

# CROSS-PARTY GROUP ON CHRONIC PAIN

## Minutes of the Meeting on 3<sup>rd</sup> September 2013

### Previous Minutes

Approved

### Speakers

1. "The Scottish Service Model for chronic pain: where are we?" HIS
2. Specialist Residential Service Consultation – Outputs from Alliance Meeting  
Andrew Strong Policy and Information Officer

### Following on from the HIS Presentation

There was discussion of HIS's commitment to increasing patient representation on the chronic pain steering group. Fife patient Pete McCarron said he had tried Edinburgh and Fife in June for an application form and information but nothing had been received to date.

HIS acting chief executive John Glennie and Robbie Pearson, Director of Scrutiny and Assurance, and lead pain clinician Dr Steve Gilbert were present and asked if they had any objections to the CPG or Mr. McCarron applying or being on the Steering Group. Mr. Glennie and Mr. Pearson said they had no objections.

Dr Gilbert objected, on grounds Mr. McCarron may be duplication as the Pain Association was represented already and Mr. McCarron was a PA member.

Dr Gilbert also objected to CPG representation saying he had counted 13 CPG members who were also on the Steering Group.

The meeting challenged Dr Gilbert's objections, Mr. McCarron stated that he would apply as a pain patient, not for the PA. Several at the meeting, including co convener Jackie Baillie, said the 13 were unlikely to be active CPG members and Dr Gilbert may be counting from the CPG mailing list of over 100, which included officials who'd asked for mailings.

No objections from the rest of the meeting were raised and there was support for both Mr. McCarron and the CPG being represented, with some members pointing out that the CPG had led the way in campaigning successfully for the current Government and Parliament decision to create the first Scottish residential service. Members had done a great deal of positive work voluntarily and had been asked by the health secretary to help rewrite the former withdrawn Consultation and complimented by the health secretary and parliament for the CPG's work for pain patients. Ms Baillie said consideration may be given to taking exclusion from the Steering Group further.

Andrew Strong Presentation

Health and Social Care Alliance Scotland

Notes of chronic pain networking event, 23 August 2013

At present, people who live in Scotland, but who require a specialist, intensive chronic pain service, travel to Bath in South West England to receive a programme of care from the Royal Hospital for Rheumatic Diseases.

During a Scottish Parliament debate on chronic pain services<sup>1</sup>, the Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, committed to holding a consultation with stakeholders to find out the best way of introducing a specialist service in Scotland.

On 23 August 2013, the ALLIANCE hosted a networking meeting for people who experience chronic pain and other stakeholders in order to help clarify views on the development of such a service. The aim of the event was to discuss the Scottish Government's consultation on a specialist intensive chronic pain management service.

#### Key points from the discussion

On the whole, participants felt that there were merits across the various options present in the consultation paper. However, all participants saw Option 1 as a starting point with other ideas being added in.

Delegates felt that this should encompass the following key elements:

3. A residential option to avoid travel to Bath for those who wished it
4. The option for family carers to be involved in assisting them to participate in the programme
5. A central belt location, with good accessibility. This could potentially happen in an existing premises
6. A greater emphasis on telehealthcare
7. An emphasis on links with local services and improving knowledge of chronic pain across the country
8. Ring-fenced funding<sup>1</sup>  
<http://scottish.parliament.uk/parliamentarybusiness/28862.aspx?r=8176>

Any new specialist service should consider domiciliary care approaches as well as residential. Delegates were keen to stress that self management and coping mechanisms "for when you come home" are an important part of managing and taking control of chronic pain.

More should be done to support self-management groups and encourage education. A strong collective voice that meets individual's needs at a national and a local level is required. This could potentially be met by access to independent advocacy.

Accommodation group work therapy is something that already happens across Scotland, but needs to be built on. Delegates suggested that this could be the next stage of the Scottish Government's thinking in this area.

It was also expressed clearly that people did not want this to be a "top down" approach. People who experience chronic pain should be involved in the decision making process at all stages.

