

# Getting to GRIPS with Chronic Pain in Scotland

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Getting Relevant Information on Pain Services

Benchmarking Chronic Pain Services in Partnership with NHS Boards, Patients and Service Providers

Second edition July 2008

This report is a summary of all the information we collected. Full details can be found on our website [www.nhs.healthquality.org](http://www.nhs.healthquality.org)

NHS QIS is committed to equality and diversity. We have assessed this report for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. For a report of the equality and diversity impact assessment, please see our website at [www.nhshealthquality.org](http://www.nhshealthquality.org). The report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.

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## Foreword to the second edition

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### Nicola Sturgeon, Cabinet Secretary for Health and Wellbeing

The fact that this report is going into a second print-run gives me the chance to contribute a Foreword setting out the Scottish Government's response to the content of the report in general, and to the recommendations directed at the Scottish Government in particular.

I fully understand the degree of frustration that pervades the whole of this report. It makes the telling point that 5 previous reports on chronic pain services have been commissioned since 1994, each drawing attention to services that are inadequate and patchy. Very little has changed since 1994, except that the need for these services is greater than ever. Part of the frustration stems from a lack of national commitment that recognises chronic pain as a key area of work for NHSScotland. I have expressed my determination that that should change. I want to see all of the recommendations in the GRIPS report implemented. It gives us a clear sense of direction for moving things forward.

From my meetings with people who are living with chronic pain, I take the message that what counts most is having their pain recognised, and to be cared for by professionals who project a sense of empathy, and of optimism that the pain can be managed. The Scottish Government is happy to play its part in that process by accepting the recommendation that chronic pain should be recognised as a long term condition in its own right. Such recognition aligns very clearly the work on chronic pain management with the work we're doing, in partnership with the Long Term Conditions Alliance Scotland, on the management of all long term conditions.

There has also been a recognition for some time that services for chronic pain would benefit from a Managed Clinical Network approach, and I am pleased that this is now being put into practice in NHS Greater Glasgow & Clyde. The Network wants to establish links across the country to develop a generic template for pain MCNs. I would strongly encourage other NHS Boards to co-operate with this initiative and adopt such an approach in their area.

NHS Quality Improvement Scotland has indicated its commitment to working with other agencies to take forward implementation of the full range of work set out in the GRIPS report. I applaud their determination to do so, and I welcome their offer to report to the Chief Medical Officer's long term conditions steering group on an annual basis on progress with the chronic pain work programme.



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



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## Foreword and Acknowledgements — NHS Quality Improvement Scotland

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This is not the first report on Chronic Pain Services in Scotland. In 1994 the then Scottish Office published 'The Management of Patients with Chronic Pain'; in 2000 the Clinical Standards Advisory Group published 'Services for Patients with Pain'; in 2002 a SPICE (Scottish Programme for Improving Clinical Effectiveness in Primary Care) report on pain services was published; and in 2004 the Scottish Executive published the 'McEwen Report' on Chronic Pain Services in Scotland. All four reports have three things in common: they provide comprehensive information on pain services in Scotland; they report on the enthusiasm and commitment of the staff providing these services; and they highlight that current provision is inadequate to meet the need, that services are unequal between and within boards and that few services achieve comprehensive and seamless care. Despite these reports, which include constructive recommendations, very little has changed since 1994 and if anything, the need for these services is greater.

NHS Quality Improvement Scotland (NHS QIS) was approached by representatives from the Royal College of Anaesthetists, the Cross-Party Group on Chronic Pain, the North British Pain Society and by a range of healthcare professionals and patients all asking whether we could together act as the catalyst that would bring about change. We have worked with all these groups and individuals, and with NHS Boards and we thank them sincerely for their openness and support during the preparation of this report. In particular we acknowledge the work of Janette Barrie who has co-ordinated this project from start to finish.

Together we have delivered the most comprehensive stocktake of chronic pain services ever produced and we have reported from every perspective: that of the patients, that of the healthcare professionals providing services; and that of the NHS Boards responsible for strategic planning, funding and delivery of the services. The messages are stark and the actions are clear. We need to stop talking about what is not working and start improving these services as a matter of priority. With 'Better Health, Better Care' and the Scottish Government's Long Term Conditions Alliance we have never had a better opportunity to make a difference and we hope this report will indeed light the touch paper of improvement and change.

David Steel, Chief Executive NHS QIS

Jan Warner, Director of Patient Safety and Performance Assessment

## Key Findings

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- Despite four nationally commissioned reports in the last ten years and data from surveys indicating high prevalence (18% of Scottish population), chronic pain is not recognised as a 'condition' and is not currently included in the key long-term conditions to be addressed by the Long Term Conditions Alliance. As a result, it is not regarded as a priority by Scottish Government Health Directorates (SGHD) or by NHS Boards. (Priority Action 1)
- The provision of chronic pain services within Scotland is patchy and fragmented particularly for core secondary services. Service provision and access to services varies considerably between and within NHS Boards and we found little evidence of needs assessment or strategic planning for chronic pain services. Very few NHS Boards have dedicated funding streams for these services. The quality and effectiveness of these services is rarely monitored. (Priority Action 2 and 6)
- None of the NHS Boards could provide a complete or accurate description of the chronic pain services provided, or of the resources available to provide them. (Priority Action 2)
- There are significant discrepancies between the descriptions of available services as reported by NHS Boards and services actually provided, as reported by healthcare professionals and service users. In the main, clinicians providing services did not recognise and could not reconcile actual service provision with the service provision reported by NHS Boards. (Priority Action 3)
- Some information was available on services provided in the secondary care sector but very little feedback was provided on primary and community healthcare services although we are aware that most patients are cared for in this setting. (Priority Action 3)
- Access to specialist services is limited, with GPs often reluctant to refer and waiting times are long. (Priority Action 2)
- There is a general lack of knowledge about chronic pain and awareness of treatment options and services in NHSScotland. (Priority Action 4)
- Very few Boards offer pain management programmes (PMP) and very few patients have access to these. (Priority Action 5)

