



## Attendees

- Scanlon, Mary – Co-Convenor & MSP
- Paterson, Gil – Co-Convenor & MSP
- Simpson, Richard – (Dr.) Vice-Convenor & MSP
- Atkinson, Phil – Health Policy Scotland
- Auld, Sandra – ABPI Scotland
- Barr, Rachel – Pain Concern
- Cadden, Helen – NHS QIS Public Partner
- Deacon, David – Pain Concern
- Doherty, Sean – NHS QIS
- Donaldson, Angela – Arthritis Care Scotland
- Fotheringham, Graeme – Pfizer
- Gilbert, Steve – (Dr.) Queen Margaret Hospital
- Grice, Craig – Royal Infirmary Edinburgh
- Hamilton, Margaret – Pain Concern
- Hughes, Sally – Napp
- Horobin, Samantha – Pain Concern
- Ma, Andrea – Pain Concern
- MacPherson, Fiona – CNS Chronic Pain, Edinburgh Pain Clinic, WGH
- Paton, Bill – Napp
- Power, Ian – (Prof.) Anaesthesia, Critical Care & Pain Medicine, the University Of Edinburgh, Royal Infirmary.
- Ruglys, Anne – Sanofi Pasteur MSD
- Scott, Will – SGHD
- Smith, Blair – (Prof.) University of Aberdeen, Member of Chronic Pain Steering Group
- Thomson, Diane – Pfizer
- Wallace, Heather – Pain Concern & Co-secretary

## Apologies

- Anderson, Ryan –Service Development Manager for Napp Pharmaceuticals, Chair of ABPI Scottish Pain Industry Group
- Archibald, Susan – Member of Fife Pain Group, Person with Pain
- Baillie, Jackie – MSP
- Bannister, Jonathan – (Dr.) Clinical Lead, Tayside Pain Service, Consultant in Pain Medicine & Anaesthesia
- Barrie, Janette – Nurse Consultant for Long Term Conditions, Strathclyde Hospital
- Bishop, Doreen – BackCare
- Brotchie, Iain – External Relations Specialist, Royal Pharmaceutical Society
- Campbell, Sharon – RGN, BMI, Ross Hall Hospital
- Craig, David – Consultant Clinical Psychologist, Pain Services, Glasgow
- Deehan, Maureen – Medical Science Liaison Manager, Grünenthal
- Druce, Katie – University of Edinburgh, Psychology Student
- Dunbar, Martin – Consultant Clinical Psychologist, Greater Glasgow & Clyde, NHS
- Elder, Dorothy-Grace – Founding Member of the Cross Party Group on Chronic Pain
- Falconer, David – Director of Pain Association Scotland
- Given, Alison - Grünenthal
- Gordon, Gavin – (Dr.) Managed Clinical Network
- Green, Katy – Area Development Manager of Arthritis Care in Scotland
- Grierson, Fiona – ABPI Scotland
- Johnson, Janice – PSALV(Psoriatosis Scotland Arthritis Link Volunteers)
- Jones, Derek – (Dr.) Senior Lecturer, Glasgow Caledonian University
  - King, Ray – Chief Executive of Bupa Health
  - Logan, Irene – Fibromyalgia Friends Association Scotland
  - Ma, Lina – Pain Concern
  - MacFarlane, Gary – (Prof.) Professor of Epidemiology & Deputy Head of Institute of Applied Health Sciences
  - Nicholson, Marian – Shingles Support Society
  - Parris, Ruhy – NHS, Greater Glasgow & Clyde
  - Quadros, Paulo – Intlife Pain & Well Management
  - Roche, Patricia – EOPIC () Study Co-ordinator, University of Aberdeen
  - Ross, Douglas – Assistant to Mary Scanlon
  - Rust, Diane – Chairperson of Marfan Association UK
  - Serpell, Mick – Consultant in Pain Management
- Simpson, Anne – National Osteoporosis Society
- Townsley, Fiona – Pain Concern, Representative of Chronic Pain Steering Group
  - Weurman, Aileen – PA to Mary Scanlon
  - Whitson, Helen – Pain Concern
  - Wilson, John – Consultant in Anaesthesia and Pain Medicine, NHS Lothian, Glasgow

