Meeting of the Scottish Parliament Cross Party Group on Chronic Pain
Held on: 20 September 2006
Held in: Committee Room 5, The Scottish Parliament, Holyrood, Edinburgh

Present

- Dr Jean Turner MSP - Convenor
- John Home Robertson MSP (*left at 19.10 hours after item 22).*
- Nanette Milne MSP
- Dorothy Lynas - Secretary
- Gillian Wilson - Secretary
- Dr Norma McGeoch – Dr Jean Turner's Office
- Ryan Anderson
- Phil Atkinson – editor, Scotland's Health Magazine
- Dr. Jon Bannister, Consultant in Pain Management, Dundee; North British Pain Association Council Member
- Janette Barrie - Practice Development Project Coordinator, NHS Quality Improvement Scotland
- Mike Basler – Consultant in Pain Management and Anaesthesia, Glasgow Royal Infirmary; Secretary of North British Pain Association (NBPA)
- Helen Cadden – NHS QIS public partner, patient
- Lynne Calman - Arthritis Care in Scotland
- David Craig – Consultant Clinical Psychologist, Glasgow
- Dorothy-Grace Elder – former convenor of cross party group on chronic pain; journalist
- David Falconer, Director, Pain Association Scotland
- Steve Gilbert – Consultant in Anaesthesia and Pain Medicine, Dunfermline
- Dr Gavin Gordon – Consultant in Pain Management and Lead Clinician South Glasgow
- Sally Hughes – Medical Representative, Napp Pharmaceuticals
- Mrs Janice Johnson – PSALV, patient
- Gerry Lafferty - patient
- John Macgill - BPS Policy Officer for Scotland
- Dr Pete Mackenzie – Consultant in Pain Management, Southern General Hospital, representative of the Royal College of Anaesthetists, also regional adviser in pain management in the west of Scotland
- Margaret McLachlan – PSALV, patient
- John Mclennan - Lead Physiotherapist, Lothian Chronic Pain Service
- Mick McMenemy - lead clinician, Greater Glasgow Back Pain Service
- Fiona Macpherson – Clinical Nurse Specialist, Western General Hospital, Edinburgh
- Dr Bill Macrae – Consultant in Pain Medicine, Tayside
- Bernard Mills – Candlelight Association; tutor on pain management programme; patient
- Sandra Mills – Chairman, Candlelight Association
- Ruth Quinn - Grunenthal
- Anthony Sneider - National Officer, British Psychological Society
- Nicola Stuckey - Head of Clinical Psychology, Astley Ainslie Hospital; Chair of North British Pain Association
- Diane Thomson - Government and Health Policy Manager Scotland, Wyeth Pharmaceuticals
- John Thomson – Patient
- Heather Wallace – Pain Concern; patient
- Adam Wragg, Manager, Pain Services, Medtronic Neurological

Apologies
Mary Scanlon
Eleanor Scott MSP
Pauline McNeill MSP
Dennis Canavan, MSP
John Swinburne, MSP
Irene Oldfather, MSP
Annabel Goldie, MSP
Karen Whitefield, MSP
Professor Sir Michael Bond, Glasgow University
Dr Blair Smith, General Practitioner
Lars Williams, Southern General Hospital
John Norden, Nurse Educator in Pain Management, Lanarkshire
Derek Jones, Lecturer in Occupational Therapy, Queen Margaret University
Dr Denis Martin, Lecturer in Physiotherapy
Professor James McEwan
Dr Ruhy Parris, Royal Victoria Infirmary, Glasgow
Dr Mike Serpell, Gartnavel Hospital, Glasgow
Michael Walton
Paulo Quadros - Director, Integrated Living Network
Professor Ian Power, Dept of Anaesthesia, University of Edinburgh
Keith Tippey, BackCare
Judith Rafferty, Lead Nurse for Pain Services in Tayside
Judith Corcoran

1 **Jean Turner** thanked Mary Scanlon for asking her to help out with the cross party group. When Mary Scanlon decided to stand for election, Jean agreed to take over as convenor of the group. Nanette Milne was kind enough to replace Mary Scanlon for the Conservatives. Jean Turner thanked John Home Robertson for his continued support.

2 AGM – Election of Office Bearers
***Co-Convenor*: Jean Turner** - nominated by John Home Robertson and Nanette Milne.
***Co Convenor* : John Home Robertson** - nominated by Jean Turner, seconded by Nanette Milne.
***Vice Convenor:* Mick Macmenemy** - nominated by David Falconer
***Secretaries:* Gillian Wilson and Dorothy Lynas**. Nominated by Jean Turner, seconded by Nicola Stuckey.