## Priority Action Points

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### **Priority Action 1**

Scottish Government to designate chronic pain as a condition in its own right, welcome the inclusion of chronic pain on the agenda of the Long Term Conditions Alliance and support uptake of Managed Clinical Networks (MCN) in Chronic Pain

### **Priority Action 2**

NHS Boards to develop core secondary services, clear referral pathways from primary care to secondary care chronic pain services, and for tertiary services such as Spinal Cord Stimulators (SCS), Intrathecal Drug Delivery (IDD) and Pain Management Programmes (PMP). These should take into account the administrative reforms recommended by the McEwen Report, Chronic Pain Services in Scotland, 2004 and will support the development of chronic pain services at Managed Clinical Network and Community Health Partnership (CHP) level

### **Priority Action 3**

Information Services Division of National Services Scotland to develop and roll out a minimum data set with associated monitoring reports through the Core Data Set Group based in the Information Services Division and aligned with the eHealth strategy. This must be aligned with the Scottish Government's (SG) long term conditions toolkit

### **Priority Action 4**

NHS Quality Improvement Scotland to build on NHS QIS Best Practice Statement and NHS Education for Scotland to develop and roll-out a competency framework based on a training needs assessment

### **Priority Action 5**

Scottish Government to review current SG funded provision of Pain Management Programmes provided outwith Scotland and consider investment in the development and provision of Scottish regional and local pain management programmes, including a residential facility for patients unable to attend as outpatients

### **Priority Action 6**

NHS Quality Improvement Scotland to consider the development of clinical standards for secondary care chronic pain services

## Introduction

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'Chronic pain management is probably one of the most challenging problems in medicine today. Its origins, assessment and treatment are complex. Chronic pain is a debilitating condition. Its prevalence is known to be widespread and it is a major claim on health care resources and the national economy' (Scottish Office, 1994).

'The lives of one in five people are disrupted by pain on an almost daily basis'. (Breivik et al 2006)

### Our Starting Point

Chronic pain affects nearly 8 million people of all ages in the UK and 25% of those diagnosed are unable to continue working as a result of this. We spend nearly £4 billion every year on incapacity benefit payments to those diagnosed with the condition and chronic pain is one of the most common reasons people seek medical help. Over 4 million GP appointments are made every year by people seeking help and relief from chronic pain and in many cases, they leave without answers and without effective pain relief. This leads to further appointments, further frustration and further despair.

The International Association for the Study of Pain defines chronic pain as 'pain without apparent biological value that has persisted beyond normal tissue healing time' (3 months). Traditionally chronic pain has been viewed as a symptom of another condition and not a medical condition in its own right. Consequently there has been a long-term lack of investment in chronic pain services and their development, including undergraduate training, specialty recognition and funding. Many approaches to pain management have been short-sighted and access to specialist services remains low: only 3% of people in Scotland living with chronic pain currently use these (Breivik et al 2006).

### Our Building Blocks

The spotlight was first trained on chronic pain services in 1994 when the Scottish Office published 'The Management of Patients with Chronic Pain'. In 2000, a further report was produced on 'Services for Patients with Pain' (Clinical Standards Advisory Group), and in 2002, a SPICE report was prepared for the Scottish Parliament, giving an overview of services in Scotland. These reports found there was much to build on in Scotland but that the organisation of and access to pain services was patchy and inequitable (Currie 1994, CSAG 2000, SPICE 2002).

The Scottish Parliament set up a cross-party group for chronic pain in 2001 with the aim of raising the profile of chronic pain and acknowledging the impact it has on people and their lives. It includes patients and a wide range of health professionals united in their desire to see these services funded, developed and accessible to all who need them. They were concerned that despite the recommendations made in each of the three reports referred to above, little progress has been made and in response to their concerns, the Scottish Executive commissioned a further review of these services which was carried out by Professor James McEwen in 2003 (McEwen 2004).

'There is a universal view that current provision is inadequate to meet the need, that services are unequal both between and within boards and that few services attain the ideal of comprehensive and seamless care'.  
(McEwen, 2004)

McEwen found that there was tremendous professional enthusiasm and commitment and that many early pain services had been started by an individual who, irrespective of clinical background, had been aware of the needs of those with chronic pain and had worked to set up a service to meet these needs. Many of these services depend on goodwill and there is a growing professional drive to match this with the necessary resources. He confirmed that while all boards do have some provision for pain services, few provide a comprehensive service and even fewer include these services in their strategic planning frameworks.

Since the publication of the McEwen report there have been four further key developments:

1. 'Delivering for Health' (SEHD, 2006) set out the strategic vision for health services in Scotland and focuses on a shift from hospital based care to community based services that are preventative and anticipatory, delivered as close to people as possible. Long-term conditions were identified as one of the main strands of this strategy.
2. The Long Term Conditions Alliance has been set up by the Scottish Executive and provides a strategic forum for the development and monitoring of services. It involves all the key partners.
3. Scottish Government support for the development of a pilot Managed Clinical Network for chronic pain.
4. The publication by the new Scottish Government of 'Better Health, Better Care'. This document builds on 'Delivering for Health' and again focuses on long-term conditions and on reducing inequalities in health across NHSScotland.