## MINUTES OF THE MEETING

1. **Welcome:** Mary Scanlon MSP opened by welcoming everyone to the meeting and thanked Medtronic for supplying the refreshments.
2. **Election Of Office Bearers:** Mary Scanlon MSP announced to the group that due to Scottish Parliamentary rules Office Bearers needed to be elected.
  - **Co-conveners:** It was proposed that Mary Scanlon MSP and Gil Paterson MSP would be re-elected as Co-conveners. This was unanimously accepted.
  - **Vice Conveners:** A proposal that Richard Simpson MSP would continue as Vice Convener was unanimously accepted.
  - **Co-secretaries:** Heather Wallace and Andrea Ma, both from Pain Concern were nominated for Co-secretaries and was unanimously accepted.
3. **Minutes of meeting held on 16 June 2010:** The minutes of the last meeting were accepted as a true and accurate account.
4. **Matters Arising:** There were no matters arising from the last minutes to discuss.
5. **Susan Archibald a member of the Fife Health Board will talk to us about her story of pain and discrimination:** Due to unforeseen circumstances Susan Archibald could not attend the meeting therefore this item will be submitted for another meeting.
6. **Chronic Pain Steering Group an update from their interim chair, Prof. Blair Smith**

Mary Scanlon MSP welcomed and invited Prof. Blair Smith, Professor of Primary Care Medicine at the University of Aberdeen and General Practitioner in Peterhead, who is acting as interim chair of the Chronic Pain Steering Group (CPSG), to present an update of the CPSG's work.

Prof. Blair Smith thanked Mary Scanlon MSP and introduced himself formally to the group. He explained that he was asked to stand in on an unofficial basis as chair for the CPSG, which is being run in Quality Improvement Scotland (QIS), first of all due to Dr Pete MacKenzie's illness and now his resignation as the Lead Clinician in Chronic Pain and with that the Chair of the Chronic Pain Steering Group. He re-iterated that he has stood in as Chair for the CPSG and not as Lead Clinician, therefore the report will just concern the Steering Group.

- 6.1 Dr Pete MacKenzie's resignation was noted at the last meeting of the Chronic Pain Steering Group (CPSG), held 2 November 2010 where it was informed that a process is now in place to appoint a replacement for Dr Pete MacKenzie, both as Lead Clinician and Chair of the CPSG. Once the process is complete there will be someone in place to drive the agenda forward. This will be a two-day a week appointment for three years, so it is a substantial appointment. Mary Scanlon MSP asked if advertisements had been submitted for the position. Prof. Blair Smith informed the group that the process is not quite at that stage at the moment and in partnership with his colleague Sean Doherty from Quality Improvement Scotland (QIS), he is working on that. It will not be a formal advertisement in the newspapers but just to ensure that people who are interested

in applying, are aware of the opportunity. He explained that this is the usual process for all other Lead Clinician appointments and that the fact that this process is being followed shows that Chronic Pain has now risen in importance and is up alongside Cardio, Diabetes and Cancer who also have Lead Clinicians which is very positive.

- 6.2** Prof. Blair Smith informed the group that the CPSG has twenty-one members and is a multidisciplinary group consisting of pain specialists, primary care and other secondary care professionals, nurses, physiotherapists, charity organisations, patient representatives, different branches of the NHS and Scottish Government from the Long Term Conditions Unit.
- 6.3** Blair encouraged the group by announcing that at the last meeting of CPSG, QIS informed them that the Agenda for Chronic Pain was firmly and officially embedded in the QIS work programme. A business case is being made to cost that up.

The work programme agenda has three objectives to deliver which the CPSG and QIS will evaluate at the end of the three years:

**Objective 1:** Establish a Quality improvement infrastructure to support NHS Board chronic pain improvement groups or Managed Clinical Networks (MCN) by the end of 2011.

**Objective 2:** To develop a core chronic pain data-set in partnership with Information Services District of National Services Scotland NHS (ISD) by the end of 2011. This is to allow data on people who are attending Pain services, and receiving treatment to be collected in a uniform way, which will allow audit and comparison between boards and allow comparisons with any standards set.

**Objective 3:** To develop the Scottish Intercollegiate Guideline Network (SIGN) guideline, which is the gold standard that Scotland has for clinical guidelines on treatment, therefore developing a SIGN guideline for the prevention and management of Chronic Non-malignant Pain is a proposal which the CPSG have submitted formally to SIGN, and it has been accepted by them. However it still has to be formally approved by the QIS board, but it is looking promising and hopefully we will be able to report back at the next meeting that that will go ahead. If it is accepted it will be a very positive but difficult piece of work, and many individuals here will probably be sitting on the guideline development group, trying to formalise a standard.