## Appendix 1 – notes from participants

### What should the service be?

- There should be an option 4 – aspects of all options. 1, 2 & 3 are required to improve the service.
- All 3 options are required in order to provide the services that is needed
- Southern General is being rebuilt. Why not build a specialist residential centre for chronic pain
- We need a residential centre but also need improvement in local services
- Consensus – option 1 – need a specialist residential centre Scotland.
- Option 1 plus outreach
- One centre, residential where required **Where should it be?**  
Delegates expressed a range of views, including:
  - Must be in the most easily accessible place to most of the population, e.g. Perth
  - Jubilee Hospital? Unit could be built there and they have accommodation already
  - Homeopathic unit in Gartnavel Hospital – could that be used
  - Location of residential building should be in the central belt due to easy access, excellent physician skills
  - Additional place to have a meeting would be at NHS Centre of Integrative Care at the Glasgow Homeopathic Hospital as majority of patients with long term chronic pain issues

If it is to be located at the NHS Centre of Integrative Care then it needs to be fully integrated service i.e. not two separate teams of staff.

NHS Centre of Integrative Care has all facilities needed already in place – OT, physiotherapy, group work rooms and room for expansion. Phase 2 was to include hydrotherapy unit. Pond Hotel for additional rooms.

Central location with peripatetic service hand in hand.

Residential option central belt. Former premises. Family accommodation and Centre of Excellence, telehealth is an important tool for Self Management. Video conferencing. Make it attractive to professionals. University links. Option 1 is the only viable option

Rural and urban may need more outreach/transport etc **How it should be delivered**

Centre of excellence

Any service dealing with pain should be fully holistic – not medicalised.

Take in grassroots learning and requirements and valuable learning. Pre- education is required for all healthcare professionals and doctors. Holistic review.

Patients input required at level 3

It should start bottom up (from the patient) to the top level (Doctor). Not from the top people down to the people with chronic pain

Patients must be brought in to discussions right from day 1 and through all meetings as it all starts from us on pain problems. It's up to us patients to get this up/running successfully

Living with chronic pain requires initial assessment/ongoing treatment as required. "Patient" may not be healed

Chronic pain is neglected and needs a holistic approach – specifically to education

Guaranteed ring fenced funding

Who is going to be in overall charge? It needs to operate without area influence. Its own finance.

Train medical students in the discipline of chronic pain. Need full time dedicated pain specialists

- Regular reviews because people develop other chronic illnesses
- Possible role for national co-ordinator to ensure patient choice is respected
- Better to upskill local services
- Services should be tailored to the needs of the individual
- Early diagnosis, self-help and support groups
- Peer Support. Reviews in Medication. Review Patients. Getting the right people from a range of specialisms
- As a service user I find being with other service users is less lonely than being with professionals
- Being with people who understand you helps
- Access to complementary therapies as well as research based integrative care **Future consultation events**

Potential meeting places:

- o Aberdeen/Inverness (North)
- o Stirling (Central)
- o Fife (East Coast) or Edinburgh
- o Dumfries and Galloway (Borders)

**Advocacy**

- Individual advocacy is needed on a local and wider scale
- Independent advocacy
- Advocacy. Local people designing services
- Collective advocacy – so that people can get together to influence service design and delivery, campaign, network and provide mutual support
- Access to independent advocacy for everyone with chronic pain
- Local people should be involved in the design and delivery of services
- Specialist advocacy in the model of a national co-ordinator role to ensure the patient voice is respected **Other issues raised by delegates**
- Better to have local pain clinics and immediate access. We have hundreds of members who can't get access

- People don't know how to be referred to pain services and GPs don't either
- The service for integrated health is available at the Homeopathic Hospital which is being under used because of a lack of knowledge
- "People self support groups" are up and running in Paisley and Drumchapel. More are required around Scotland
- More groups other locations need information to send out about meetings, discussions at Parliament etc.
- GPs lack education about chronic pain and don't know where to send sufferers
- Concern about time it is taking and about what happens in the interim – i.e. a lack of services, ongoing treatment, education of specialists, information, holistic approach, need specialist medical input
  - Who will refer folk to this service?
  - Should the service model be renamed to patient model?
  - How is phantom pain going to be treated (for service personnel i.e. army)
  - Patients have a habit of underplaying their pain. Saying three instead of six or more.
  - Does each health board have a clinician in pain?
  - How are patients assessed to reach referral levels?
  - Widen the scope of illness model. Community Health Partnership inviting patients to input
  - Chronic Pain Symposium - podcast it to the wider community
  - Is there a clear definition of chronic pain?
  - Properly funded ongoing self help groups

