SCOTTISH PARLIAMENT
CROSS PARTY GROUP ON CHRONIC PAIN
AGENDA AND MINUTES OF MEETING
Held On THURSDAY 10 MARCH 2011 at 6.00 p.m. in Committee Room 5
Refreshments from 5.30 p.m.

AGENDA

1. Welcome.
2. Minutes of meeting held on 24 November 2011
3. Matters Arising
4. Chronic Pain Steering Group: a tabled report from their interim chair, Prof. Blair Smith
5. The Managed Clinical Network Dr. Gavin Gordon, consultant in pain medicine will give a tabled report on the being done in Glasgow and Clyde
6. Steve Gilbert will be addressing the group on obtaining funding for expensive treatments (e.g. spinal cord stimulators and pain management programmes) and the lack of specialist units
7. Fiona Townsley will give a witness statement on spinal cord stimulators
8. Marion Beatson will give a witness statement on the importance of pain management programmes
9. Discussion of the Legacy Paper for next parliament
10. Any other business
11. The next meeting is on: Wednesday 15 June 2011 6.00pm-8.00pm

(Please be aware that this meeting date and time may be subject to change)

Please sit around the table if you wish to speak.
Please switch on your microphones before speaking and announce your name clearly to all. Thank you.

Attendees

- Scanlon, Mary – Convenor & MSP
- Archibald, Susan – Archibald Foundation
- Atkinson, Phil – Health Policy Scotland
- Baillie, Jackie – MSP
- Barlow, Gordon – Patient driver
- Barr, Rachel – Pain Concern
- Barrie, Janette – Nurse Consultant NHS
- Beatson, Marion – Patient Representative
- Brannigan, Judy – CNS NHS Lanarkshire
- Brotchie, Iain – External Relations RPS
- Dunbar, Martin – Cons. Clin. Psychologist
- Elder, Dorothy-Grace – Founding member of Cross Party Group, Journalist
- Fotheringham, Graeme – Pfizer
- Gilbert, Steve – Queen Margaret Hospital, Consultant in Pain Management & Anaesthesia
- Given, Alison – Grünenthal
- Horobin, Samantha – Pain Concern
- Hughes, Sally – NAPP
- James, Sabu – Cons. Monklands
- Ma, Andrea – Co-secretary & Pain Concern
- Scott, Will – SGHD
- Serpell, Mick – Cons. Anaesthetist
- Simpson, Richard – MSP
- Thomson, Diane – Pfizer
- Thomson, John – Patient
- Todman, Jonathan – Clin. Psychologist
- Townsley, Fiona – CPSG
- Townsley, George – Patient Driver
- Turnbull, Andrew – NAPP
- Wallace, Heather – Co-secretary & Pain Concern
- Wilson, John – MSP

Apologies

- Paterson, Gil – Co-convenor & MSP
- Simpson, Richard – Vice-convenor & MSP

- Bannister Jonathan – Lead Clin. & Cons. Pain & Anaesthesia
- Bannon, John – MBE health rights campaigner, a member of NHS Greater Glasgow and Clyde Health Board
- Bond, Michael – Prof, Sir- University of Glasgow, IASP Liason Officer with World Health Organisation, Patron of Pain Concern.
- Cadden, Helen – NHS QIS Partner
- Campbell, Sharon – RGN, BMI, Ross Hall Hospital
- Falconer, David – Director of Pain Association Scotland
- Gordon, Gavin – MCN, Glasgow
- Green, Katy – Arthritis Care in Scotland
- Grieve, Michael – Patient Driver
- Johnson, Martin – Clin. lead of RCGP effective 1st April
- Logan, Irene – Fibromyalgia Friends Association Scotland
- Lopes, Victor - Consultant Maxillofacial Surgeon in Edinburgh
- MacPherson, Fiona – CNS Chronic Pain, WGH
- Nicholson, Marian – Shingles Support Society
- Onions. Pat – Patient Driver
- Paton, Bill – Napp
- Quadros, Paulo – Intlife Pain & Well Management
- Ruglys, Anne – Sanofi Pasteur, MSD
- Simpson, Anne – National Osteoporosis Society
- Smith, Blair – Interim Chair CPSG
- Wilson, John – Cons. Anaesthesia & Pain Medicine, NHS

MINUTES OF THE MEETING

1. **Welcome:** Mary Scanlon MSP opened by welcoming everyone to the meeting and thanked Medtronic for supplying the refreshments.

2. **Minutes of meeting held on 24 November 2010:** The minutes of the last meeting were accepted as a true and accurate account.

3. **Matters Arising:** There were no matters arising from the last minutes to discuss.