The priority now is to move from talking about what is not working in the provision of chronic pain services to improving the quality of care provided. In response to this, NHS QIS put in place a programme of work aimed at:

- building on existing information to inform the planning and development of services
- locking chronic pain services into current strategic initiatives
- developing practice to support healthcare professionals in delivering these services
- supporting the development of a pilot managed clinical network, and
- developing standards and reviewing performance against these.

This report addresses the first stage: getting detailed information on the current provision of chronic pain services within Scotland to inform the planning and development of services. The work has been led by a small group representing the Royal College of Anaesthetists, the North British Pain Association and members of the public and has sought to strengthen the findings of existing reports to allow a more comprehensive gap analysis and develop solutions to meet these.

## Our Approach

The overall aim of the project was to establish the current adult Chronic Pain Services provision across primary, secondary and tertiary care in each NHS Board area.

This work has been carried out over a short timescale to maintain momentum. We used a three tier approach based on feedback from:

- NHS Boards on their arrangements for planning and providing chronic pain services
- healthcare professionals of chronic pain services on what they provide
- those using these services on what they receive.

The collective findings from these three perspectives provides a powerful three dimensional analysis of current service provision that has several key themes running through and across each tier. Further, the findings have informed the development of practical solutions to address the themes, gaps and priorities we identified.

## Tier 1 NHS Board

This tier was aimed at in NHS Boards. It involved completion of a self assessment that covered four key issues:

- NHS Board assurance – are chronic pain services included in the NHS Board's strategic planning and what reports does the Board receive on the effectiveness of these services?
- Needs assessment and service planning – how does the Board know what is needed and how does it plan to meet these needs?
- Clinical Leadership and Resources – who leads on these services and what resources are allocated?
- Patient focus and quality improvement – how are patients and carers involved and how does the Board performance manage chronic pain services?

It also involved completion of a self-assessment but this time describing services actually provided as reported by healthcare professionals.

## Tier 2 NHS Healthcare Professionals

This tier was aimed at healthcare professionals providing chronic pain services and the approach used involved regional focus groups with healthcare professionals who refer patients to chronic pain services and who provide these. This included Consultant Anaesthetists, General Practitioners, Nurses and Allied Health Professionals.

## Tier 3 Patient Feedback

To underpin Tier one and Tier two, the patient experience of chronic pain services was captured by holding focus groups throughout Scotland. People who live with chronic pain and service users were identified through a number of organisations and invited to take part.

## Detailed Findings

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### Tier 1 - What the NHS Boards said

The McEwen report recommended NHS Boards adopt a strategic planning role to chronic pain service issues, including accountability, service coverage, planning, investment and patient involvement.

The accountability arrangements across Scotland vary widely. The responses show that the person designated as Board lead clinician and therefore accountable for the local chronic pain services is the Medical Director in 6 NHS Boards, the Nursing Director in 1 NHS Board, the Strategic Planning Director in 1 NHS Board, and a consultant anaesthetist in the States Hospitals Board for Scotland. Four NHS Boards provided no information. However, while most Boards are clear about who is accountable for the service in secondary care, it is unusual in primary care. It is rare for NHS Boards to receive an annual report about the service - indeed, only two Boards stated that an annual report was issued.

While many people with chronic pain are treated in primary care, it is rare to find a Board area reporting specific chronic pain services in the community. It is clear that service provision in the secondary care sector continues to take place at a relatively small number of sites and that population size is not a particularly good predictor of service provision.

Most Boards do not run a Pain Management Programme (PMP), although four Boards have indicated that they have plans to do so in the foreseeable future.

The NHS Boards report that the provision of specific chronic pain clinics remains predominantly in secondary care, with no regional services in place. The profession of the person providing clinics varies in most Boards, however, four Boards reported that they do not have clinics provided by anyone other than a doctor.

Seven Boards reported that multidisciplinary working is operating in their area and that this includes multi-disciplinary assessments of patients. However, of these, only three have protected time for case conferences and planning.

## Strategy and Planning of Chronic Pain Services

There is a wide range of people with responsibility for strategic planning at the Boards, most at Director level.

Some Boards have yet to develop their Long Term Conditions (LTC) strategy but most either have included or intend to include the chronic pain service in it. Only two Boards indicated that this then translates into their Local Delivery Plan (LDP) probably because these tend to focus specifically on Ministerial targets. Few Boards have included chronic pain services in other strategies and only three Boards have produced a specific action plan for their chronic pain services.

In most Boards, the focus for chronic pain services remain within the secondary care sector. Only 6 reported having arrangements for including the chronic pain services in Community Health Partnerships and most their plans for this are at an early stage.

Only two Boards report that they have undertaken a health needs assessment (HNA) within the last 5 years. The arrangements for patient involvement in service development for chronic pain tend to be non-existent, limited or unclear in most Boards.

## Cross Boundary Flow (CBF)

The movement of patients between Boards for the treatment of chronic pain reflects inadequate core chronic pain services in many NHS Boards. While the funding for CBF is based on Service Level Agreements (SLAs) in most Boards, these have an historic basis and no longer reflect current patient flows. Most Boards reported that the local chronic pain services receive no designated funding for the patients they treat from outwith the Board area.