3 **Minutes** of the meeting held on 28 September 2005 were approved by Mike Basler, seconded by Anthony Sneider.

4 **Dorothy-Grace Elder** gave Mary Scanlon's apologies and asked if there had been an update on the questions Mary had sent in. We have had the Minister's reply (26/1/06). Nicola Stuckey and David Craig's letter (8/2/06) raised some important points about clinical psychology. Dorothy-Grace Elder also asked if any of the executive's surplus from last year would be invested in chronic pain facilities. On June 28th this year Tom McCabe had declared an underspend of £235 million last year, and the executive will receive several hundred million pounds from the treasury over the next 2 years.

5 **Jean Turner** said there had been stalling in Glasgow. The clinicians had the facilities for a pain management programme, but no money to start the service.

6 **Mike Basler:** There are two issues:
1. West of Scotland pain management programme was put on hold for financial reasons I can now say that we have the go ahead from Greater Glasgow Health Board for

funding a tertiary pain management programme in the west, like Astley Ainslie's programme. They plan to advertise posts and get going in New Year.

2. Regarding ACADs (Ambulatory Care and Diagnostic Units), there have been plans to fuse small units into 2 larger units. There is a 2-year delay but it is happening.

7 **Bill Macrae:** I brought up the question of Highland Health Board at the last meeting - Andy Kerr said he would try and do something. Highland Health Board held a meeting - but there has been no progress. I had 3 referrals from Highland this week – there is a service agreement but people travel in pain from Wick to Perth to be seen. There are no MRI scans, patient notes are not available, etc.

8 **Jean Turner:** The minister states that money is given to the health boards for services – the minister needs to know what is going on. Glasgow Health Board had to clear £58 million before they could start the new programme. Funding is not ring-fenced. How long do people have to wait for this service?

9 **Mike Basler:** There are now patients waiting to use the new service. Glasgow services are comparatively well funded. Argyle and Clyde have been incorporated into Glasgow – we now have to see patients from Argyle and Clyde and Lanarkshire as well. Referrals have gone up by 40%.

10 **Bill Macrae:** Scrutinise what Highland Health Board say. They are doing nothing. Tayside patients are suffering because our waiting times are being pushed back due to Highland referrals.

11 **Jean Turner** read out Highland's reply to the McEwan Report. There is a limited outpatient chronic pain service in Fort William and Wick by consultants with an interest. Limited referrals are made to Aberdeen and Dundee. The majority of care is provided by primary care. An objective of Highland Health Board for 2005-6 is to support chronic pain management. A full scoping exercise against the recommendations of the report will be presented to Highland Health Board in October 2005.

12 **Bill Macrae:** There is a tiny clinic in Wick, nothing in Inverness. We get referrals from all over Highlands.

13 **Jean Turner** suggested that people write to the minister themselves. And we can write from the cross party group.

14 **Helen Cadden:** The situation is not acceptable to people with chronic pain. The public are being let down. Lack of provision of services is a false economy. Chronic pain devastates sufferers, families, friends, and carers. If services were available when needed, patients would respond better. They can get back to work and become constructive members of society again.

15 **Jean Turner:** It would be cost effective to the health service if chronic pain were dealt with properly. We need to push the minister, invite him again.

16 **Dorothy-Grace Elder:** In April 2002 Highland Health Board were take to task for lack of chronic pain services. They promised to look into it. Now 2006 – no progress. Kerry McEwan, 20-year-old chronic pain patient from Highland region had to be referred to a hospice for chronic pain relief, although she was not terminally ill, simply because there was no other pain service in her area.

17 **Jean Turner:** The minister is the only person who can push the boards. MSPs and everyone affected should write to him.

18 **Helen Cadden:** People are frightened to come forward – scared their treatment will be affected or stopped.

19 **Jean Turner:** Patients and clinicians should speak out. Patients should not feel fear.

20 **Pete Mackenzie** spoke of a lot of delays in pain management developments in Scotland. The minister does not want personal responsibility for service development, but he has communicated with NHS QIS. They have made an offer to take forward a managed clinical network and prioritise the standards of chronic pain services in Scotland.

21 **Mike Basler:** We have to be clear exactly what is on offer. It is a paced long-term approach. It is a step to highlight deficiencies in the service and document them.

.

21.1 The first offer is a stock take of existing resources. And although people here do not have faith in replies from health boards I would say that boards have a statutory requirement to notify NHS QIS what is going on. What would that do? It would tell us what is there and what is needed where, and with reasonable statutory clout.