#### Attended

Jackson Carlaw MSP  
 John Wilson MSP  
 Jackie Baillie MSP  
 Mark Feeney

#### Apologies

Bill Paton  
 Sally Hughes  
 Colin Rae  
 Diane Thomson

Phil Atkinson  
Prof Nick Alcock  
Heather Cameron  
Kenny Boyle  
Gabrielle Stewart  
Christine Martin  
Anne Simpson  
Rose Mcdonald  
Andrew Strong  
Jacqui Kelly  
Rachel Dunk  
Gill Vickers  
Helen McLuskey  
John Thomson  
Anne Cassels  
Mairi O'Keefe  
Anne Simpson  
John Glennie  
Stephen Gilbert  
Robbie Pearson  
Marion Beatson  
Peter McCarron  
Shaben Begum  
DG Elder  
Frank Mawson  
Linda Mawson  
Prof Martin Steultjens  
Jacquie Forde

Rachel Atherton  
Anna Marie Mgregor  
Pat and David Onions  
Susan Archibald  
Ian Semmonds  
Malcolm Clubb  
Bea Nicholson  
Sabu James  
Janet McFarlane  
Graeme Fotheringham  
Ros Meek  
Janette Barrie  
Martin Johnson  
Jean Rafferty  
Ross McDonald  
Thomas Kay  
Pat Roche  
Joan Kerr  
Lord Foulkes  
Martin Tighe  
Paulo Quadros

#### HIS Update for Chronic Pain Cross Party Group: September 2013

The following represents a summary of the main aspects of the work Healthcare Improvement Scotland (HIS) is leading in partnership with key stakeholders to improve chronic pain services nationally. The Service Improvement Groups currently being established in each Board in Scotland will provide the vehicle through which meaningful improvements will be driven locally and, into the future. We are keen to engage with the Cross Party Group in terms of sharing our plans and the progress

being made. We have therefore included some specific questions after each section of this update report that we would be keen to have the CPG's views about.

### Improvement Action Plan

For 2013-14, HIS has identified an Improvement Action Plan which has eight key specific action points with detailed action plans and timescales to ensure our aims are achieved by the end of March 2014. These are:

9. Supporting national sign up to the use of the Scottish Service Model for Chronic Pain (SSMCP)
10. Supporting Boards to establish Service Improvement Groups (SIGs)
11. Producing resources, advice and guidance for SIGs to support them to both organise themselves and implement the SSMCP
12. Identifying future SIG support requirements for 2014 onwards and providing this information to the Scottish Government who will continue to monitor the SIG's performance
13. Developing and undertaking a national data collection exercise
14. Producing high quality advice/guidance and information resources for the public and patients with chronic pain
15. Producing high quality educational advice/guidance and information for Healthcare Professionals
16. Publishing a SIGN Guideline for the Primary Care Management of Chronic Pain

### 1 – 4; Supporting Boards to establish SIGs

- We have been supporting Boards to develop and submit their plans for service improvement to the Scottish Government (SG).
- SG has now received plans for SIG development from all 14 NHS Boards.
- We expect the most recent bids to be approved by SG before the end of August.
- All Board SIGs provide regular updates to the Scottish Government Clinical Priorities Team and to the Chronic Pain Steering Group.
- We are in the process of building a resource pack and organising twice monthly web discussions (webex) for SIGs to ensure that progress and lessons learned are widely shared
- A meeting of the SIG's on 12<sup>th</sup> December will establish a network and strengthen links between them to promote sharing of good practice

- A further national meeting of SIG's on 20<sup>th</sup> March 2014 will check on progress and set out the timetable for future work in 2014 - 15

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Question to the Cross Party Group

Q: Is the CPG assured of the plans and progress to date?

5; Measurement and Monitoring Chronic Pain Services nationally

The need for up to date information about chronic pain services nationally has been agreed. We envisage that this information will help to guide SIGs as they develop and also provide a level of assurance that services for patients are improving.