4. **Chronic Pain Steering Group: Tabled Report**

Chronic Pain Steering Group update no: 1

Scottish Chronic Pain Project Steering Group meeting held 24/02/11, next meeting due to be held 19/05/11

1. Recruitment of the National Lead Clinician for Chronic Pain

Currently, short-listing of applications has been completed and interviews have been arranged for mid-March. It is anticipated that a new National Lead Clinician for Chronic Pain will be in post before the summer, as this will allow for time from the person's employing body to arrange to backfill the sessions devoted to the post.

The National Lead Clinician for Chronic Pain will Chair the Scottish Chronic Pain Project Steering Group, and maintain its focus on developing the Scottish service model for chronic pain to:

- Improve prevention and management of Chronic Pain for people in Scotland;
- Improve services at all levels;
- Minimise the burden of pain on individuals and the community; and
- Promote the aims of other institutions involved in supporting pain management practice, education, and research and speciality recognition; including supporting improved self-management programmes.

The Chronic pain model is also integrated with the pathway for referral into services currently being taken forward through the Musculo-Skeletal (MSK) Programme of the Adult Framework for Rehabilitation and the Lead Clinician will be expected to help develop and maintain this important link.

The National Lead Clinician will secure work and engage key stakeholders within NHS boards to deliver roll out of the agreed service model across NHS Scotland.

A report on activity will form a standing item on the agenda of the Scottish Chronic Pain Project Steering Group.

2. NHS QIS update

NHS QIS has provided administrative support (and will continue to do so), to the National Lead Clinician for Chronic Pain.

Chronic Pain, as part of the LTC programme of work in Healthcare Improvement Scotland (from 1st April 2011) continues to be an important piece of work with the NHS QIS business case for Chronic Pain (draft) based on the following 3 objectives:

Objective 1 (Implementation and Improvement support)
To establish a quality improvement infrastructure to support NHS board chronic pain networks.

Objective 2 (Implementation, improvement and support)
To develop a core chronic pain dataset in partnership with ISD.

Objective 3 (Advice, guidance and standards)
To develop a SIGN Guideline for the Prevention and Management Of Chronic Non-malignant Pain.

As part of the chronic pain objectives (1 & 2), a scooping exercise building on previous work undertaken regarding the service model, and more recently the collation of the regional pages for the community website, will be undertaken. This exercise will take place throughout the NHS boards to ascertain their level of chronic pain services and how they would fit into the agreed Scottish service model for chronic pain.

This scoping exercise will commence as soon as possible, following the appointment of the new National Lead Clinician for Chronic Pain.

NHS QIS (and Healthcare Improvement Scotland from 1st April) will circulate an update report to the Scottish Parliament Cross Party Group on Chronic Pain prior to each meeting in the future.

This is led by Sean Doherty (NHS QIS)

3. SIGN Guideline on the Management of Non-malignant Chronic Pain

Regarding objective 3 in the NHS QIS business case for Chronic Pain (draft), the establishment of a SIGN guideline on the Management of Chronic Non-malignant Pain, this has been included in the SIGN work programme and will commence during 2011-12.

Work has commenced to ensure that the scope of the guideline is refined sufficiently to ensure that it is deliverable to the wider service in an effective and timely manner.

At the SPaRC event (31/03/2011), there will be a breakout session entitled **Moving towards a SIGN guideline** based around the following outline:

Scottish Intercollegiate Guidelines Network (SIGN) Guidelines are internationally recognised gold standards that inform the management of many clinical conditions (123 by February 2011). Few of these relate directly to chronic pain (though guideline 106 is on the treatment of pain in adults with cancer). However, NHS QIS has just approved funding and oversight of the development of a SIGN guideline for Chronic Pain. This is a good opportunity in many ways, but also presents a major logistical and academic challenge. This workshop will identify the challenges presented and discuss methods of addressing these, with a view to informing the guideline development group which is soon to be formed.

Following on from the SPaRC event, there will be a meeting to formalise the remit for the guideline, honing down the key questions that the guideline will then address. Work will commence formally towards the latter part of 2011, led by Dr Lesley Colvin.

4. Launch of the Scottish Pain & Research Community (SPaRC) – Thursday 31st March 2011, West Park, Dundee

As part of the Scottish Government improvement plans for chronic pain services, the Scottish chronic pain research sub-group, working under the authority of the Scottish Chronic Pain Project Steering Group, has set up SPaRC as a network of individuals throughout Scotland who are actively involved in chronic pain research, who are keen to share information about their work (with each other and with clinical colleagues), and who might be interested in considering potential collaborations. This is led by Professor Blair Smith.

It is anticipated that this activity will be through a combination of email and web-based communication, with the possibility of conferences and other meetings. The network will lead in the sharing of current knowledge and best practice in relation to chronic pain throughout Scotland.

The launch meeting will introduce both SPaRC and the community website around which much of its activity will focus. It will include a range of oral and poster research presentations, workshops and talks, encouraging a mutual understanding of each other's research, and collaboration. To date, 90 people have registered to attend as delegates representing a wide spectrum of the chronic pain research community in Scotland.