NHS Boards cannot quantify the number of patients flowing into or out of their Board area for chronic pain services. The reported data submitted from NHS Boards could not be reconciled. This represents a considerable gap in some NHS Boards between clinical workload and the funding provided.

Most cross boundary referrals are for core secondary services rather than tertiary services (for example spinal cord stimulators). The number of cross boundary referrals into NHS Boards tend to be fairly small, (ie <50), except Greater Glasgow & Clyde (520). This reflects the presence of geographical adjacent NHS Boards with no or little provision of chronic pain services in secondary care.

In the period 2005 – 2006 over £200,000 (central funding provided by SEHD) was spent on NHS Scotland patients receiving outpatient assessments and in-patient programmes based in England. In the year 2006 – 2007 this figure rose by 13%. This figure excludes travel costs which are met by individual Boards. However, from the information returned it appears only a few patients have been referred to these specialised Pain Management Programmes in England.

## Funding

Most Boards do not provide a separate identifiable budget for their chronic pain service. It is not possible to quantify the amounts involved even where separate budgets are known since these are not always expressed in terms of cost (for example, they may be expressed as whole time equivalents (WTE). Where the budget is known, it is clear that population is not always a good predictor of the amounts involved.

## Chronic Pain Services in Primary Care

Only four Boards reported having specific primary care chronic pain clinics and the number of patients attending these is small. Once again, NHS Board and service provider data do not match. The purpose of the clinics in primary care varies by Board. There are no obvious patterns either in relation to the length of appointments or for waiting times.

Not all clinics were able to provide data on patient numbers so it is not possible to provide an all Scotland figure for patients being treated at these clinics. Only one clinic was able to give details of their total identifiable budget. One clinic was being run as pilot.

Only a few staff are involved with delivering the clinics in primary care and these are all on a part time basis. There do not appear to be any major staffing issues in relation to the current services provided in that no board is reporting either vacancies or long-term sick leave.

Some form of audit or evaluation is undertaken in most boards, although it does not necessarily follow the Quality and Outcomes Framework (QOF) standards for General Practice; it may not be done on a regular basis; and it may not include outcome data.

The use of referral criteria is patchy for the primary care clinics themselves and for onward referral to other services.

## Core Services in Secondary Care

There is variation in the provision of core services between NHS Boards.

For the purposes of this report a chronic pain clinic in this setting is defined as “a clinic seeing patients with chronic pain as their initial presentation only”. This is to be compared with a Rheumatology or Orthopaedic clinic where patients may have chronic pain but are presenting with different medical and surgical problems.

Ten Boards report that they offer chronic pain services across multiple hospital sites. The spread of hospital sites does not necessarily represent population distribution.

## Range of services provided

### Number of clinics per NHS Board per week

It is difficult to quantify the number of different types of clinic because Boards describe their clinics in different ways as shown on the attached disc. Data are also incomplete or not presented in a consistent way for the number of clinics. A table on sessions provided in the West of Scotland has been included in the report and highlights some of the challenges in collecting data on clinical services for chronic pain management. However, the table prepared for the West of Scotland does provide a broad picture of activity with most providers having services led by a range of different professionals (Table 1).

**Table 1 Provision of Chronic Pain Services in West of Scotland NHS Boards**

Disciplines	Direct Clinical Care Sessions			
	Medical	Psychology	Nurse Specialist	Physiotherapy
Southern General	11	2	8	2
Victoria	7	2	10	4
GGH/Western Infirmary Glasgow	9	2	5	6
Glasgow Royal Infirmary	7	1	8	5
Stobhill	6	2	4	6
Inverclyde Royal Hospital	6	1	5	0
Royal Alexandra Hospital	0	0	0	0
Crosshouse	4	1.5	2	0
Ayr	3	1.5	2	0
Dumfries	1	0	0	0
Wishaw <sup>1</sup>	4	0	0	0
Monklands	0	0	0	0
Hairmyres	0	0	0	0
Forth Valley <sup>2,3</sup>	17	3 ses/2 ses alternate weeks	1 ses every 2 weeks	

1 A nurse consultant in chronic pain has been appointed in Wishaw but they were not in post at time of survey. They will be full time.

2 Stirling and Falkirk chose to be counted together as Forth Valley.

3 Forth Valley also has a "pain management specialist" for 2 sessions a week. They felt that this did not fit into the categories above.

**Information correct at the time of publication**

### **Number of patients seen and waiting times**

Patient information is patchy in relation to number of patients seen and waiting times per NHS Board. More information tends to be available on the length of scheduled consultation times for first and follow up appointments. These show considerable variation across sites in Scotland.

### **Staffing**

Again, it is not possible to provide staff numbers by professional group as Boards have submitted their staffing data in different ways.

### **Ability to identify specific budget for their chronic pain services per NHS Board**

Of the 8 service providers who reported having a specific budget for their service, only 4 were able to state the amount of money involved.

### **Multidisciplinary working**

Five NHS Boards have multidisciplinary assessments but most do not. In the six clinic sites where multidisciplinary reviews of patients are undertaken, meetings tend to last 1-2 hours per week with all staff attending. Table 17 on the attached disc shows the wide range in terms of numbers of patients discussed at these sessions. Most service providers do have regular (typically monthly) multidisciplinary team meetings covering issues such as service development. Where multidisciplinary working does not take place, the main reason cited was insufficient staff/time.