A data collection exercise will be undertaken during September – November 2013. This will have two parts:

o Part 1. Service level data: via semi structured interview of the SIG's in each Health Board, by Dr Gilbert and the facilitators which will provide accurate and detailed information about how services are:

- configured,
- waiting times to first and second appointments,
- staffing compliments i.e. WTE per professional grouping
- and active timescaled plans to develop further

o Part 2. Patient level data: This will be a 4-week snapshot of patient related activity which will provide information about:

- patient referral numbers
- patient demographics ,
- sources of referral,
- type of pain,

- patient outcome and experience via a patient reported outcome measure (PROM) and a patient reported experience measure (PREM) A report will be produced in March 2014

Question to the Cross Party Group  
Q: Is the CPG assured that this plan will meet the information requirements that they are particularly interested in? 6,7; Providing Advice, Guidance & Information Resources Over the last two years, we have collated a considerable 'library' of resources for patients/public and healthcare professionals. These are currently provided on the Managed Knowledge Network web site (<http://www.knowledge.scot.nhs.uk/pain.aspx>), feedback about which, in terms of its usability, has not been favourable. We are therefore redesigning the web platform and in parallel undertaking a review exercise of all the resources to make sure that they are useful, easily

accessible, valued and reliable. These will be available on the new web platform for greater ease of access, which we plan to launch in December 2013. Question to the Cross Party Group Q: Is the CPG assured of the plans and progress to date?

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8; Publication of the SIGN Guideline on Management of Chronic Pain in Primary Care

The guideline will be published and launched on the 12<sup>th</sup> of December 2013.

#### Increasing Patient Involvement

We are committed to increasing and improving patient involvement in our work. Together with our Scottish Health Council colleagues and using our patient participation standards as a guide, we have reviewed our approach and put into place a number of actions.

##### a. Steering Group Membership

We have increased the number of patient representatives on the National Chronic Pain Steering Group. We now have four seats to compliment the current patient representative bodies of the Pain Association Scotland, Pain Concern and The Alliance. Susan Archibald has kindly agreed to fill one of those seats with the remainder of nominations coming directly from the Board Service Improvement. We are keen to have widespread geographical representation. We will provide patient representatives with development and support to ensure they can play a full part in the work of the committee. We will use the Scottish Health Council Participation Toolkit ([http://www.scottishhealthcouncil.org/patient\\_public\\_participation/participation\\_toolkit/the\\_participation\\_toolkit.aspx](http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/the_participation_toolkit.aspx)) to ensure that involvement of public representatives will be transparent and of maximum benefit to the Chronic Pain improvement programme.

##### b. Service Improvement Groups

Strong patient participation will be a key feature of the new Service Improvement Groups as they establish and move forward with their action plans. We will emphasise this strongly within the resource pack being developed to support SIG development. This will also form an aspect of the reporting they will be required to do to Scottish Government over the next few years.

##### c. Measuring Patient Experiences

We are finalising our approach to capturing patient experience of services and the way in which such information will be used to drive local improvement. We will use the results of the October data collection exercise for this purpose. The patient experience tool focuses on five specific elements that relate to patients' views about:

access, involvement, dignity, understanding and outcome as well as an indication of overall satisfaction.

#### d. Our Emphasis

We are hosting a National Share and Learn Day in December at which in addition, the SIGN Guideline for Primary Care Management of Chronic Pain will be launched. The Minister for Public Health will also attend it. We have invited two individuals with Chronic Pain to open the day with accounts from their own experience to ensure that the context of what we are doing and why is more than clear. We also intend to have a specific session on patient involvement to support SIGs and emphasise the crucial need for this.

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#### Referrals to Pain Association Scotland

We are working with other NHS colleagues to develop the ability for GPs and other HCP's to refer patients directly to Pain Association Scotland through the SCI Gateway (an electronic referral system used in primary care) irrespective of where in Scotland they live. This should provide a much more streamlined process for patients and easier, faster access to PAS services.

#### Question to the Cross Party Group

Q: Is the CPG assured that our approach to strengthening patient involvement is appropriate?

#### Other Areas of Work

There remain several other areas of work including improving provision of pain management for Children and Young People, Older People, development of On-line and Telehealth resources, which we will also be developing and planning in more detail at the December SIG's meeting.

#### Conclusion

- We now have the commitment of all NHS Boards to take improvement of Chronic Pain management seriously and the mandate to progress the development of SIGs
- There are great examples emerging from the SIG's which were established in 2012 of what can be achieved and we will ensure that these are shared widely
- We have strengthened the patient voice and input to our work

We have developed a measurement framework of service provision, patient experience and outcomes to monitor progress and emphasise accountability

We will publish a SIGN Guideline for the Management of Chronic Pain in December 2013 Question to the Cross Party Group Q: Overall, Is the CPG assured of the progress to date?

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