If any member of the cross party group has a particular interest in chronic pain research an invitation is extended to them and they can contact Vicky Rigley at vicky.rigley@nhs.net;

5. Community Website

NHS QIS, working with the Knowledge Services group within NHS Education for Scotland (NES), has developed a Community website similar to ones produced for Vulnerable Families and for Long Term Conditions. The website is being launched at the SPaRC event (31/03/2011).

The community website is an ideal platform for moving the chronic pain agenda ahead. It will act as the basis of a chronic pain information resource for primarily the service, though is also available to the public.

The community website set up includes the following pages:

Home
Projects Steering Group
Regions
Research
Members and contact us
Help

Local pages for each NHS board will be the responsibility of each board, while the national pages will be the responsibility of the project steering group.

Ownership of the Chronic Pain Community website is held by the Scottish Chronic Pain Project Steering Group with the majority of pages being updated on an ongoing basis by the steering group support.

This is led by NHS QIS

6. Completion of the Learning Needs Analysis – Chronic Pain in Primary Care

NHS Education Scotland (NES) commissioned Baccus Consulting Ltd to undertake a learning and development needs analysis associated with the management of chronic pain in primary care across Scotland, building on and complementing earlier work undertaken by the Chronic Pain Managed Clinical Network in NHS Greater Glasgow and Clyde.

The specific aims and objectives of this piece of work were four fold:

1. To explore the learning and development needs associated with chronic pain in primary care across Scotland, highlighting the skills and knowledge required as well as desirable values, attitudes and behaviours.

2. To articulate and analyse the key learning and developmental needs identified.

3. To identify any specific local learning and development needs in geographic or territorial board/Community Health Partnership areas.

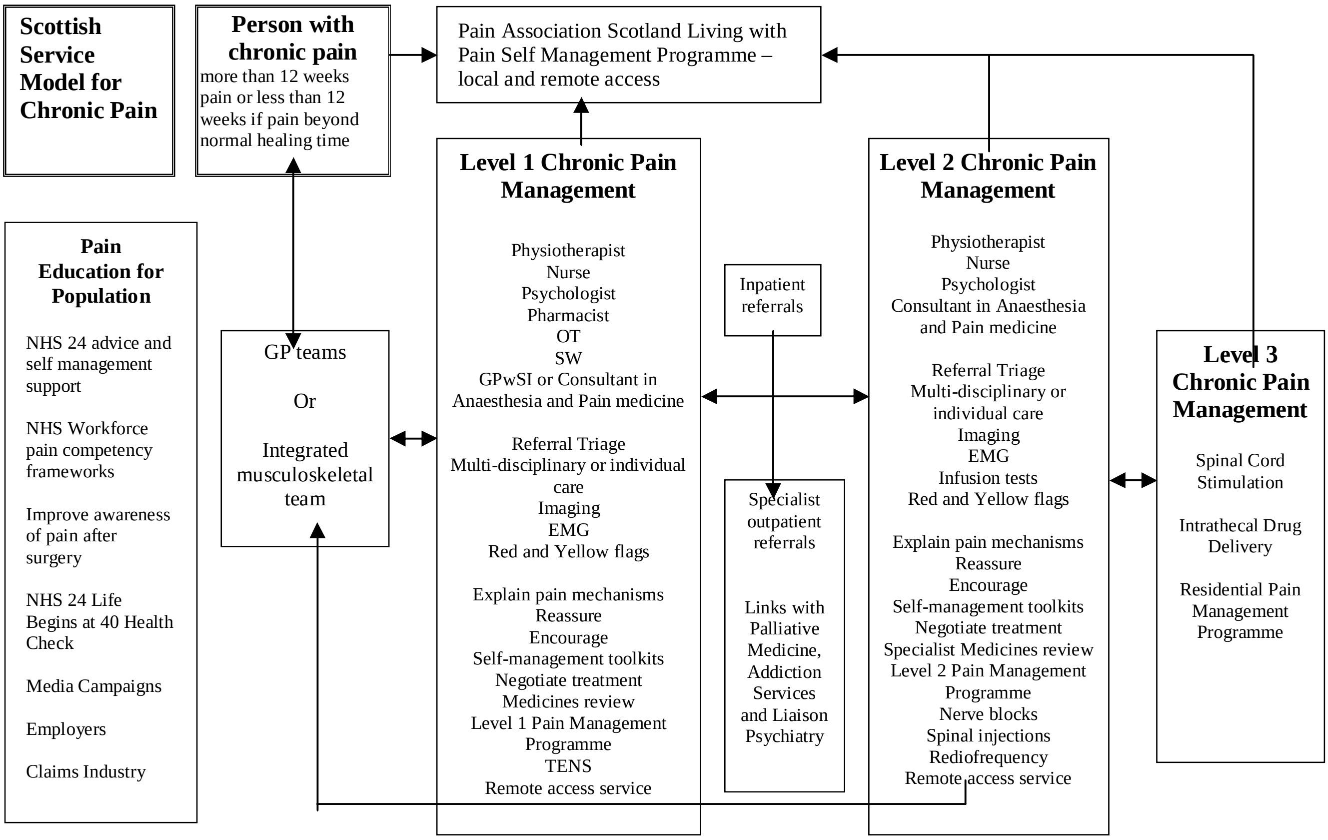
4. To suggest possible ways to address learning and development needs identified based on the findings of the learning needs analysis.

