

SCOTTISH PARLIAMENT CROSS PARTY GROUP ON CHRONIC PAIN

Meeting & AGM October 4, 2017

1. Welcome from Rona Mackay MSP (chairing) This meeting clashed with health awards that night at Holyrood, which had to be attended by some MSPs and CPG members, some of our supporters are to be congratulated as nominees by patients for awards.

AGM Election of Office Bearers. MSPs Elaine Smith, Rona Mackay, Miles Briggs, Anas Sarwar had all agreed to serve again and were elected co conveners. Dorothy-Grace Elder was re-elected honorary secretary and Kathleen Powderly volunteered to help. Miles Briggs MSP said that the voluntary secretary had shown exceptional dedication in pursuing difficult cases for the CPG - with success - over most of the year and she was thanked by the meeting. Minutes of 20th June meeting and of the previous AGM were approved.

Result of CPG complaint to the UK Statistics Authority. The UK Regulator, Ed Humpherson came from London with two of his team members to meet MSPs Alex Neil and Elaine Smith and the voluntary secretary over the CPG's complaint that Scotland's independent statistics body, ISD, had been asked by Govt officials to cut facts on pain waiting times at clinics from Summary information. ISD had also been told by one Clinical Priorities official that they did not want return patient waiting times published (shown in an email trail through FOI) The Clinical Priorities dept is "Team Leader" on improving chronic pain services for patients and also on neurological conditions, so many thousands of patients are in their remit. Cuts were made, work on return patient info was halted.

After these approaches by Clinical Priorities officials, the statistics regulator's published finding was that "ISD made a series of misjudged decisions", had not been transparent, had "catered more for the needs of policy officials than of those outside Government, leading to the erosion of user confidence". The regulator declared that the CPG's case was an example of "where public confidence in health statistics needs to be improved and what the role of policy officials of the Scottish Government should be, and should not be". A Clinical Priorities Team Leader's email had also objected to ISD publishing return patient data, but the regulator recommended ISD resume pursuing this, as MSPs and the CPG had requested. (The CPG has long urged that return patients cannot be ignored)

Clinical Priorities officials claimed that they had acted on "patient feedback" and "feedback from patient representatives". But the regulator found that only one patient had been asked, who had not recommended the cuts Govt officials wanted and had not objected to return patient data. The regulator urged more patients than one must be consulted.

Yet despite the regulator's evidence, replies to Parliamentary questions still

claim “patient feedback” and “patient representatives”. (plural)

CPG Patients spoke of remaining concern that this had been “a shocking example of interference” with ISD’s independent work and deplored these behind scenes moves, unknown at the time. The regulator will review other ISD publications in the autumn and has urged ISD to keep the CPG informed and work with them in future. This has been done by ISD.

The CPG passed a motion saying they had no confidence in the Strategic Planning and Clinical Priorities department being “fit for purpose” on improvements for chronic pain patients, and requested the transfer of work for chronic pain services to another department, asking the health secretary to take personal responsibility.

Better News The ISD leadership made contact with the CPG right after the regulator’s response and met with return pain patient Liz Barrie, Alex Neil, MSP, Rona Mackay MSP, Alex Cole Hamilton MSP and the secretary to outline future, positive involvement with the CPG, which was welcome. There was no contact by Clinical Priorities. Mrs Barrie told eloquently of the “life destroying” agony suffered by patients like her, in being a year over treatment renewal time, and of the stress on excellent clinicians with too few staff. This whole issue was a nine month David v Goliath battle for volunteers but with some success for patients.

Brief consultation by ISD on pain waiting times publications. This initiative by ISD also followed the above experience helpfully. The result showed that the majority of respondents backed ISD obtaining return patient information to show how long these presently uncounted patients waited and the full pressure on pain clinic staff. The CPG advised that, in future, ISD should give longer than a month on consultations. ISD leaders also volunteered to address the next meeting of the CPG, to which they will be welcome. (Subsequently, ISD restored the missing information on new patient waiting times and resumed work on return patient data)

Update on musculoskeletal pain. The meeting welcomed Prof. Martijn Steultjens, Professor of Musculoskeletal Health, Glasgow Caledonian University. His talk showed how, from Scotland, Prof. Steultjens co ordinates an extensive European study on arthritis pain, financed by the European Commission. This is a major example of EU health improvement work – but what about other projects after Brexit? One accidental finding was that some patients told researchers a main reason for being isolated and not going out was the shortage of time at traffic lights. “They feared these crossings.” Researchers then timed and proved there was not enough time for those with painful disabilities. They discovered that a primary schoolgirl had won an ideas prize for suggesting that traffic lights have a second button, for those who need more time. Prof Steultjens thought this bright idea worth pursuing.

Update on the Centre for Integrative Care’s future after bed closure. Patient

Catherine Hughes reported that the CIC, since the bed ward closure, was now reduced to only two or three nurses. The hospital had 22 nurses in 2010 but had been targeted for cuts regularly since 2010, despite their treatments being praised by patients and reducing the drugs bill. The CIC now deals with outpatients and cannot help throughout Scotland due to the ward being closed. There was now also concern that physiotherapy services needed more protection.

ATTENDANCE: Co conveners Rona Mackay MSP; Miles Briggs MSP. Non MSPs: Prof. Martijn Steultjens, Christine Martin, John Thomson, Helen McCluskey, Laura Clark, Janette McDowall, Alan McGinley, Dr Jo McParland, Dr Patrick Trust, Catherine Hughes, Anne Hughes, Kathleen Powderly, Neil MacDonald, Alison Culpan, Martha Heaney, Margaret Miller, Paulo Quadros, George Welsh, Carole Brown, Frances Boyle, Hazel Young, Tanith Muller, Dorothy-Grace Elder (secretary)