This is what the CPSG is tasked formally to do, however there are other pieces of work that the group is involved in.

- 6.4** Dr Pete MacKenzie was involved in developing a service model for managing chronic pain within Scotland. The model leads from pre-pain education, primary and secondary education, primary care to first level specialist (e.g. physiotherapists) and GPs with special interest, to second level specialists (e.g. hospital clinics), to third level specialists which are the sublevel clinics (e.g. spinal cord implants). Once the model is finalised rolling it out to patient groups in management programmes, such as the one run by the Pain Association Scotland group with a view to enabling people with chronic pain as best we can, to function to the best of their capacity, and lead a healthier life is possible. Dr Pete MacKenzie worked very hard on that, and this was his main piece of

work just before he was ill. He reached the stage that he received approval from the key clinical groups and he presented it to the Northern Regional Planning Group who also approved it. The expectation was that the other two Regional Planning Groups would also approve it and then trickle it down to the boards. Unfortunately it stalled at that place, but the hope would be that the new Lead Clinician will pick it up and get it embedded within the NHS probably at board level rather than regional planning level. That would then be a model that boards would be expected to provide a service according to.

- 6.5** Blair spoke about the development of a Community Website, which will form a platform for pushing forward the Steering Group and getting the QIS agenda as a resource. Blair said that it was under development and that he possessed a draft for him to comment on and give feedback to the developers: NHS Education for Scotland (NES). It is not too far away from going live and it will be accessible to all with different level access, according to your status (e.g. health professionals, patients). It will contain key resources such as practice statements, allow communication within the group and have the key educational and research elements of the group and provide information for the patients and carers.
- 6.6** Another element of work is in education, where there is recognition generally within Scotland that health professionals are undereducated in the area of chronic pain. Blair informed the group that this is not a unique situation and is a wide-ranging problem. The difficulty is in the identification of the specifics of the under education and the problem of how to deliver the gap in that education. There has been a learning needs assessment carried out on chronic pain among primary care professionals, which Cheryl Harvey from NES led, that was commissioned to the organisation Bacchus who have submitted a draft report at Primary Care level. That report is available for some of the group to review and will either be presented or commented on at the next CPSG meeting with a view to implementing the recommendations.
- 6.7** There has been a lot of work centred around the Managed Clinical Networks (MCN) and a separate report has been submitted under Agenda Item 7.
- 6.8** Research also continues to be a work focus within the CPSG and there is a research subgroup within the CPSG, which Prof. Blair Smith is officially chairing rather than being interim chair. The subgroup contains a group of enthusiastic research active professionals carrying out three main objectives:

**Objective 1:** To ensure that pain research across Scotland is clinically relevant where possible.

**Objective 2:** To ensure that pain clinicians in Scotland are aware of current research particularly the research coming out and particularly relevant to Scotland.

**Objective 3:** To establish Scotland as a centre of excellence in pain related research. There are a number of world-class international individuals and groups researching chronic pain across Scotland but it does tend to be in their own groups therefore, the aim of the subgroup is to bring those groups together with a view to collaborating and applying for the large grants available. A number of people have expressed interest in being members of a research group across Scotland, the Scottish Pain Research

Community (SPRC), which is due to be formally launched at the end of March, and Blair said that he would be happy to keep the group updated.

- 6.9** On a final note Prof. Blair Smith informed the group that at the last CPSG meeting Carole Sinclair from Better Together attended and talked about her work. He expressed that the CPSG felt very positive that they could work with Carole in a patient-centred view of assessing quality in conjunction with the core data set (mentioned in Item 6.3, Objective 2) and feel that a patient view of the services provided would be an important view of the quality of pain services as they are developed and spread out. Mary Scanlon MSP thanked Prof. Blair Smith and said she is impressed with the progress but also recognises that there is still a long way to go.
- 6.10** It was mentioned to the group that the development of the service model is very much integrated with the work being done in developing a service for musculoskeletal conditions because of the clear link between those and chronic pain. Dr Pete MacKenzie developed a working relationship with Dr Sarah Mitchell who has been leading the musculoskeletal work. Although Dr Pete MacKenzie has not been able to work on this, Dr Sarah Mitchell has remained mindful of the fact that chronic pain needs to be embedded in the model and she is taking that forward.
- 6.11** Richard Simpson MSP asked Prof. Blair Smith if there were any NICE guidelines for chronic pain and would the SIGN guidelines duplicate NICE? Blair informed the group that there are NICE guidelines on lower back pain, diabetic neuropathic pain and neuropathic pain for non-specialists, but nothing dealing with chronic pain as its own entity. The SIGN guideline will be a broad all encompassing guideline. Blair also said that there are differences in objectives between NICE and SIGN so there would not be duplication.