The analysis was completed in November 2010 with recommendations made. Following on from this, the analysis was circulated to Chronic Pain Steering Group members before being discussed at the last Scottish Chronic Pain Project Steering Group meeting on the 24th February.

In order to ensure that the valuable work undertaken continues, and recommendations are followed up, decisions were made to ensure appropriate follow ups.

Ongoing follow-up discussions between NES and NHS QIS with input from the new National Lead Clinician for chronic pain when appointed, with a view to setting up a chronic pain education sub-group (working under the auspices of the Scottish Chronic Pain Project Steering Group) to move ahead with recommendations identified in the analysis. This is led by Cheryl Harvey (NES).

Scottish Service Model for Chronic Pain



5. The Managed Clinical Network Dr. Gavin Gordon, Consultant in Pain Medicine Tabled Report of the work being done in Glasgow and Clyde

The main change to report in the MCN is the appointment of a coordinator. Mrs Camilla Young was appointed in October last year and has experience of MCN work in that she is also the Stroke MCN coordinator. She is clearly working part time for us but her willingness to take on tasks especially around the sub groups is already having a significant positive impact for us.

As the LTC group fades the Health Board will absorb all their MCN's into their Planning Group. This will inform our future objectives in coming annual reports.
We have no word as yet as to whether the MCN will continue beyond April. That date marks the end of the 2 years funding from Edinburgh but the hope is that as with other MCN's the cost will be absorbed by our parent directorate within the health board.

I circulated our annual report last autumn and the only other thing to update is that the process of formulating standards is now underway. The National Steering Group will update on the SIGN guideline.

Dr Pete Mackenzie retired from the NHS on 31st January 2011. We hope to have an informal social event with him in May. Lastly I retire at the beginning of June and will notify you of who succeeds me as lead for the MCN.

Gavin Gordon 1/3/2011

Mary Scanlon MSP welcomed the tabled report on this wonderful piece of work being done in Glasgow and Clyde. Both the MCN and the SCPSG were two positive pieces of work.

6. Steve Gilbert addressed the group on obtaining funding for expensive treatments (e.g. spinal cord stimulators and pain management programmes) and the lack of specialist units.

Expensive treatments

- Spinal cord stimulators - £8-9,000 at least. Inclusion of assessment, post-management and follow-up costs totals to £10,000+
- Residential Pain management - £843 for assessment and £9,547 for a 3 week course for adolescents. Approximates to £11,000.

But in context...

- Private hip replacements - £10,000 (NHS £3,500)
- CABG – Coronary Artery Bypass Graft- £10,000
- Intensive Care - £2,000 per day

Show me the money

- Clinical Advisory panel – comprised of Medical Director, Clinicians and Administration
- Some areas just run it past their clinical directors or management committee
- Hold Central Health Board budget
- Department of Health

All you would need to do is get in touch with a senior member of the management team going through the medical director or financial director to find the appropriate person to approach and provide them with:

- Patient history
- Evidence for the proposed treatment
- Likely cost

Getting the Information required

- NICE 2008 guidelines, information from BPS (spinal cord stimulators)

- Tertiary centres regarding cost (Victoria in Glasgow, Ninewells in Dundee)
- www.bathcentreforpainservices.nhs.uk/
- Outcome data - /outcomeadoles.aspx.

Costs of sending Adults to Bath

Year	**Cost**	**No. of Patients**
2008-9	230,000	23
2009-10	185,000	18
2010-11 (first 6 months)	207,000	21

Why people are being referred to Bath is because there aren’t any services available in certain regions especially Highlands and Islands, Grampian and Tayside. We could probably install and run services a lot more economical than this.

Information resource

There is a lot of information you can get from the minutes of the Chronic Pain Steering Group on the Internet. However, Steve Gilbert said he wanted to find out more so he contacted Tayside to find out why and how they sent people to Bath. Apparently they get accepted automatically due to their funding coming from a central Scottish contingency fund not Tayside Health Board and the only cost to the health board themselves is for the travel. In that way there is no incentive for Tayside to start up their own services because Bath is an easy option for them.