### **Compliance with good practice**

The availability of referral criteria is the exception rather than the rule. Audit is undertaken in 7 sites but it does not always comply with the British Pain Society standard and may not include outcome data. Where it is undertaken, it is usually done on a regular basis.

### **Access to inpatient beds**

Most chronic pain service providers have access to inpatient beds. However, this is usually via agreement with colleagues in other departments such as orthopaedics.

## **Dealing with cancer pain**

Most chronic pain services accept cancer patients but the number of patients tends to be very small. Where the provider does not accept direct cancer patient referrals, they usually work closely with their palliative care colleagues.

## **Dealing with non-cancer inpatients**

It is common for chronic pain services to accept non-cancer inpatients; however, Board size is not a good predictor of the number of patients involved.

## **Out-of-hours provision**

Although some chronic pain services do provide an out-of-hours (OOH) service for tertiary services, it is very unusual for a formal rota to be in place.

## **Chronic Pain Services in secondary care - specialised services**

Specialised services include pain management programmes, spinal cord stimulators and intrathecal drug delivery. Only 3 NHS Boards provide all three of these at 6 sites across Scotland. Other Boards provide some or none of these services.

### **Pain management programmes (PMPs)**

Five NHS Boards provide PMPs and four manage and deliver them in the secondary care sector. Three of these Boards run these programmes themselves and 2 use the voluntary sector to provide them. Of the 5 Boards that provide PMPs, 3 Boards report that they meet the British Pain Society standards. A limited number of patients are treated as part of a programme outwith their Board of residence. Three further Boards indicated that they do intend to provide PMPs in future and that these will be community-based. Nevertheless there is a lack of provision of formal tertiary referral PMPs (see Priority Action 5).

### **Spinal cord stimulators (SCS)**

Only 3 Boards provide an SCS service and a separate budget is identifiable for it in 2 cases. The number of patients receiving this treatment in 2005/06 was 16. Support for SCS patients OOH does not tend to be provided on a formal

basis. Cross boundary flows (CBF) potentially do occur but numbers are small.

### **Intrathecal drug delivery (IDD)**

Only 4 Boards provide an IDD service with no separate budget being identified. The number of patients receiving this treatment in 2005/06 was 26 patients across Scotland and most were cancer patients, as shown in table 29. Support OOH is being provided but often on an informal basis. Cross boundary flows (CBF) are rare.

### **Data Health Warning**

It is clear from the stocktake that most Boards have struggled to provide the data to describe comprehensively their chronic pain services on a consistent basis that would allow an all Scotland picture to emerge. The data provided by the questionnaire returns are self reported and unvalidated although NHS Boards have signed off their returns.

There are some inconsistencies between what NHS Boards and their healthcare professionals report, especially in relation to budgets and services provided. For example, one Board reports that there is no separately identifiable budget for the chronic pain services whereas the providers indicate that there is a separate budget of almost £1.2m. Similarly, another Board reported that there are no chronic pain services in primary care whereas the providers have given details of a programme which is a separately funded ongoing service.

Despite these data problems, it is possible to get a high level picture of the extent of chronic pain services provision across Scotland and we take assurance from the Chief Executives who countersigned that the response reflects as accurate a response as possible from their NHS Board.

## Tier 2 - What the health professionals said

An independent consultancy was commissioned to carry out focus groups with NHS staff and four staff meetings were held.

A total of 33 staff attended the meetings from medicine, nursing, physiotherapy, psychology and management; 2 of the medical staff were GPs.

### Format of the meetings

Feedback from the service user sessions (see Tier 3) was shared with staff including:

- what service users felt had been good about the NHS response to their pain
- what service users felt had not been so good about the NHS response to their pain
- what service users considered to be the priorities for improving services.

### Staff response to service user feedback

Staff were broadly in agreement with service users' perceptions around what was good and not so good about the NHS response to their pain. They did suggest that those service users attending groups might have been more knowledgeable, more motivated to work towards service improvement and more educated about chronic pain than the general population of those with chronic pain; for example, staff felt that many more people came to pain services 'seeking a cure' than was reflected in the feedback from service users' discussion groups.

### Common issues in Chronic Pain Services

Staff across the different groups identified several themes on a consistent basis. These included:

- the inconsistency in funding for pain services across the Scottish NHS Boards, reflecting the different attitudes to and history of chronic pain services. Staff noted that there was a culture of provision or non-provision for services and that it is very difficult to get new services or significant expansions to services established
- all patients should have access to specialist pain services where that is needed; this would need to incorporate more basic education for GPs and clear referral pathways for them to use
- the need for a strategic approach to services at national level to drive local provision. There was support for the

idea of having a national centre of excellence, particularly in relation to interventional aspects of treatment. Attitudes towards GPs with a Specialist Interest (GPSI) taking the lead at a local level were mixed; some staff felt this would be useful and would give GPs a ready referral route and easy access to expertise; others felt that better access to core secondary services would be preferable and that, at the same cost per session as consultant input, GPSIs would be a costly way to improve access to expertise

- the development of clinical standards for chronic pain services was seen as being a way to ensuring improvement and equity across the country IF standards 'had teeth', that is, if the outcome of standards measurement was paid attention to by Chief Executives and NHS Boards
- approaches to chronic pain work best when they are based on multi-disciplinary team working; establishing teams may also make recruitment of for example psychologists and physiotherapists easier
- service users, clinical professionals and others need to engage in a debate about complementary/alternative therapies. That is not to dismiss the considerable issues even in brokering such a debate with its attendant tensions between individual experience and evidence base, however staff recognised that service users are vulnerable and need advice and guidance in this area.