Richard Simpson MSP commented that he was delighted to see that Robin McKinley received a category award at the Health Awards dinner and wondered if the group wanted to send a note to him congratulating him on his achievement and work in chronic pain. He is the lead specialist in Forth Valley.

At the Awards dinner there was also an award for Acute Pain, based on this Richard Simpson MSP asked about the relationship between the management of acute pain and how it works within Chronic Pain?

Prof. Blair Smith said that this was an important point and one point to make is that chronic pain is not just acute pain that has lasted longer, it is different in that there are other mechanisms going on, but there is one view that if we manage acute pain then we are getting it at the right time and preventing chronic pain, and certainly the epidemiological evidence supports the fact that of all the known risk factors for chronic pain, acute pain is by far the most important. However, it is easy to go off on a tangent and ignoring the factor of managing chronic pain as a separate entity. Prof. Blair Smith was in agreement that health professionals need to be aware of the preventative aspect of acute pain but there is still a huge need to manage the disability associated with chronic pain separately.

- 6.12** Prof. Ian Power commented that a NCEPOD (National Confidential Enquiry into Patient Outcome and Death) report has just been published of pain and death in the elderly

entitled 'An Age Old Problem (the report can be accessed through the NCEPOD website) which the author described as “demoralising”. There is so much acute pain in hospitals, it is prevalent. While Ian commends this group and is fully supportive of Prof. Blair Smith, the fact of the matter is that in many hospitals, including the Edinburgh Royal Infirmary, many people come in for surgery already suffering from chronic pain before suffering an injury or trauma, which makes it worse. Ian said that sometimes it is very good to separate out the different types of pain but he would agree that life is not quite like that and that somewhere in the assessment of persistent pain you have to take the acute injury into account.

**6.13** Mary Scanlon MSP informed the group that in parliament today they were looking at the Death Certification Bill and they signed off the stage one report on the Palliative Care Bill, which is a members Bill in the name of Gil Paterson MSP. They were also to discuss Margo MacDonald’s End of Life Assistance Bill, but that has been moved to next week, so the committee is immersed in the issues of pain. Mary also stated that one thing that concerned her about Margo MacDonald’s Bill was that many people said they were scared of the pain

**6.14** Gil Paterson MSP re-iterated to Prof. Blair Smith that the work of the CPSG is positive and from what was thought a few years ago, Pain research/issues have come on leaps and bounds. Prof. Blair Smith said that the CPSG was made up of many dedicated people, many sat round the table at the moment and that it was the efforts of the whole group that has made it successful not just himself as interim chair.

**6.15** Gil Paterson MSP also asked for more information about the Scottish Pain Research Community, SPRC, as he has not heard about it before. Prof. Blair Smith said that he was not surprised, as it only exists on paper at the present. As he said earlier there are a lot of researchers around Scotland working in their own-pocketed groups, some at a local level, some at national level and that is concerning everything from pain at a molecular level to pain at a large population level. There is great scope for collaboration and many health professionals working in the clinical arena are not aware of the research that is being conducted in Scotland. Using the clinical networks Blair said he sent out an email inviting anyone that was interested in research and being part of a network to send him their details and so far Blair said he has about eighty or ninety people who are interested.

It was asked that whether SPRC was looking to secure funding outwith Scotland? Blair said that there was no need for financial support for the SPRC itself, as it is based on a website and just a pooling of researchers. The SPRC serves as a collaboration for applying for external research funding (e.g. Medical Research Council, Arthritis UK or National Institute for Health Research (NIHR) funding). Many already have external funding of that nature but it is a competitive challenging arena to get funding in. One of the main issues in pain research is that there are no natural wealthy funding organisations under whose umbrella pain sits, so different spins have had to be put on research projects in order to get the grants required.