21.2 The second offer: A pilot Managed Clinical Network (MCN) It will not have resources pumped into it at a clinical level. It has to have integrated standards, which are evidence based. It is multidisciplinary and has a quality assurance framework - and political assessment of progress. It is only a pilot in the west of Scotland, no promise of a rollout to other areas. No promise that it is going to translate into resources, but it can be seen as a step forward to our goals. If we look at the recommendations of the McEwan report we can see that most of the resource implications could be highlighted by an MCN.

Advantages are: A clear offer that our voice will be taken on board and MCNs are key to the Kerr report - more pressure on boards to deal with deficiencies.

22 **Helen Cadden** welcomed items put forward but standards take 4 years to come into use, which is a long time for patients to wait.

23 **Pete Mackenzie:** Appreciated NHS QIS standards could take time to happen but thinks there will be knowledge within health boards that they are going to happen and that preparations will be made to try and meet the standards. We must make it clear what they are likely to be. Bench marking can be done now and the MCN is something that can be got on with. Agreement is needed on how these proposals can be taken forward. It would be a positive step to say the professions working with chronic pain in Scotland want to take this forward as soon as possible. Pete Mackenzie has been asked by the chair of the Scottish Board to consult with colleagues and would like to respond to this offer from Jan Warner from NHS QIS. There is some debate about how this is done. Should it be through the next meeting of the North British Pain Association? We need to make some sort of response in the interests of moving forward.

24 **Jean Turner** agreed that we need to move forward. Chronic pain cannot be seen, and therefore is not seen as a priority. The private sector does not necessarily do this better. Treatment centres may do things quicker but destroy putting NHS facilities in place.

25 **Nicola Stuckey** supported some of the ideas put forward.
The minister said last year there was no pot of gold. His policy was to encourage health boards to come up with the cash through prioritisation. We need to form a lever by setting up standards for health boards to see. It is a long process but it is the only way we are likely to get consistency. Because services are so thin on the ground patients have to travel long distances.

26 **John Thomson:** It takes one and a half hours to travel from Glasgow to Astley Ainslie – 40 minutes on a good day, but sometimes three hours.

27 **Nicola Stuckey:** A stock take would clarify where disparities are within services. Each set of clinicians needs to be involved, so that it is not just a health board response.

28 **Margaret McLaughlin** asked*:* Will there be statutory patient involvement in Managed Clinical Networks, or just the odd one here and there?

29 **Mike Basler:** It is a statutory requirement for patients to be involved with MCNs. They are patient focused. They cut across regional boundaries. The only central funding is for a manager for 2 years. Gavin Gordon has done most of the work on this. If the pilot is successful, we need to get the minister to agree for the MCN to be spread out to other areas – Highland, Tayside etc. We need to put this in our reply.

30 **Jon Bannister***:* Stock take would show what isn't there. Very pleased with what Mike says. Very concerned about English situation. PCTs are buying private services and as a result good pain clinics are closing. Private services only provide regional nerve blocks.

31 **Steve Gilbert:** It is good we are getting something going in Glasgow but in our response we must say an MCN and an audit is good but we must have some funding. People get burned out trying to run a service with little or no resources,

32 **Mike Basler:** The offer is coming from NHS QIS Scotland whose function is to set standards and monitor if these are met. There are no resources. It forms another lever. We can ask but resources are unlikely. We want NHS QIS to do a thorough independent stock take.

33 **Jean Turner:** An election is due in May - a good time to push.

34 **Nicola Stuckey:** The Minister wanted this to be seen as coming under the management of long-term conditions within the framework of the Kerr report. Lothian Health Board is saying this is a generic approach across primary care and trying to link it with secondary care issues.

35 **Mick McMenemy:** Health Minister acknowledges that chronic pain is becoming an identifiable separate issue. We have identified it as a specific issue. It must not be lost in long-term conditions.

36 **Jean Turner:** McEwan report said £1000 per patient could be saved if there was proper chronic pan management. We need more evidence.

37 **Helen Cadden:** As the chair of a long-term conditions group for the rehabilitation framework for which there is no resources, it would worry me if chronic pain got lumped in with that.

38 **Gavin Gordon:** NHS QIS proposals are worth pursuing. An MCN needs standards. These proposals are in addition to what is already going on. Polite persistence is needed. Health boards are the paymasters but regional planning groups have clout. We must keep primary care on board.

39 **Bill Macrae:** supports these proposals. Need to look at best practice in Scotland. Tayside health board does listen and resources generously. Highland just says that people cope. We must benchmark good services such as Greater Glasgow's back service and the pain management programme at the Astley Ainslie. Why don't we have a residential pain management programme that everyone could attend?