- http://www.knowledge.scotnhs.uk/pain.aspx

Mary asked what we needed in Scotland, is it a residential programme we are missing that makes us send people to Bath? Steve said that it wasn’t the residential programme; it was the fact that there are no ordinary outpatient programmes available in certain areas and the only viable option is to send them to Bath. There are very few people that need an intensive residential programme like Bath; however, there is no other option in some areas. Mary also asked if it would be possible for us to set up services in Scotland with the amount of money it costs to send people to Bath. Steve said that the Chronic Pain Steering Group looked into this and found that setting up a residential programme was not economically viable at the moment.

Jackie Baillie was concerned at the increase of people going to Bath and costs of sending them there and asked if it is possible to use that money a little smarter by providing more services in Scotland. Steve said that one of the aims from the GRIPS report was that there would be equitable pain provision throughout Scotland. Martin said that in Glasgow, which he is the clinical lead for, they see about 500 patients per year at an approximate cost of £400,000, which sounds a lot, but when you think that you can probably treat 8 people at an outpatients pain management clinic compared to sending 1 patient down to Bath it's not very much.

Mary asked do we need to set up the same services as they have in Bath or do they offer something above what we have in Scotland already? Martin Dunbar replied that a very small amount of people do benefit from a residential programme and need 24 hour care but many only need outpatient services which are not being provided at the moment in

Scotland and the only option is to send them to Bath for a residential course because of the distance. Funding really needs to be made available to set up more outpatient pain clinics, but we would need more than the £200,000 which is currently being used to send people to Bath.

Will Scott said that he had read the North of Scotland Planning Group report which stated that 4 in 100,000 would benefit from a residential pain management course when trying to identify if Scotland needed to use Bath as a model for services here. He wanted to know if the clinicians in the room could identify with that figure. Steve Gilbert said that this is the actual problem we have: we need to find out: what is the need and what is the unmet need for services in Scotland. When we are getting people along to an outpatient’s programme- why are they not being helped by that, or is it because they are not attending due to being too disabled to get there? In an ideal world we would have something like Bath in Scotland and it may not have to cost the earth. Steve said he had looked into the Welsh programme at Bronllys which started out in 1994 which was set up in an unused building with a full complement of staff including psychologists and physiotherapists. They were able to see people much more cheaply than sending people to Bath. In the case of children, with chronic pain, which is a more common problem than we think, somewhere like Bronllys or Bath would be an ideal facility to use. Steve said he thinks there were only 8 children last year sent down to the adolescent pain management programme at Bath from Scotland but that could be due to uprooting them from their family. Mary didn’t realise that children were being sent down to Bath. She asked what ages were being sent and Steve informed the group that it was between puberty and 18 especially between 16 and 18 because there is a huge gap in the services for these young people.

Dorothy Grace added that she also was not aware that children were being sent down to Bath and said that this was absolutely shocking. She knew things were not good for children with chronic pain but to send them to Bath which is a 1000 mile round trip and if travelling by train it is four train changes, there are very few flights which go down there and the car journey is nine and a quarter hours without a stop from Aberdeen. She went on to say that the situation for children is quite serious and in urgent need of attention in both Glasgow and Edinburgh. There is no funding for chronic pain services in the Royal Sick Kids Hospital in Edinburgh and they have to beg and borrow time from colleagues, as there is not a dedicated bed ward for them. In Glasgow, there is a dedicated bed ward for children with chronic pain however the health board told the clinicians that no new patients were to be admitted after their 14th birthday. Dorothy-Grace contacted the health board regarding this and shortly after this the health board contacted the clinicians saying that they could be flexible. Bear in mind that this was only after a media enquiry and she could almost guarantee that this would not be flexible for long. She found out that the health board had told the clinicians that children over 14 would be treated in a new state of the art facility which was being built and due to open in 2015 which is not ideal. In the meantime these children are being sent to adult services. Dorothy-Grace said she had checked with Gavin Gordon regarding the waiting list in Glasgow and was told it was at around 500 at the moment. She also said that she had been in touch with the lead clinician at Bronllys in Wales and asked how much per patient the programme was. She was told £5,400 per patient for three weeks.

Steve Gilbert explained that Wales was one step ahead because of the MP for Plaid Cymru at the time, who was a chronic pain sufferer and he put a lot of effort into the unit in Bangor where he worked.

Jackie asked the clinicians what their main 3 asks would be?

Martin Dunbar: Equity of provision
Education within the Health Professionals
More investment in Psychology

Diane Thomson: NHS not realising savings that pain management programmes can have so there are no incentives to spend on this service.

Mick Serpell: Better education
Rapid/local assessment

Steve Gilbert: Same as above
Get the message out that lots can be done to help and not all treatments are medication based
Prevention, much more expensive to help people further down the road a patient goes.

Sabu James: Education
Health boards need educated regarding funding benefits
Need more transparency for funding

Mary said that it was apparent to her that it was more costly not to treat people.

7. Fiona Townsley witness statement on spinal cord stimulators

Fiona Townsley is a person who has been living with chronic pain. She sits on the Scottish Chronic Pain Steering Group and is a volunteer with Pain Concern.

