

DECEMBER 17 2013 MEETING OF THE CROSS PARTY GROUP ON CHRONIC PAIN. DRAFT MINUTES

Co-conveners present: John Wilson MSP, Jackie Baillie MSP, Jackson Carlaw MSP.

(Attendance and apologies listed at end.)

WELCOME: John Wilson MSP chaired and welcomed everyone.

Secretariat Jacquie Forde was unable to attend this meeting and her apologies were noted .

Minutes of the meeting of September 3, 2013 were approved unanimously, to be posted. ACTION: Jacquie Forde, voluntary secretary.

John Wilson MSP introduced the speakers:

Fiona Collie of Carers Scotland, who spelled out the problems and money shortages of carers, many of whom deal with chronic pain.

Dr Lesley Holdsworth of Healthcare Improvement Scotland (HIS) gave an Update presentation on her work, which included part of the new data collection. She said HIS was anxious to get it right and a full report would be issued in the spring. She confirmed data would include staffing time/numbers and patient numbers and data on continuing patients as well as new referrals, among points which the CPG sought.

The meeting agreed Dr Holdsworth's preliminary presentation be circulated to the CPG and thanked her for what was obviously extensive work. ACTION: Jacquie Forde.

At the suggestion of John Wilson, it was agreed and that the "sole purpose" of a future meeting would be to discuss important developments.

PATIENT REPRESENTATION: ACCEPTANCE AND EXCLUSIONS

A letter from Michael Matheson, public health minister, assured the CPG that Government had heeded their request that more patients be appointed to the National Steering Group and sought "patient representatives from across Scotland".

But the Group questioned why the only three local patients appointed represented only the east (Tayside, Lothian and Forth Valley). HIS informed that they were the only three who had applied.

This led to considerable discussion. Members challenged why there had been continuation of limiting patient volunteers to those chosen by local Service Improvement Groups (SIGs) despite getting poor response, instead of opening applications to interested patients widely.

The meeting heard that other patients had tried to volunteer but found no information. Pete McCarron from Fife again raised how he had been treated as a voluntary pain helper for many years, saying he'd been promised application information by Fife last June but nothing was sent. He updated that, in October, he had been rejected without interview or earlier contact in an email from lead pain clinician Dr Steve Gilbert (Fife area). Pete said that Dr Gilbert's earlier objection to him (Sept 3 minutes) was that Pete might be "duplication" as he was a Pain Association member and the PA had a

representative on the Steering Group. Pete said that, in Dr Gilbert's email of October, the objection was different: that Pete was a past, but not a recent or current patient, with the Fife service. Pete said Dr Gilbert's email also advised that Clinical Priorities had informed him that the CPG also could not be represented as a Group.

A current Glasgow patient also notified the meeting that he had tried to apply, found no information but emailed health dept, the only contactable point he could find. Martin Tighe wrote that he is 36, had suffered chronic pain for 20 years, had current experience of Glasgow day services, also had residential treatment at Bath, experiences he thought useful.

HIS reported that they'd been particularly concerned about no patient application from a SIG in the West, had contacted the Glasgow SIG/MCN and they had now nominated a patient.

The meeting challenged selection methods over seeking only patients recommended by their local establishments, excluding wider patient interest, and lack of information for keen volunteer patients. Jackie Baillie MSP said: "However it is window dressed, this amounts to blocking. We must get a fair system for choosing patient representatives once and for all."

Objections were also heard over the continued exclusion of a representative of the CPG on the Steering Group, considering the Group had campaigned for over 12 years for a Scottish residential service to replace Bath and for radically improved day services, now Government & Parliament policy. But the

Dec. 6th letter from public health minister Michael Matheson, said it was "a long standing principle" (not a rule) applying to over 80 CPGs, not to have a CPG represented on Government bodies such as Steering Groups. Some members pointed out that no Government position was raised at the September 3 meeting although a Government Clinical Priorities civil servant was present. Disapproval of a previously unnotified barrier was voiced by several members who wished to know what or who had involved Government since Sept 3.

It was pointed out that when Dr Gilbert made a sole objection at the Sept 3 meeting to CPG representation, his grounds were that some Steering Group members were also on the CPG mailing list. Nobody mentioned a Government view.

