



JEC HEALTH GROUP

Minutes of Voice Conference Held Tuesday 8th February, 2011

Present: Chair - Emma Williams (EW), Matthew's Friends
Sally Gomersall (SG), JEC Executive
Joanne Hill (JH), Quarriers
Fiona Kettell (FK), Epilepsy Wales
Pete Scott (PS), Epilepsy Action
Anissa Tonberg (AT), Epilepsy Scotland
Esther Whitten (EW), ESNA
Sharon Wood (SJW), JEC

1. **Apologies and Introductions**

Apologies were received from Jenny Rush (NSE), Alison Cornell (NCYPE), Aisling Farrell (Brainwave) and Gerard Gahagan (Quarriers).

Group members were introduced.

2. **Minutes of Meeting 24th September, 2010**

Minutes from the September 24th meeting were agreed as a true record of that meeting.

3. **Matters Arising**

There were no matters arising.

4. **Work Plan/Future Action and Confirmation of Budget Allocated for Group 2011/12**

Group members agreed that a work plan should concentrate on ensuring implementation of NICE, SIGN and Service Directive Guidelines, with timely responses to outside influences including newly published research, reports, government policy etc. It was recognised that the results of the Epilepsy 12 Audit, which focuses on outcomes

Action

and measures in part against NICE Guidelines, will be published in May 2011 and that the Health Group should focus on these to maximise impact. AT confirmed that Scotland are involved in this work, with an audit pilot site in Dundee and SJW suggested that NCYPE were also involved and that AC should be asked for further information and an update on the audit. Additionally, further details of the audit can be found on <http://www.rcpch.ac.uk/Research/ce/Clinical-Audit/National-Epilepsy-Audit>.

FK advised of the results of an audit of the Welsh Service Directory for Epilepsy and results are not good, as expected. Results can be found on the Welsh Assembly Website searching for Audit Result of NLI AH.

EW advised that Epilepsy Specialist Nurse posts are still causing concern with funded posts not being continued, nurses being returned to ward duties part-time etc. This situation was confirmed by many group members. JH advised that in Scotland, ESN job descriptions are being redrawn.

The publication of a statement of existing facts around the inadequacies of current health service provision, or a "crib sheet" of facts and figures pulling from all the resources/reports that are currently available was agreed as an objective for the group. Due to financial restraints, it was agreed that this could be carried on the JEC website and SJW advised that she was working on a resource section for each working group to carry resources of this kind. All members to consider suitable resources which may be of interest to other members and to forward these to SJW for inclusion.

SJW confirmed that in the absence of a firm budget submission from the group, she had proposed the sum of £1,500 to cover two face-to-face meetings in 2011/12 with a small sum remaining for printing costs for any document the group planned and that this amount had been approved by the Executive. EW thanked SJW for securing this.

5. **JEC Executive Annual Review Meeting – 1st April 2011**

SJW extended an invitation to the Chair, or other representative of the Health Group, to attend the next JEC Executive Meeting when Chairs would be asked to briefly present on past work of the group and proposed work plans. EW confirmed that she would attend and will circulate a draft presentation to group members for agreement. SG discussed the publication of the provisional new NICE Clinical Guideline.

All

EW

6. **NICE Update**

SG advised that a further meeting of the NICE Guideline group will take place tomorrow (9th February) when latest consultation submissions will be discussed. Half an hour has been allocated to look at implementation issues. No set date for publication of the update has been set, although this is expected to be in June. SG will keep group members informed.

SG

7. **Verbal Reports from Group Members on Any Relevant Health Related Activity and Campaign Work on Health Matters**

Epilepsy Action: PS reported main work has been on consultations on NHS reforms and Disability Living Allowance/Personal Independent Payment plans. The latter seems to be a way for the Government to get around indefinite awards by regular reviews and the consultation closes on 14th February.

Epilepsy Action will shortly be launching a Geriatrician's Guide to Epilepsy.

PS drew member's attention to the Atlas of Variation, which contains relevant epilepsy charts which may be of interest.

Epilepsy Scotland: AT advised Epilepsy Scotland are running a series of round table briefings on behalf of the JEC for Scottish parliamentarians in the run-up to the May Scottish elections. One of the key documents being used is an 'Epilepsy Challenge' document, aimed at tackling the treatment gap in epilepsy services. The briefing for Labour MSPs went well, a further briefing for Conservative MSPs takes place tomorrow and a third, for LibDems, takes place on the 10th March. SJW confirmed she is attending the March briefing.

Epilepsy Scotland are launching a new Occupational Health Guideline at the end of February, aimed at employers.

Epilepsy Wales: FK confirmed elections for the Welsh Assembly will take place in May and work is ongoing to work with AMs.

Epilepsy Society: SG advised that a main campaign strand for the Epilepsy Society currently is the "Not in My Backyard" campaign concerned with disability living allowance.

ESNA: EW confirmed that ESNA are currently looking at documentation used by ESNs with the aim of compiling an on-line resource library.

More nurse-led workshops in relation to non-medical prescribing are planned, but unfortunately the main funding of this has been withdrawn.

JEC: SJW reminded group members about the second reading of Valerie Vaz MP's 10 Minute Rule Bill scheduled for 4th March, 2011. The only chance that this will be heard is if the Government makes time for it, therefore, all members are being asked to encourage their members and supporters to write to David Cameron to ask for this. A template letter has been circulated to all members and can be found on the JEC website.

SJW updated the group on work on the JEC statistics and advised of an excerpt from the NICE Partial Update of the Clinical Guideline 20 which quoted a figure of 492,000 people with epilepsy in England – this figure in accordance with the new, but disputed, JEC commissioned figures. It had therefore been agreed that Simon Wigglesworth would now finalise his stats report, including reference to the NICE statement in order for the new JEC stats figures to be signed off by the Executive and then disseminated further.

SJW also drew the group's attention to a situation which had arisen regarding a paper from the Council of the Society of British Neurological Surgeons (SBNS) which included a table of "Interventions of Lower Clinical Value" which includes surgery for epilepsy and vagal nerve stimulation. How to respond to this, which could be a very serious situation, is currently being decided. SJW to circulate an email with further information for member information.

Matthew's Friends: EW advised that cuts to dietician services are beginning with dieticians not being replaced and posts being withdrawn. Matthew's Friends are working as hard as possible to lobby against this and where possible fill some of the gaps, but these cutbacks, together with the withdrawal of disability living allowance and respite care are inevitably going to have major affects of the most vulnerable

8. **Any Other Business**

There was no other business.

9. **Date of Next Meeting**

It was agreed to re-schedule the proposed date of 25th March for the next meeting of the group as Purple Day takes place on the 26th March and some members may be involved in activities for this. SJW to circulate some dates for the following two weeks for members' to

SJW

SJW

respond to. It was agreed that the meeting should take place in London, venue to be advised.

|