**6.16** Mary Scanlon MSP asked if the SIGN guideline on chronic non-malignant pain includes palliative non-malignant pain and what were the kind of time-scales for the guidelines? Blair said that they had yet to scope the details of this. Blair assumes that Dr Lesley Colvin would be leading this to map out the details. Blair also said that the

guidelines are on non-malignant pain and would not be including cancer pain and palliative malignant pain. Blair said that the guidelines were a couple of years away from completion.

Mary Scanlon MSP also asked whether this had been done before, to look at chronic pain anywhere else in the world? Blair said there were a number of guidelines available in many countries but none of them are as systematic and comprehensive as SIGN would be. Blair also said that Ian Power had been involved in guidelines in other areas and these would probably be used in the process of setting the guideline.

Ian Power said that Blair was correct and that SIGN methodology would apply a level of scientific proof to this. There have been other guidelines to give to clinicians treating chronic pain but it sounds like it is still looking for high level evidence and SIGN grades that, and people will respect that. Blair said that it was an ambitious piece of work but it was one worth going for especially with the international standing that SIGN has.

Will Scott mentioned to the group that while developing the guidelines, apart from pain associated with conditions there is the chronic pain not associated with any conditions, pain from mysterious origins and this will need to be kept in mind.

- 6.17** Mary Scanlon MSP said it would be appropriate at this point, having heard of the progress that is being made to say that none of the Cross Party Group would be there if Steve Gilbert had not put in a petition to Parliament to ask about chronic pain services within Scotland in 1999 and it was through that petition that chronic pain got onto the agenda and the cross party group formed.
- 6.18** Steve Gilbert informed the group about the (Managed Clinical Network) MCN website which can be found through the knowledge network website. It contains information on what is happening in the steering group, research and regional information.
- 6.19** Steve Gilbert also said that he had been given some questions by Dorothy-Grace Elder to submit to the group. With regards to the Bacchus report, is education going to be a key stream of the steering group? Blair answered that it was with regard to educating primary care professionals.
- 6.20** Steve informed the group that a study was conducted in Canada that people studying veterinary medicine get eight times more education in pain than medical students. With regard to this he asked if it was the intention to roll out the education to medical school? Blair said that he was aware of these studies and that medical education does start at medical school however, the agreed priority was to target the primary care level to improve the situation now. It is all part of an ongoing programme we can strive to achieve from first year undergraduate to ten-year post specialist training. All we can do is what the resources allow at the moment.
- 6.21** Steve asked a question of Will Scott with respect to the MCNs. Was there any pressure back from the Parliament on the health boards in implementing the GRIPS report and is there any checking on standards and what has actually been done? Will Scott answered specifically on the MCN point, the rigor there comes from the fact that an action was put into the Long Term Conditions action plan around chronic pain and developing a

MCN project. At that time it was to develop it at regional level but now that it has been looked at more closely with the numbers involved, it is more likely that this needs to be done at NHS board level now rather than regionally. Will said that he was pleased at the support that Greater Glasgow and Clyde has given to the MCNs and if you can show the results from a region that encompasses a large proportion of the population he hopes that other regions will pay real attention to that and see the benefits. He also said that the community of practice website that has been developed will have a large role to play there. The terms in the Long Term Conditions action plan are monitored by the Long Term Conditions Programme Board that sees reports on the progress. This has been put on hold at the moment due to Dr Pete MacKenzie's illness but this will be picked up again once the new post-holder is in place.

**6.22** Mary Scanlon MSP said that she had received another point from Dorothy-Grace Elder about the fact that the Long Term Conditions Alliance has a budget of £900,000, and it has been discussed that chronic pain is part of many of the long-term conditions; does any of this money go to chronic pain? Will said that Angela Donaldson might want to comment on the Alliance point, but the money that comes from the Health Directorate is to pay the salaries of the people who are employed by the Long Term Conditions Alliance, the rent of their premises, which includes the long term conditions hub and that is about £550,000. Will said he didn't know where the figure £900,000 came from. They do have the self-management fund, which had been £2m in the last two financial years, which funds 81 projects.

**! Action Point:** Mary Scanlon MSP requested a written response for the questions above (for distribution purposes and to use as a written record).

**6.23** Diane Thomson from Pfizer asked if there was any opportunity with the new SIGN guideline to look at the potential for (NHS Quality and Outcomes Framework) QOF points, as QOF has real attraction and support within Primary Care? Prof Blair Smith answered that the simple answer was no, due to SIGNs focus on scientific evidence for managing conditions.