"I had an accident in 1997 where my wrist was severely damaged, after several ortho-operations I was told nothing else could be done and to get on with my life! I could not use my arm and was living on painkillers trying to get through life but wishing it was all over! I eventually got myself referred to see Pete MacKenzie who changed my life. I got a spinal cord stimulator in 2007 and it has given me my life back."

Fiona's accident in 1997 lost her the use of her right arm. She had five ortho-operations and was told nothing else could be done and to go away take painkillers and get on with her life. She was told she would never work again and would never be able to do anything with her life. In 2004 she decided that she could no longer go on living her life on painkillers and not work so she found Pete MacKenzie's pain clinic on the internet and got herself referred to it. Fiona said that it was quite ironic as the clinic was in the same corridor as her orthopaedic clinic but they didn't communicate with each other. In 2004 Pete started Fiona on different treatments from nerve blocks, changing painkillers and radio frequency. Unfortunately this didn't work and in November 2007 she had a spinal cord stimulator implanted and for the first time in ten years she was able to move her thumb as it had been locked tight since the accident. After the implant Fiona said she didn’t need to wear a splint or a sling, all her painkillers stopped and she was able to continue her work full-time. It totally transformed her life. She has a flat and now lives on her own and is completely independent. She can now drive a normal car without modifications. The spinal cord stimulator was the last option for Fiona as the health professionals were looking at amputating her arm and now she can move all of her fingers and her arm. This is all thanks to Pete MacKenzie but from Fiona’s point of view the frustrating thing was that it took that length of time between the accident in 1997 and her discovering the pain clinic in 2004, the experimentation with treatments, till the implant in 2007. The lack of communication between the two departments, which were literally two doors away from each other and the consultants knew each other, no one had thought to put her forward for this clinic before. Fiona said that she hopes that other people don’t go through what she had to, to achieve pain relief and the care that they need.

Mary Scanlon thanked Fiona for her contribution and looked to health professionals in the room to explain what a spinal cord stimulator is and if it is available to everyone across Scotland. Mick Serpell said that as a pain specialist it is important to go though all aspects of treatment but as we have seen in Fiona not all self management techniques work, and spinal cord stimulators are obviously an effective treatment for cases such as these. He explained that it is the clinics' job to identify individuals who would benefit from such treatments. Spinal cord stimulators are a specialised treatment. There is only one spinal cord stimulator unit in Glasgow and they are funded to undertake 12 implants a year, so it is a small and select group. Mary enquired if this has been recommended by NICE or SMC and if budgeted to provide more than 12 implants a year, would there be more demand in Scotland? It was established that more could benefit if the budget wasn’t capped. A spinal cord stimulator is like an epidural catheter, which has electrodes in it and is inserted through the skin into the epidural space with x-ray screening. Patients are usually awake when this is done and it is stimulated to get to the right level, but this is the temporary trial. The final implantation of the battery which is like a pacemaker is usually done under general anaesthetic.

Dr James added that it is important to get people early enough because as you go further down the line success reduces. He said that they are funded to send people to Glasgow for these stimulators however; he has people like Fiona who are responding well to other treatments, because they were caught early enough. It is based on personal circumstances. He stipulated the importance that GPs and other health care professionals realise quickly if a person needs further help which they cannot provide, to refer them on to the appropriate pain management services. Mary asked if there was a NICE guideline with a set list of procedures before suggestions of spinal cord stimulators are made. It was said that there were NICE guidelines on certain types of pain especially neuropathic pain, however, if these aren’t working and the individual is not responding to these treatments GPs have to realise they need to refer on to specialist treatments. Mary said she was concerned that people were parked on painkillers rather than being referred on to other treatments. Janette Barrie highlighted the lengthy process involved to actually refer people on to spinal cord stimulators and obtain funding from your health board. The cost per patient is £12,000 and you need to make a special application for funding and then the patient has to go through several tough screening processes, not all people who are referred get accepted.

Dr Martin Dunbar stated that part of the screening was psychological screening as well as physiotherapy screening and from speaking to Dr Andy Crockett, who does the operations in Glasgow; this screening has doubled the success rate of implantation. He added that Glasgow is only charging for the cost of the machinery and those other costs aren't included. The £12,000 is just for the machinery and excludes surgical costs and costs of screening. If it did include these, the cost could easily be £20,000-30,000.

Heather Wallace notified the group that she knows people who have had implants for 10 years or more and they had them replaced recently because of them being worn out. She reported that the implants last a long time and the cost is spread over several years. It provides economic activity as seen with Fiona who has a responsible job as a manager with ASDA so the initial cost of the implant should be seen in this context. Mary agreed that it should be seen against the savings from other treatment costs. Dr Martin Dunbar said that there had been a Cochrane review, which stated that the implants were cost effective and save money in the long-term.