40 **John Thomson:** It needs to be patient focused. Some patients contemplate suicide because their pain is so bad!

41 **Nicola Stuckey** said the suicide issue – not uncommon – is a hidden cost. The McEwan report highlights that it is important to have sufficient funding for psychological services within pain services. There are not enough funded posts to address the issues. The minister says that there has been additional funding for training within the profession – but not for funding posts. This is why David Craig and herself wrote to the minister but with no effect.

42 **Jean Turner:** Where they say there are more clinical psychologists they are not experienced to work in the chronic pain services. Chronic pain and depression should not be treated in isolation of each other.

43 **Nicola Stuckey:** We need integrated services.

44 **Mike Basler:** We are going to be competing with epilepsy, MS, etc. so the stock take and audit and our standards need to be credible and not just a wish list.

45 **Pete Mackenzie** supported the notion that professionals working within the services do contribute to the bench marking exercise in how the process is done. Feels NHS QIS is looking for some advice on the type of information needs. Two years ago in Glasgow a needs assessment was carried out and tabulated by professional group, and compared to what the national group had recommended about core services. The information is available. Need to avoid complicated discussions about how it is to be done.

46 **Jean Turner:** Could this be linked in with GP referrals - where chronic pain services are working well GP referrals to other areas, such as neurology, etc., are reduced?

47 **Helen Cadden:** This is all talk. Those of us who are experiencing pain want action now. Patients need to be involved at every stage so it remains patient focused. If we can get our pain treated quickly it will become cost effective.

48 **Dorothy-Grace Elder** is frustrated at the lack of action. Money saving is the big thing for the big parties. There is an election coming. The parties want votes. They need reminding of the strength of patient numbers – 550,000 sufferers and up to one million people living with a sufferer of chronic pain. Need to lobby MSPs.

49 **Jean Turner:** We know you had difficulty getting this group up and running but we are now much further on than before. Doctors feel frustrated because they cannot do what is needed. GPs are paid per item of service – not helpful for chronic pain. Specialist training may also be needed.

50 **Mike Basler:** NHS QIS have made an offer. Managed Clinical Networks have a statutory requirement to involve patients. That is a way of making your voice heard.

51 **Margaret McLaughlin:** Agreed with Mike Basler. MCNs are needed everywhere. Members of SALV could actually sit MCNs. This would ensure that patients involved knew what was involved.

52 **Jean Turner:** Must preserve what is good in Tayside and Glasgow for MCNs to work. Then it can be spread across Scotland.

53 **Dorothy-Grace Elder:** Can medical members here give us an audit of patients coming from other areas? Are there sizeable numbers going to Bath, Manchester, etc?

54 **Nicola Stuckey:** This would under-represent the need as patients are not referred away if they cannot travel.

55 **Jeanette Barrie:** Cross-boundary travelling will be included in QIS figures. Malcolm Daniels, consultant anaesthetist from Glasgow, is pulling a draft questionnaire together.

56 **Mike Basler:** The offer of an MCN came at the consensus conference, not through the cross party forum. This is why Mike is speaking to us. Work has already taken place and we need to ensure everyone feels included.

57 **Jean Turner:** Asked whether jobs in chronic pain are either not advertised in advance or not at all, to save money, as is the case with psychology.

58 **Nicola Stuckey:** There are no funded posts in chronic pain.

59 **Jean Turner** asked how many posts would be needed?

60 **Nicola Stuckey** replied that this would be part of the bench marking work.

61 **Jean Turner** may write a letter to Andy Kerr on behalf of the patients at this meeting to give the patient case.

62 **Dorothy-Grace Elder:** Andy Kerr needs to be reminded of what he said at the original debate. Gavin Gordon asked Jeanette Barry if we could ask NHS QIS how this benchmarking is progressing to prevent duplication of effort.

63 **Jeanette Barrie** did not see this as a problem.

64 **Mike Basler** did not see this as a problem. They were waiting to see whether this group wanted to take this on and move forward. The offer was made at the consensus conference when it seemed that the executive were almost rebuffing the McEwen report's recommendations. We now need to write back and say yes.

65 **Pete Mackenzie:** I wanted to suggest we set a deadline to agree what sort of questions we wanted on the benchmarking exercise

66 **Mike Basler** replied that we could not do that until we had agreed that we wanted to take the offer up. Now he would go back to Malcolm Daniels and he would write to NHS QIS that we wish to accept. They would then see the right people are consulted.

67 **Jean Turner** asked do you want us to write a letter from the cross party group after this meeting?