Prof. Ian Power said that it might be attractive to make recommendations based on SIGN guidelines and submit them to QOF, as it would be a benefit to patients. Blair informed the group that entry into QOF is now regulated by NICE therefore if there are no NICE guidelines QOF points are highly unlikely. Will Scott also stated that QOF was UK based and it was a very difficult process to influence.

**6.24** Heather Wallace informed the group that Martin Johnson's initiative has managed to get pain a priority in the area of the Royal College of General Practitioners (RCGP) between the years of 2011-2013. She asked if it is going to impact in Scotland and will the Royal College up here be involved in that? Blair answered that the RCGP is a national organisation so anything that will affect England will affect Scotland. He said that he had yet to see how it would work, but there is a RCGP pain group which consists of one member from each of the four countries in the UK, and he is the Scottish Representative so he said he would keep the group up to date on the progress.

As a further point Heather asked if Blair could try to get representation from the RCGP along to the Cross Party Group as all attempts to date have failed.

**6.25** Anne Ruglys, from Sanofi Pasteur MSD asked with reference to the SIGN guidelines, would it recommend the vaccination against shingles as part of the prevention? Blair said that this was a specific intervention in the prevention of neuropathic pain resulting from *herpes zoster (shingles)*. He said he didn't see any reason why they should not be looking at the effectiveness of that, especially with the current literature available.

**7. The Managed Clinical Network Dr. Gavin Gordon, consultant in pain medicine will update the group on the work being done in Glasgow and Clyde**

Dr Gavin Gordon could not attend the meeting but has submitted a report, which will be tabled.

**8. Opioid discussion – why has there been such a dramatic increase in Opioid painkillers in the past 10 years? We have Steve Gilbert addressing us on the advantages and disadvantages of the use of opioids**

Steve Gilbert from Queen Margaret Hospital introduced himself to the group and said that he was asked to talk about the rise in Opioid use as pain relief. He said that his is a topical issue within the clinical world.

**8.1 *Opioids have been around for a long time***

- Opium poppies have been found in burial sites from 4000 –100 BC
- It was used for Sumerian “joy juice” in 3200 BC
- 1500 BC opium as a cure for headache
- Cure for a crying child
- Throughout history it has been a useful and effective medicine
- During the middle ages it was use as an antidote for the purgatives that were given to get rid of the evil humours that were inside of them
- 1300 they had a brief fall in use during the Spanish Inquisition and Puritism
- Re-introduced by a gentleman who received the nickname of Paracelsus, he went over and spoke to the Arabic doctors and found they were still using opium
- Became popular in the 19<sup>th</sup> Century in Laudanum particularly for period pains and vague kinds of pain

**8.2 *British history***

- Opium was introduced to China by traders in the middle ages
- Chinese Emperor banned it in 1800
- East India Company started trade in opium again with China
- In 1838 Chinese Emperor seized a cargo of Opium worth £10m today
- Britain started the first opium war, they lost
- Britain started the second opium war in which China was forced to accede to legalise opium again
- Wide-spread opium addiction in China which did not improve until a dictatorial Emperor sorted things out

**8.3 *Opium in 20<sup>th</sup> Century***

- Opium, Heroine, Morphine were becoming a problem in the west
- Conference on opium use in The Hague 1909 lead to the Harrison Act in America and international consensus on restriction of Opiates in 1914

- Medical research conducted into an opiate type analgesic which wouldn't give all these problems with addiction
- Synthesised Morphine 1817
- Codeine 1832
- Heroin 1897, called Heroin because it was the answer to morphine and codeine addiction. Marketed as a cough medicine for children
- Oxycodon in 1916
- Methadone in 1939
- Fentanyl and other compounds after 1950s

After the Harrison Act in America there was quite a bit of Opiophobia where they were worried about the dangers of using opioids as pain relief. It was only allowed on restricted prescriptions and was reserved for the last stages of life and people with cancer.

#### 8.4 Quotes from textbooks:

*"All the drugs that are affective in controlling pain are habit-producing and therefore must be used sparingly"* Cole, Management of Pain in cancers, American Text Book on Palliative Care 1950s

*"One resorts to narcotic drugs when habituation is an accepted as the lesser of two evils"* Harrison, Principles of Internal Medicine 1960s

It got to the point that people were being denied adequate analgesia and were having terrible pain associated with cancer and terminal illness.