8. Marion Beatson; witness statement on the importance of pain management programmes

Marion Beatson is a person living with chronic pain.
"In 2001 I had an accident, for 3 years since I was told that the pain was in my head and to just get on with it I tried to find information on my pain. In 2004 I changed my GP and he had me seen by a specialist. Within 2 weeks of seeing the specialist I discovered I had disc and nerve damage and was referred to a pain clinic for medication and pain control.

Depression took the next 3 years of my life until I went to a psychologist who sent me on a pain management course changing my life for the better. It taught me that I wasn't alone and the only one in pain, who has problems and feels guilty for getting frustrated. It was ok to do things a step at a time.

I feel it is important to get out the information and provide the help that people need to prevent them from feeling alone and isolated. It is also important to educate the families of those in pain to ensure that they get what is needed for their loved one (e.g. aids, nurses, etc)."

Marion said that her life changed when she fell at work on a floor. She was told by the hospital that she had bruised her lower discs, when she explained to them that she was numb along one side and in pain they said that during the next 6 months it would heal and get better and to go home and get on with her life. Ten years down the line she was still the same, if not permanently damaged.
The doctor, Marion had then, kept telling her to continue taking the tablets he was giving her and to carry on working, to do her exercises and go swimming but what he didn't realise was that she fell on a wet floor and was terrified of going out in wet weather, snow or even walking across wet floors. She said that she would have panic attacks if she found herself in that situation. She therefore avoided them and was housebound because of the weather. Marion said that she became a recluse and withdrew and ended up being depressed.
It wasn't until she moved home that she got seen by another doctor who was going to put a complaint in against her first doctor regarding the prescription drugs that he had

given her. Marion said she was taking them like sweets and she found out from this new doctor that she was doing herself severe harm by taking them. She said that she was literally overdosing herself to keep going through the pain. The new doctor sent her to a private clinic and the neurologist found that there was damaged discs and that the nerves were trapped in the discs causing the numbness all down her body. The neurologist told Marion that it would never get better and that she would have to learn to live with the pain and get on with life.

Marion said she was referred to the pain clinic at the Royal in Glasgow to get her pain medication sorted and to start living a better life. The consultant in the pain clinic referred Marion to Dr Martin Dunbar because she was a recluse. After explaining her situation to Martin, he found that there were a lot of barriers to break down before Marion could benefit from the self-management of her pain. Martin referred her to the pain management clinic he was setting up in Glasgow where she was accepted. Here she met people with different kinds of conditions but were all in pain and after they shared their stories they all found that there were many people like themselves and that they weren't alone. Slowly the clinic broke down the defences and taught them how to manage their conditions. Going through this process Marion found that her life changed. She wasn't afraid anymore, she could hold her head up high and she started talking to people again. She now does things that she hadn't done for ten years, like swimming and going out in the snow. Marion said that she would have liked to have seen more information in the mainstream regarding pain management. It was only when she met Martin that she found out about services relating to her condition. Her frustration was at not knowing where to go for help. Now her ambition is to get that help into the community with access to pain management clinics everywhere. She said that everybody everywhere deserves to get the help that she received. The health professionals need to talk to each other because many don't know about these services. When people learn that they can receive help, they can get their lives back and start living again.

Mary said to the group that there is no greater testimony to pain services than from the people that they help like Marion and Fiona.

Will Scott agreed with Fiona and Marion that we need more communication between the different departments and there is a need for non-specialists to understand the specialist help that is out there, and a need for good information provision for the public. Managed Clinical Networks should carry out that type of work. Mary said that the MCN in Glasgow needs to be rolled out to other areas so that all can benefit. In the Highlands and Islands there are no pain services available because the one pain service that did open up is now inundated and they were told to cease new referrals.

Dorothy-Grace said that it was wonderful to hear testimonies from patients, but reported that in Scotland we are not doing well and we need a few more knights in shining armour in order to cover the need for pain services.

Mary congratulated Susan Archibald for being elected to the Fife Health Board in recent elections. Susan said that Steve Gilbert was her doctor and that she echoes the sentiments of Marion and Fiona. If it wasn't for Steve she would not be here today. She said that she thought it was very important to get this help to the people suffering with chronic pain. Pain Association was her lifeline. Since Steve put her in touch with them it has changed her life. She said meeting people who were suffering the same as she was and realising she wasn't alone gave her the strength to go out there and inform the public that there is help and where to find it. Susan also said that more information needed to be given out in the public arena and more education to the GPs so they know what services are there. Marion said that all the speakers want to go out and help others and in turn become an extra resource. What they have gone through can become therapy for other users of pain services.

9. Discussion of the Legacy Paper for the next Parliament

A legacy paper was given out to the group just in case the parliamentary elections change the MSPs that attend the group.