## Other issues raised

### Staff attitudes and education

Several staff supported the experience of service users that some clinical staff – GPs, consultants from a range of specialties and some Allied Health Professionals (AHPs) – appear not to 'believe' in chronic pain. More education for GPs, nurses and AHPs would change attitudes and benefit patients through early recognition and referral.

The development of Managed Clinical Networks for Chronic Pain was mentioned as being one route to ensuring equity across the country and of organising GPs' and other staff's education.

### Learning from good practice

Lessons can be learned from examples of good practice in pain management; schemes mentioned included those in England, Canada and Australia. However, this has to be set in the Scottish context where there are already huge variations on provision and practice across the NHS Board areas.

## **Patient education programmes**

Patient education is seen by many staff as being central to good and successful pain management and the development of a realistic approach to living with chronic pain; early education is important and enables patient empowerment. Comprehensive education programmes also allow for patients' attitudes and beliefs to be re-framed within a structured, supportive environment.

## **Prescribing**

There seems to be a difficulty in some areas of the country with GPs being willing to continue prescribing drugs that consultants have commenced but which are 'off-licence'. The need for a new approach to controlling prescribing budgets was also mentioned, the feeling being that quality of life/suffering issues are not given sufficient priority. The role of pharmacists in ensuring compliance with treatment was also mentioned, as was the role of nurses – practice nurses and district nurses - in maintaining ongoing contact with patients between appointments or treatment episodes.

## **Tier 3 – What the patients said**

An independent consultancy was commissioned in December 2006 by NHS Quality Improvement Scotland to conduct the service user component of this stocktake of Chronic Pain Services in NHSScotland. Work commenced in January 2007 and 11 focus group meetings were held. A total of 54 service users attended the groups. The full report of this work is included on the attached disc.

## **Attitude of participants**

Participants in the groups were overwhelmingly positive. Whilst all of the individuals involved had criticisms to make about existing services, they were made constructively with groups retaining a focus on the need to make services better. Participants were fulsome in their praise for the NHS, for local services and for particular individuals where they felt that was deserved. That said the negative comments outweighed the positive experiences and observation by a rate of about 5:1.

## **Format of the sessions**

The sessions were built around 4 discussion questions:

- What has been good about the NHS response to your pain?

- What has not been so good about the NHS response to your pain?
- What would an acceptable pain service look like?
- What would be your priorities for improving pain services?

### **What has been good about the NHS response to your pain?**

Good GPs – several people had had a good experience of presenting to their own GP with chronic pain. To participants a good GP was one who listened to them, believed them, supported them and empathised with their situation, pain and distress.

Crucially, people mentioned that 'good' GPs were also those who referred them on for specialist help if necessary. 'Patients' also valued GPs who were able and willing to discuss ideas about pain management and who encouraged them to try different things, or through their own efforts to explore different things.

Pain Management Clinics - where people had access to these clinics, their experience was overwhelmingly positive. They spoke of valuing the multi-disciplinary nature of the clinics and like the idea that a whole team with their varying perspectives and input were looking at their issue. People also appreciated the obvious specialist knowledge that staff had and spoke of feeling relieved to speak to someone who believed them, accepted their description of their pain and who knew what they were talking about. Patients welcomed support from specialist physiotherapy, occupational therapy and psychology – but not psychiatry support.

Clinics that taught self management techniques like breathing and pacing were mentioned as were interventions like hydrotherapy and TENS (Transcutaneous Electrical Nerve Simulator).

Overall, the empathetic and understanding attitude of staff was praised.

Pain management programmes/courses were highly valued. Whilst only a minority of participants had had access to these courses, the majority, although not all, had found them very useful indeed. A very few participants had attended residential pain management courses in England – either when living there or at the expense of their own NHS Board - and the experience was very positive.

Although not provided by the NHS, a majority of participants spoke in glowing terms of the support and understanding they had found through attending meetings of The Pain Association Scotland, contact from Pain Concern, the Arthritis Care course based on the Expert Patient Programme, and the Thistle Foundation.

## What has been not so good about the NHS response to your pain?

Almost everything mentioned as a 'positive' also merited some mention under this heading, with experiences of GPs' limited access to pain clinics and pain management courses and a lack of recognition of chronic pain at all levels in the health service featuring.

Many patients recounted experiences of GPs who "don't listen, don't understand the experience of chronic pain, don't believe in chronic pain, don't know what to do about it and don't know what's available in terms of specialist services and treatments". This reflects GPs' frustrations and a lack of knowledge. Patients understood the time limitations on GP consultations and that GPs cannot themselves be experts in everything, but they felt that they should at least believe patients stories and be referring them on for specialist help.

The 'unwillingness' of GPs and other staff to discuss complementary and alternative therapies was a recurring issue for participants and will be discussed as a separate issue later in this report.

Limited access to specialist pain services was the experience had by many participants. People experienced long waits even in areas where services are available and many spoke of months or even years of little help before being able to access specialist services. Being 'bounced from pillar to post', trying drug after drug with no emphasis on self-management or dedicated input, were common experiences. The variability of what was on offer within 'specialist' services was also discussed and there was clear variation in practice provision across the country.