#### 8.5 Dame Cicely Saunders 1960s

- Showed that Palliative care patients could be treated with strong opiates and revolutionised Palliative care.
- Showed that Morphine was more effective than diamorphine and both were more effective than the commonly used Brompton Cocktail (opium, morphine and alcohol)
- Conducted objective research with Richard Twycross, which found that most people with a painful disease could be helped with strong painkillers. There wasn't the danger and didn't develop a tolerance that was shown in people with addiction and provided the base for the World Health Organisation (WHO) analgesic ladder. This worked well for people with cancer but still not enough support for people with non-cancer pain.

#### 8.6 Steve said that not long after he started as a consultant in pain medicine he was given an article by **Ron Melzack**, *"The Tragedy of Needless Pain"* 1990 in *Scientific American*

- Melzack found that there were many people with chronic pain who were travelling around America trying to find doctors who would prescribe strong painkillers and that there was a regulatory persecution of doctors who did prescribe strong painkillers.
- *"Pain is a more terrible lord of man than death itself"* Albert Schweitzer
- Ron Melzack pointed out that there were a lot of differences between pain sufferers and addicts. A drug addict has got a craving to escape from reality where as pain sufferers want to get back to normal. He hypothesised that there were different pain pathways going on.

- Quoted a paper about a burns hospital in Boston. 5000 patients through with burns and they received morphine. They had a tiny incidence of addiction and the headline comment at the end of the paper said that the Doctors that were working in the burns hospital were ten times more likely to become addicted than the patients.
- Lead to people like Michael Cousins writing papers about pain being a human right.

### **8.7 Pain in Europe survey 2003**

- 1 in 4 patients said that their GP doesn't know how to manage their pain
- 2/3 believed that their medication wasn't sufficient
- Strong opiates are hardly used at all in some countries
- Difference in prevalence of pain across different countries in Europe
- Norway 30% people with chronic pain vs. Spain 11%, UK 13%
- Use of opioids; Britain 12%, Italy 0%, Spain 1%

### **8.8 Cochrane Review 2009**

- Pain: 35% on opioids respond to treatment vs. 31% on placebo
- Physical Functioning: 29% improve on opioids vs. 26% on placebo
- Side effects: 23% on opioids vs. 15% on placebo
- Overall there is some affect but not great

### **8.9 Problems with Research**

- Mostly short-term assessments
- Average benefit for all, conceals major benefits
- Artificial response
- Placebo

### **8.10 There have been some papers that do suggest there is no added benefit for opioids.**

- Editorial in Pain Magazine 2006 "*Opioids for Chronic Pain: Taking Stock*" which was looking at the experience in Denmark which were as enthusiastic as us for prescribing opioids for chronic pain.
- "*We believe that they have established the success of opioid treatment of acute and terminal cancer pain can be reproduced in the case of chronic pain and if only we could overcome Opiophobia we would improve the lives of chronic pain patients*"
- "*We know that there are patients whose lives have improved and even transformed and nobody wants to revert to withholding opioid treatment from those with chronic pain conditions but there is a growing body of evidence which suggests that not all patients benefit and a cautious and structured and selective treatment approach could be the best way to preserve opioid treatment for those that do rather than us going on to be too enthusiastic, getting into problems and going back to Opiophobia*"

**8.11** The British Pain Society (BPS) in conjunction with Faculty of Pain Medicine at the Royal College of Anaesthetists, College of GPs and the Faculty of Addictions at the Royal College of Psychiatrists produced some Guidelines. Although these guidelines have been written with the input of the Royal College of General Practitioners (RCGP)

they have not been circulated to the all GPs only to members of the BPS. These guidelines are evidence-based and centred on sensible advice on how to use opioids for chronic non-malignant pain and persistent pain. The Guidelines and Patient Information Booklet can be downloaded from the British Pain Society website.

**8.12 *Opioid prescriptions in Scotland over the last four years have increased substantially***

- Morphine and Buprenorphine have increased by 40%
- Fentanyl and Oxycodon have increased by 75%
- This is due to prescribing behaviour not through the rise of incidences of pain

**8.13** Steve concluded that having been asked to give this talk, made him think that it is time that people in pain services “Took Stock” and discussed these issues. Also to take the advice of the BPS etc. and discuss options with the patients on the alternatives to pharmacological management of pain.

**8.14** Prof. Ian Power made the point that the little booklet on prescription of opioids done by the College of Anaesthetists seems to have had such little impact which he found shocking. He went on to say that it could be that Anaesthetists don’t share enough.