68 **Mike Basler:** From the NBPA point of view we will write to NHS QIS saying we are fully supportive of the offer.

69 **Dorothy-Grace Elder:** It is only funded for 2 years.

70 **Mike Basler:** This is what is on offer.

1. Stock take of what is available now.
2. Pilot MCN looking at west of Scotland. No guarantee in writing that it will be rolled out
3. Standards will be produced.

71 **Dorothy-Grace Elder** asked has there been any improvement since the McEwan report? Wants a letter written tonight noting our frustration.

72 **Mike Basler:** The Glasgow pain management programme is going ahead. He has been told the McEwan report has pushed pain higher up the agenda.

73 **Pete Mackenzie** informed the group that there is a new lead clinician in Glasgow and there is a group set up in Lanarkshire to look at chronic pain.

74 **Norma McGeoch** advised that if patients were going to write to the minister, to put it through MSPs - get your MSP to send your letter for you!

75 **Margaret McLaughlin** asked Mike to confirm if all 3 steps on offer were needed and urged the group to support them.

76 **Helen Cadden** asked have we got patient representation?

77 **Mike Basler:** We need to be clear where we are - step 1 - no plans yet from QIS. Step 2 – the MCN - is not yet set up.

78 **Helen Cadden** will be going back to NHS QIS because she is a public partner. She will be pushing to be involved and pushing for public representation.

79 **Gavin Gordon:** NHS QIS offer should be taken. Does not stop patients or anyone else asking for more. Health boards understand one thing – waiting times. Facing shorter waiting time deadlines both this December and next. They will understand pressure if their patients are waiting. Use this to make your case.

80 **Dorothy Grace Elder:** Many GPs are not well informed about pain services. Is there any way this group could encourage GPs to refer patients to pain services?

81 **Steven Gilbert:** Could be worth our group approaching the Royal College of General Practitioners. Medicine and surgery control the curriculum at medical school. We need to convince them that medical students need to learn about pain management.

82 **Bernard Mills:** Most patients are unhappy with services. Six minutes with their GP is insufficient for full discussion of symptoms – felt they were being treated as guinea pigs – try yet another medication. Patients should be a big part of planning and progress.

83 **Jean Turner:** The proposal Mike made is going to tell us exactly where we stand. We will have facts to give back to NHS QIS. We are making progress. Before patients can get what they need the GPs and clinicians have to be convinced.

84 **Heather Wallace:** These 3 steps are good way forward and the issue of GPs not referring is important. Had a meeting with Jean Turner to look at representation on this group. As a result of that we have approached the RCGPs, RCN, and other groups have now been contacted.

85 **Jean Turner:** Any other relevant groups people know of would be good. Jean Turner read out list of apologies of those who could not attend.

87 **Nicola Stuckey:** Final pulling together. Will write on behalf of NBPA to the minister supporting NHS QIS proposals and to NHS QIS. Situation needs to be addressed at local and national level. Plus a letter to the minister from this group and from individual patients.

88 **Helen Cadden:** Expressed an appreciation of the group's work on behalf of patients. They will continue to push until they get a service they can work with.

89 **Jean Turner:** Are we clear what we are going to do? We will support what Mike has put on table.

90 **Gill Wilson** asked how often should we meet?

91 **Jean Turner** pointed out that April 3rd is the last meeting of parliament. Agreed we should write to the minister again on behalf of patients and the group, saying what the group has decided and asking when in January he could come.
Jean Turner asked who would the group like to come and speak to them?

92 **Ruth Quinn** suggested Dr Martin Johnson, Chair RCGP pain group who could put forward GP's perspective.

93 **Pete Mackenzie:** Rosalie Dunn is a GP in Lanarkshire. She is actually working in Scotland. He is not optimistic that the minister will attend the next meeting. We could go to press but we need to go to press with one voice.

95 **Jean Turner:** Thinks it is worth Andy Kerr being given the chance to refuse. Could point out in her letter that members are so frustrated they wish to go to the press.

Meeting ended at 20.55 hours.
The Convenor thanked **Medtronic** for sponsoring the refreshments

Action Points

- Jean Turner to write to Andy Kerr – invite him to next meeting + patients concern.
- To write to NHS QIS accepting offer on behalf of group.
- Mike Basler, Nicola Stuckey and others to write to to NHS QIS accepting offer on behalf of own organisations
- Secretariat to ascertain room availability + Andy Kerr in January.
- Secretariat to circulate details of the Long Term Conditions Alliance's conference on *The Voluntary Sectors Approach to Self Management Programmes* (Flyer tabled at meeting by Lynne Calman - Arthritis Care in Scotland)