Some helpful interventions seemed to be available on a short-term basis only, with TENS, hydrotherapy, acupuncture and physiotherapy cited as examples of interventions where "if they work, they're taken away from you". People talked about spending large sums of their own money to continue these helpful treatments when courses of NHS help had finished.

There was a feeling that provision in the NHS in general was very much along the lines of: if it doesn't work, you're on your own – there is little follow-up or ongoing support; if they can't cure you, they don't care or feel overwhelmed and staff are often threatened by patients with knowledge.

Some other comments include:

- no funding – pain services are a 'Cinderella' service
- too big a focus on drugs. Although some people had relief (temporary or longer term) from drugs, there was a

general feeling that the NHS relies on drugs too much at the expense of concentrating on other self-management techniques

- poor communication between different bits of the NHS – between GPs and hospitals, between disease specialists and between different hospitals, and
- lack of recognition of the effect of chronic pain on wider aspects of people's lives – work, family life, ability to socialise.

### **What would an acceptable service look like?**

The groups were asked to outline what they thought an 'acceptable' as opposed to a 'gold standard' service would look like. There was a broad understanding of the need to ensure that all services in Scotland are brought up to the level of the best and that equally everything that constitutes 'the best' is not likely found in any one service.

Between them, the 11 groups came up with a wide range of features of an acceptable service, although there was also some commonality across the groups. Features mentioned included:

- more accessible services – a helpline, self-referral, more convenient appointment times
- clearer care and treatment planning at the start and better follow-up
- a more structured approach to treatment between GPs, the hospital and patients
- advance directives – so OOH services don't limit drug treatments and dosages that patients know they need when in crisis
- support for families
- more licensing/registration for alternative therapists
- more education for all NHS staff about chronic pain, so they believe people and are empathetic
- awareness of travel difficulties for people with chronic pain
- better links to the benefits system so patient do not have to 'prove' their disability and inability to work
- services that can come out to very remote communities, even if just for assessment purposes
- capped waiting times, quicker diagnosis, and earlier interventions to prevent deterioration

- more investment in specialist services
- better-structured access to alternative therapies; at least an open-minded approach, and
- one-stop shops for pain services.

### **What would your priorities be for improving pain services?**

Several points came out repeatedly when groups were asked to prioritise all of the things they had raised in relation to what an acceptable service would look like. These were:

- Funding – people recognised that although some improvements could be made within existing set-up, significant improvement would probably be funding dependent. There was a feeling that this needed to be driven from the top with a greater priority given to chronic pain by politicians and health service leaders.
- Recognition of chronic pain as a condition – again as with the funding issue, there was a feeling that this needed to be driven by politicians and health service leaders and that without this, significant improvement would be unlikely.
- Participants talked about needing a 'stepped' approach to managing chronic pain with the emphasis firmly on supported self-management but including local GPs or nurses with a specialist interest in pain who could treat in some instances and refer appropriately in others; regional pain management clinics, where the bulk of people needing specialist intervention and support would be seen; a national pain management centre that could lead education and research initiatives and where residential pain management courses could be run for those who would benefit.
- Faster access to comparable services across the country – an end to the situation in Scotland where some have access to relatively good specialist services and some have no access at all; an emphasis on sharing expertise and good practice so as to build on the best available and ensure comparability. Participants also talked about the need for open access to pain services until local services and GPs are 'upskilled'. There was also a feeling that once you are 'in' the pain management service, you should be able to refer yourself back again without going through the whole referral process again.
- Education for GPs (and other staff) about chronic pain – how to recognise it, how to refer on.
- A needs-led service with a focus on self-management – people know that living with chronic pain is very much about techniques they can use on a day to day basis to manage their own pain and they would value assistance and ongoing support with that.

## Issues of particular note

### Complementary and Alternative therapies

There emerged a clear need for an open and comprehensive debate involving staff, policy makers and service users about the role of and approach to complementary therapies in chronic pain.

Participants in the groups understood well the contentious nature of discussing complementary and alternative therapies and arguments around evidence-base, efficacy and the concerns of health service professionals about the legal ramifications of being seen to 'endorse' particular 'therapies. However, people with chronic pain are vulnerable and desperate - whether to find a cure or simply to find some relief- and in their search are spending money, often on 'remedies' of little or no value.

People with chronic pain - certainly those who participated in these groups - would welcome some guidance from the NHS about what constitutes an evidence base, how to assess the effectiveness of therapies and the risk of side effects, how to tell if someone is a reputable practitioner and other issues. These concerns are not unique to people with chronic pain, but were raised so consistently as to merit special mention here.

### Support for voluntary groups and self-management

With the obvious proviso that many of our participants were nominated by Pain Association Scotland and Pain Concern Scotland and are therefore likely to view them favourably, there was an understandable call for some support to be given by the NHS to support groups as is already happening to a small extent in some areas. For example – people could not understand why these groups have to pay for meeting rooms when hospitals, local health centres often have accommodation that could be used in the evenings. This raises the question could the NHS help with funding for information/publicity about the groups? Funding for self-help courses run by voluntary groups would also be welcome. People were also clear though that help would have to be given without compromising the independence of these groups.

## Summary and Action Plan

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Gathering information from those responsible for chronic pain services, those providing chronic pain services and those using these services has been fascinating and frustrating in turn. Much work is underway and many skilled practitioners are leading and developing services that are highly valued. There is no doubt that commitment, energy and enthusiasm are driving this agenda and that there is a real appetite to further improve access to, and use of chronic pain services. Three reports have been commissioned in the last ten years, all led by very experienced individuals and all reaching the same conclusion: chronic pain has to be recognised as a condition in its own right and services and treatment have to be available to patients.