Some members averred that the CPG had promoted excellent cross party relations and there had been no negative intervention from Government previously, who had indeed thanked the CPG for major campaigning achievements for patients, including the first Residential Service which Government and Opposition backed.

Conveners agreed further questions should be asked on how Steering Group and SIG appointees were recruited. Also, clarify the criteria for patient representatives. ACTION: Conveners.

LACK OF INFORMATION ON PAIN SERVICES Many in long-term pain were unaware that NHS Scotland had any chronic pain clinics, new CPG member, William Sinclair, Edinburgh, stressed. He'd had no idea that a GP could refer patients, until he heard of the CPG. Another member pointed out that even the pharmacy poster campaign of last year did not mention NHS pain clinics or that sufferers could ask a GP if they might be suitable for referral and asked if this omission might be because clinics were overloaded. HIS intimated they were considering a further pharmacy poster on chronic pain –officials were asked if there were audited figures on response and overall cost for the 2012 poster by the Scottish Government. Heather Wallace of Pain Concern confirmed her charity had received £10,000 from a Government agency for their involvement with the poster which she said they used to “pay the printer’s bill”.

Gillian Gunn from Clinical Priorities said she hoped to provide info on overall costs and authenticated response. ACTION: Clinical Priorities

HEALTH SECRETARY DECISIONS DUE ON RESIDENTIAL SERVICE. Dr Patricia Roche could not be present but asked that the CPG knew her views, which were read to the Group, on the creation of the first Scottish residential service/s to replace patients travelling to Bath. She strongly supported this being one national centre for Scotland and her personal view was that the Centre for Integrative Care/homeopathic hospital in Glasgow would be ideal for its services, (traditional and new) and its peaceful atmosphere. It was agreed that Dr Roche be informed, and the meeting given clarity, that the health secretary had first to decide in January 2014 if it should be one national centre or alternatives, after he had studied the public consultation results. Following that, a site, unknown at present, possible to be announced around the spring.

Other points raised: PAIN AND AGE

It was noted that HIS had held a successful launch on December 12 for the SIGN guidelines for primary and community care. A member thanked HIS for producing a special booklet for patients to summarise issues but suggested that the cover illustration, showing elderly people in a gym, was one of several recent illustrative examples implying that CP was an age problem when it was encountered across all age groups.

CPG MEMBER NAMED A SCOTTISH HERO

The meeting congratulated CPG member Mairi O’Keefe who’d been awarded “Scottish Community Champion of the Year” in the STV series “Finding Scotland’s Real Heroes” for saving from closure the respite centre Leuchie House, East Lothian. The centre helps those suffering many chronic conditions, including pain.

Thanks to the co-conveners for personally paying from own pockets for the tea, coffee and biscuits for this meeting.

MORE NEW MEMBERS

We extend a warm welcome to new members William Sinclair and Dr David Weeks.

Next meeting:

ATTENDANCE

Jackie Baillie MSP
John Wilson MSP
Jackson Carlaw MSP
Dr David Weeks
Pete McCarron
John Thomson
Anne Murray
Ann Cassels
Catherine Hughes
Dorothy-Grace Elder
William Sinclair
Dr Lesley Holdsworth HIS
Dr Steve Gilbert
John Glennie HIS Acting CEO
Robbie Pearson HIS deputy
Paul Cameron
Norma Turvill
Heather Wallace
Marion Beatson
Susan Archibald
Gill Gunn
Prof Blair Smith
Irene Logan

APOLOGIES

Sally Hughes
Anne Simpson
Gabrielle Stewart
Ross McDonald
Christine Drennan
Martin Johnson
Linda Mawson
Frank Mawson
Nick Alcock
C JMacFarlane
Pat Onions
David Onions
Malcolm Clubb
Boyd Meiklejohn
Graeme Fotheringham
Janette barrie

Sabu James
Ann Ruglys
Jean Rafferty
Martijn Steultjens
Dr Richard Simpson
Charles Martin
Kenny Boyle
ian Semmonds
Michael Serpell
Colin Rae
Jacquie Forde
Pat Roche

Approved Minutes