10. Any other business

The work that Prof. Blair Smith and Dr. Gavin Gordon described was acknowledged by Mary Scanlon MSP as fabulous and this progress is something to mention in the debate, but Mary also wanted to discuss consistency across Scotland within Pain Management Services. Mary invited the group to contact her, Jackie Baillie and John Wilson with issues that people would like raised in the Scottish Parliament in the members debate on 17th March at 12.30pm. Mary added that she appreciated the fact that many of the group had clinics or other work related obligations and were not able to attend the members' debate however, she would find it helpful that suggestions be sent for where the Cross Party Group would like to go for the next Parliament after May. This is the first debate on Chronic Pain since February 2002 when Dorothy-Grace Elder held the first one. Since that debate enormous progress has been achieved however, people are still being sent down to Bath to receive specialist pain services and we do not have a consistent service across Scotland.

Jackie Baillie MSP said that this was the first meeting that she had attended and would like to ask the general question to get an understanding of how things are now and what work has been done, how that improvement has played out and where is there a lack of funding for clinics in certain areas of Scotland. Jackie said that this would be the main point for her in the members' debate. Mary Scanlon MSP informed Jackie of Dr. Pete MacKenzie, widely known as the Pain Tsar, who was the Lead Clinician for Chronic Pain and has been very ill and unable to take many of the issues forward that had been discussed at both the Cross Party Group and the Scottish Chronic Pain Steering Group. However, Blair Smith stood in for Pete but a new Lead Clinician will be appointed shortly. Will Scott gave an update on Pete MacKenzie who he had seen on Monday and commented on how well Pete was looking on his new course of treatment and in his general well being. Will Scott also mentioned that the appointment of a new Lead Clinician was a crucial decision because that person would have to keep prodding and pushing forward all the issues that need to be resolved.

Dorothy-Grace Elder highlighted that much of the work that Pete MacKenzie and other people pushing for consistent pain services is dependent on finance. Chronic pain is not on a high level when compared to obesity. She also informed the group that £12m was being given to the Commonwealth Games from the flu contingency fund and e health (£10m from flu contingency fund and £2 from e health). Dorothy-Grace also mentioned that £4m was set aside for National Health Service Health Board Spin Doctors while services for chronic pain remain under funded. There is also £600,000 spent on spin doctors and special advisers for the health secretary (all quoted from parliamentary questions). All that is set-aside at the moment is £60,000 per year for part-time lead clinicians in chronic pain, while spin-doctors are telling people that everything is moving. Dorothy-Grace said yes all the discussions and plans are ready to be implemented or investigated further however there is no funding to follow through on these. Mary Scanlon said that these were definitely points that could be raised in the debate because there was no one to answer those points at this meeting.

Mary asked Will Scott regarding the financing of the Long Term Conditions Alliance. The original funding was £976,000, which has now changed to £563,000, why has this been reduced by £413,000? Will Scott said that it was discussed at the meeting in November and thanked Dorothy-Grace for making him aware of the figure as quoted in the parliamentary question made by Mary Scanlon MSP in July 2010 to Shona Robison, deputy health minister. Shona Robison said in a letter in March 2011 that £413,000 was not handed over. Will Scott investigated the figure but still doesn't recognise it. He has spoken to his financial colleagues who had anticipated a payment of £416,000 but could not shed any light on it. He had made the assumption it was due to the Long Term Conditions Collaborative, but was not positive on that. He admitted that it is still mysterious what the payment was for. Mary asked whether she was correct in thinking that funding for long-term chronic pain services came from this budget. Will Scott explained that the budget was only to keep the Alliance going. There is a Self-Management Fund that the alliance administers which funds projects. Mary said that for next time it may be beneficial to find out exactly where the money is coming from, what it is being used for and what other avenues of funding could be given to pain services. Heather Wallace acknowledged the Alliance and it's brilliant work with self-management programmes but stated that in addition to that we need clinical psychologists because not everyone can make progress with self-management programmes. Will Scott informed the group that psychological support is one of the things that the Alliance is very keen on and that they have published a report called "Emotional Support Matters" which was published with funding from the Health Directorate. Diane Thomson said that from her understanding the Alliance is part of the voluntary sector and that's where the funding comes from to support the voluntary sector self-management programmes. However, the key point for self-management programmes to work is early diagnosis and appropriate treatment being started by healthcare professionals and the support being on the ground.

Will Scott notified the members of the group that there is an invitation for them to contact NHS QIS regarding the SIGN Guideline development and give any suggestions towards their discussions.

Heather said that there is a letter given to every group member regarding the early day motion for the Westminster. She urged everyone to encourage their MPs to sign in favour of the motion. **Action: Heather to send Early Day Motion letter via email.**

11. The next meeting is on: Wednesday 15 June 2011 6.00pm-8.00pm
(Please be aware that this meeting date and time may be subject to change)

The group would like to thank Medtronic Pharmaceuticals for the refreshments