet population needs, are effective, and that duplication of service is minimised.

### **5.3 Level 2 – Primary care**

#### **Promote self-management during consultations**

If the resources described above are to be of use, NHS Boards should ensure there is quick, reliable, and realistic access by primary care team to materials and tools to support self-management by their on behalf of their patients. In this regard, supporting the use self-management toolkits such as the 'Pain Toolkit'(28), Forth Valley's 'local pain toolkit' and 'My Support Plan', or the toolkit which is being currently developed by Pain Concern could be helpful.

NHS Boards should also support reliable access to other forms of non-pharmacological management of chronic pain, including psychological and talking therapies (online courses including under supervision).

#### **Improve recording of chronic pain and self-management**

Chronic Pain should be routinely recorded in Primary Care staff using the specific Read Code. Appropriate support to implement this change in practice should be agreed as part of NHS Board e-Health activities.

Primary care teams should be encouraged to record all forms of pain management, including self-management approaches, as part of routine patient records. This will allow the team to understand what approaches have already been explored and ensure that the overall patient pathway can be discussed and supported in future consultations.

#### **Prescribing reviews**

Regular reviews of individual prescribing for chronic pain are essential for safe, rational and effective treatment. Any patient receiving regular analgesic prescriptions must have these reviewed in line with guidance. NHS Boards should have a review strategy that outlines responsibility for conducting the reviews.

In developing the necessary capacity to carry out prescribing reviews, NHS Boards should explore what opportunities there are for up-skilling pharmacy staff through programmes such as 'teach and treat'. Support will be particularly required around discontinuation of medicines that are not working.

Nationally, considerations should be given to the introduction of a QPI (10) for medication reviews and the requirement to report progress. Such an approach would enable improvements between NHS Boards to be benchmarked.

#### **Improve referral to secondary care including development of a standard referral pathway**

Ensuring effective referral to Specialist Pain Services is essential. All such services, at whatever stage of development, must have clear criteria to support appropriate

referrals and specify what information is required to support the referral. Wherever possible, such requirements should be included on SCI-gateway.

Consideration should be given to developing an agreed care standard for referral between primary and secondary care to access Specialist Pain Services, in line with the recommendations of the Faculty of Pain Medicine (24).

### **Training for primary care staff**

Chronic pain is the responsibility of every health care professional in primary care and so all health professionals should ensure they have a basic understanding of pharmacological and non-pharmacological interventions is needed. Chronic pain can be learned about in relation to multi-morbidity and long term conditions. NHS Education Scotland should explore how best to ensure that all healthcare professionals should receive at least basic training in the principles of pain management. Chronic pain should be covered as part of the pre-registration training (a guidance document on approaching this can be found in The British Pain Society, Pre-registration Pain Education: A Practical Guide to Incorporating Pain Education into Pre-registration Curricula for Healthcare Professionals in the UK (63).

## **5.4 Level 3 – Secondary care**

### **Specialist Pain Service Provision**

Each NHS Board must ensure adequate provision of, or access to, a multi-disciplinary pain service, with sufficient and appropriately trained clinicians representing all the relevant disciplines. The minimum standards for such a service are set out in recommendations by the Faculty of Pain Medicine. This service should be accessible to all patients, in person and/or through remote access, with waiting times between referral and appointment, and between first and subsequent appointments, that are appropriate to address the needs of patients. All such services should meet the QPIs, once these are agreed nationally.

### **Improve access to services**

NHS Boards should ensure that Specialist Pain Services are included in all their approaches to improve access to health care services. This will include exploring how access to services may be maximised through more distributed models of care across existing NHS boundaries, increasing telehealth options, or service restructuring.

### **Intervention guidance**

HIS should consider facilitating the development of nationally agreed guidelines for pain relieving, repeated interventions, where there do not yet exist. These should not only include criteria for treatment initiation, but also criteria for successful pain relief and, therefore continuation/discontinuation.

### **Quantify potential future workforce and take action accordingly**

To support the development of Specialist Pain Services, NHS Workforce Planning Teams should develop a dedicated workforce plan. This must be informed by the UK

Faculty of Pain Medicine standards around the number and diversity of professionals needed for a pain service<sup>13</sup>

In relation to specialist medical training, there is some urgency for this given the need to manage succession for the existing pain specialists and the current lead time to train anaesthetic sub-specialists. In view of this, urgent attention needs to be given, at national level, to alternative methods of creating a broader, clinical workforce trained in pain medicine and management. Whilst not specific to chronic pain, all workforce planning must address the challenge of staffing remote areas.

NHS Education Scotland should explore how best to ensure that all healthcare professionals should receive at least basic training in the principles of pain management. Chronic pain should also be covered as part of the pre-registration training.

More broadly, professional development support for AHPs not formally employed within a Level 3 pain service should be extended, drawing on the work which has already been progressed for Nurses, with differentiation between roles based on both education and experience working in pain services (24).

## **5.5 Level 4 – Tertiary care**

NHS Boards should collaborate to ensure that access to Level 4 services is equitable, irrespective of the Board area where the patient resides or is being managed. Where this relates to services commissioned by NHS National Services and Screening Directorate, national criteria for referral and measurement of outcome need to be agreed (as already happens for neuromodulation, and for the national residential service).