Despite all of this, very little progress has been made. Access to specialist services is poor:

- most Boards do not know what services are required in their area and cannot provide comprehensive information on what is provided
- practitioners are frustrated with the lack of planning and development, and
- patients are confused and dismayed when their condition is not recognised and they do not have access to specialist services or have long waits before they can be seen.

We carried out this work to pull together as much understanding as possible of the different facets of providing effective chronic pain services and to provide some practical proposals aimed at turning recommendations and conclusions into action. The Action Plan described below draws on existing work, fits with the current policy for NHSScotland and with organisational structures that are being developed. It harnesses the chronic pain services experience, skills and knowledge that are available in Scotland.

## Action Plan

### Action 1

Issue: Lack of strategic direction and 'ownership' at national level

Action: Scottish Government to recognise chronic pain as a condition in its own right and to build on the work already underway within the Long Term Conditions Alliance

### Action 2

Issue: Lack of strategic direction, planning and service provision at local and tertiary level

Action: NHS Boards to develop core secondary services, clear referral pathways from primary care to secondary care chronic pain services, and for tertiary services such as Spinal Cord Stimulators (SCS) and Intrathecal Drug Delivery (IDD). These will in turn support the development of chronic pain services at Managed Clinical Network and Community Health Partnership (CHP) level

### Action 3

Issue: Lack of information about who provides what and how effective this is

Action: Information Services Division of National Services Scotland to develop and roll out a minimum data set with associated monitoring reports through the Core Data Set Group based in the Information Services Division and aligned with the eHealth strategy. This must be aligned with the Scottish Government's (SG) long term conditions toolkit

### Action 4

Issue: Lack of knowledge about chronic pain and awareness of treatment options and services in NHSScotland

Action: NHS Quality Improvement Scotland to build on NHS QIS Best Practice Statement and NHS Education for Scotland to develop and roll-out a competency framework based on a training needs assessment

### **Action 5**

Issue: Lack of Pain Management Programmes

Action: Scottish Government to review current SG funded provision of Pain Management Programmes provided outwith Scotland and consider investment in the development and provision of Scottish regional and local pain management programmes, including a residential facility for patients unable to attend as outpatients

### **Action 6**

Issue: Need to improve quality of chronic pain services

Action: NHS Quality Improvement Scotland to consider the development of clinical standards for secondary care chronic pain services

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Clinical Standards Advisory Group (CSAG) 1999 Services for patients with pain, Department of Health, London

Currie J, (1994) *The Management of Patients with Chronic Pain*, Scottish Office, Edinburgh

*Delivering for Health* (2005) Scottish Executive, Edinburgh

McEwen J, (2004) *Chronic Pain Services in Scotland*, Scottish Executive, Edinburgh

SPICe (2002) *Scottish Parliament Information Centre*, Edinburgh

## Glossary of Terms:

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CBF	cross boundary flow
CHP	community health partnership
GP	general practitioner
GPSIs	general practitioners with special interest
GRIPS	Getting Relevant Information on Pain Services in Scotland
HNA	health needs assessment
IDD	intrathecal drug delivery
LDP	local delivery plan
LTC	long-term conditions
NHS QIS	NHS Quality Improvement Scotland
OOH	out-of-hours
PMP	pain management programme
QOF	Quality and Outcomes Framework
SCS	spinal cord stimulator
SE	Scottish Executive
SEHD	Scottish Executive Health Department
SLA	service level agreement
TENS	transcutaneous electrical nerve stimulation

## Appendix 1: Current Guidelines Informing Standards for Services for Chronic Pain

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The McEwen report (2004) commissioned by the Scottish Executive, came up with 16 recommendations. The findings of the current benchmarking exercise of current services in Scotland for patients with chronic pain should be seen against the Standards which have emerged from many documents and professional organisations in recent years and also informed the recommendations of the McEwen report. These include:

- Pain Management Services – Good Practice, Royal College of Anaesthetists and British Pain Society 2003 - [www.britishpainsociety.org/pub\\_professional](http://www.britishpainsociety.org/pub_professional)
- Services for Patients with Pain, Clinical Standards Advisory Group, 2000
- Specialised Services National Definitions Set (2nd Edition no. 31), Specialised Pain Management Services, DOH
- Desirable Characteristics for Pain Treatment Facilities -International Association for the Study of Pain - [www.iasp-pain.org](http://www.iasp-pain.org)
- Recommended guidelines for pain management programmes for adults - provisional (2006), British Pain Society - [www.britishpainsociety.org/pub\\_professional](http://www.britishpainsociety.org/pub_professional)
- Recommendations for Nursing Practice in Pain Management – British Pain Society 2003 - [www.britishpainsociety.org/pub\\_professional](http://www.britishpainsociety.org/pub_professional)
- Physiotherapy Standards for Pain Management Programmes, Physiotherapy Pain Association - [www.ppaonline.co.uk/download/standards/pdf](http://www.ppaonline.co.uk/download/standards/pdf)
- Management of Chronic Pain in Adults- Best Practice Statement, NHS QIS 2006- [http://www.nhsqis.org.uk/nhsqis/files/BPSManage\\_chronic\\_pain%20\\_adults%20\(Feb06\).pdf](http://www.nhsqis.org.uk/nhsqis/files/BPSManage_chronic_pain%20_adults%20(Feb06).pdf)





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