**! Action Point:** Steve Gilbert to share presentation with Gil Paterson MSP, Richard Simpson MSP& Mary Scanlon MSP

**8.15** Steve Gilbert stated that the data is on the number of prescriptions, it isn’t divided into the different conditions. Also there could be a number of factors that artificially inflate the numbers such as shorter prescription time for easier monitoring therefore meaning more prescriptions written. Also it could be that there are multiple prescriptions for one individual (i.e. a short-acting and long-acting painkillers prescribed at the same time).

**8.16** Mary Scanlon MSP mentioned the Double Effect. Steve Gilbert said that the doctrine of the Double Effect was an insidious teaching, which comes way back from the days of the Brompton Cocktail. At that time it was felt that there was little that could be done for people with terminal cancer and they would be stupefied so there would be this Double Effect where there would be pain relief, but they would also be sedated and that would lead to respiratory problems and they would be more likely to die more quickly and that is not the way that modern palliative care works. The aim of modern palliative care is to give adequate analgesia aswell as maintaining the patients' mental faculties and improve their quality of life. He believes that the doctrine of Double Effect should be avoided.

**8.17** Mary Scanlon MSP also asked if Steve was concerned at the rise of opioid use and did he think that politicians should be concerned? Steve said that the attitudes to opioids have come and gone, and that heroine was a perfectly acceptable medicine at the end of the 19<sup>th</sup> century which could be obtained over the counter or through a catalogue. Societies’ attitudes to drugs are complicated. But we need to make sure that we do not do patients harm. Research has to be conducted and also drawing up agreements with patients and promoting other ways of dealing with pain.

**8.18** Heather Wallace informed the group that Pain Concern gets lots of testimonials from people whose lives have been changed by the use of opiates and that Steve made an important point, that it is not only opiates used with chronic pain, it is a part of a whole

pain management package. She stated that the appropriate drug had to be prescribed. She went on to say that both Blair and herself were on the NICE committee which drew up guidelines for Neuropathic pain and the advice there was to avoid opiates, but we are getting a lot of GPs that are still prescribing opioids for newly diagnosed neuropathic pain. Steve Gilbert said that there was a mixed review of evidence regarding drug use in neuropathic pain. The NICE guidelines state that there is a moderate benefit to opioid use with this kind of pain. Certainly with anti-neuropathic agents like Gabapentin and Pregabalin they have found that there is an improvement with a lower dose of each and less side-effects. It stems back to whether your patient is responsive or not.

Steve re-iterated that there is a lot of benefit for opioids and to stop them completely would be a mistake but if they are used in conjunction with other methods of pain management they should be, as long as it is not harming the patient.

**8.19** Prof. Ian Power said that all this talk of opioid use, takes him back to the Shipman case where he sat on the panel for drug use. It was agreed then that opioids should not be withdrawn from use, but the problem was the storage and hoarding of the drugs (e.g. the opioid may get stored in the bathroom cabinet and then used by someone unlawfully, however community pharmacists have a huge role in the appropriate use of opioids in large amounts).

**8.20** Steve told the group that most of his information was from a book called "*Opioids from a Historical Perspective*" published by the International Association for the Study of Pain.

**8.21** Mary Scanlon MSP said that it might be a good idea to have a more grown-up discussion at some point regarding the use of opioids and get some parliamentary questions. Steve Gilbert said that a possible way forward would be to get the medical community's impression but not to go onto parliamentary questions at the moment regarding opioids due to the possibility of hysteria. Steve also asked if a member from one of the drug companies might want to respond to his presentation.

Bill Paton, Public Affairs Manager for Napp, said that he thought that the presentation was a really interesting and balanced view of opioid use. He said that Napp would look forward to a review of opiate use and would be more than happy to participate in that.

**8.22** Mary Scanlon said that the issues of opioids could be a Cross Party Group in its own right but would leave that up to discussion.

**8.23** Helen Cadden stated being a patient representative she would like to re-iterate Heather's comment of the benefits of opioid use in pain relief for many patients.

**9. Any other business: No other business was discussed**

**10. The next two meetings are on: Wednesday 2 March 2011 6.15pm-8.30pm  
Wednesday 15 June 2011 6.15pm-8.30pm**

**The Cross Party Group on Chronic Pain would like to thank Medtronic Pharmaceuticals for sponsoring the cost of refreshments.**