Scottish Government should ensure that the national and regional NHS service planning and commissioning arrangements are responsible for long-term planning for the provision of these services, as well as for further development in light of emerging evidence of effectiveness, or in relation to the development of new techniques.

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<sup>13</sup> A specialist pain management service will have at least two consultants who have achieved competencies and experience in advanced pain medicine...”pg 33... [to supply] “peer support and cross cover” pg62 (FPM, 2015). Similarly “specialist pain management services will involve nursing, physiotherapy, occupational therapy and clinical psychology staff. These specialist will have dedicated sessional time in the pain management service and attend MDT meetings”pg33. Furthermore “any practitioner working single-handedly because of remote location must maintain formal links with colleagues/peers”pg33.

## List of Appendices

[Appendix 1: Scottish Service Model for chronic pain \(2011\)](#)

[Appendix 2: Examples of local good practice](#)

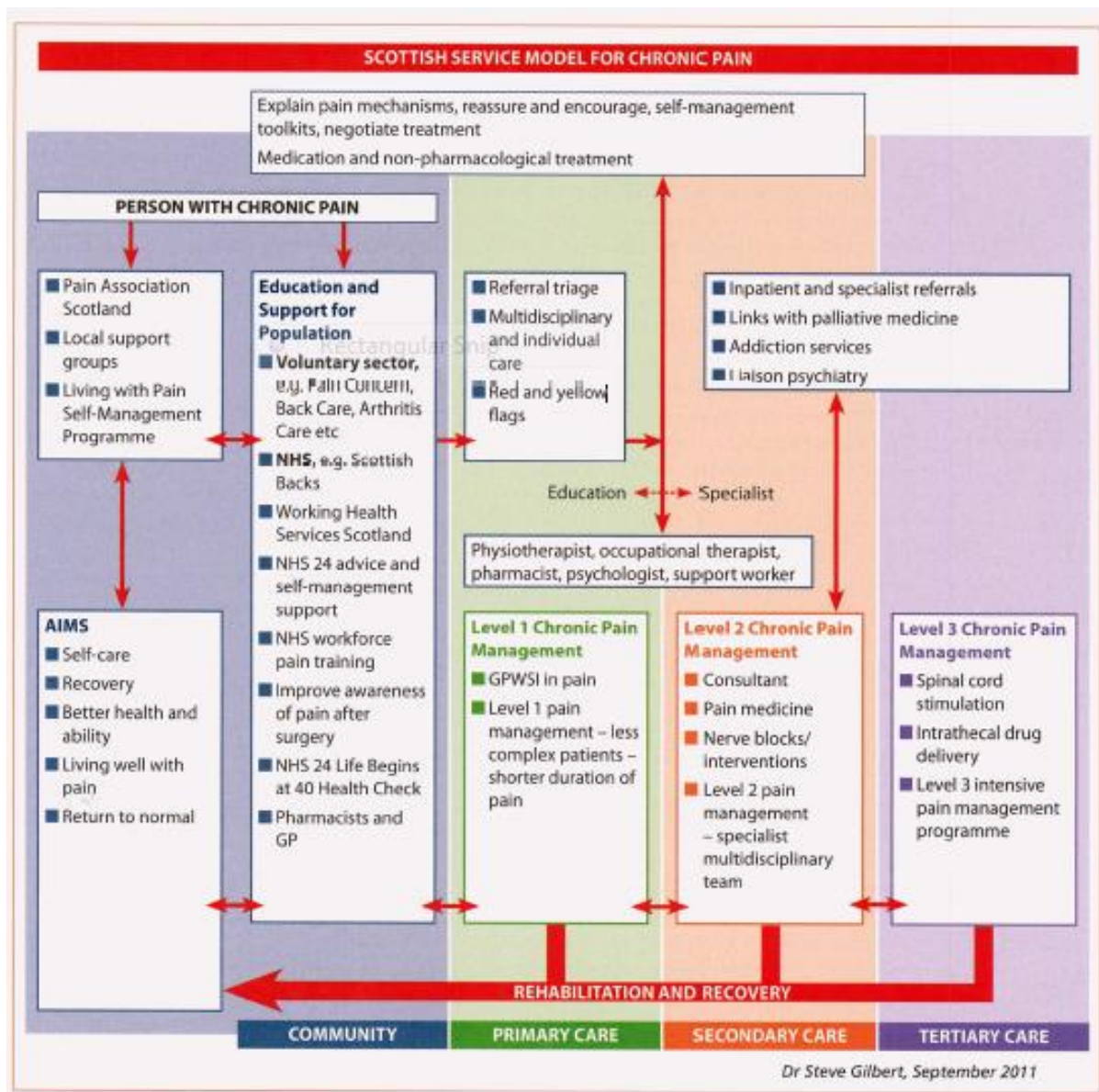
[Appendix 3: Methods for the Epidemiological Needs Assessment](#)

[Appendix 4: Methods for the Corporate Needs Assessment](#)

[Appendix 5: Service provision tables for each NHS Board](#)

## Appendix 1: Previously used Scottish Service Model for Chronic Pain (2011)

(Please see [Figure 3](#) for model currently in use)



(Source: Scottish Service Model for Chronic Pain, NHS Education for Scotland, 2011, cited in Gilbert et al, 2014 (27))

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