

# Minutes of Epilepsy Consortium Meeting held on 27 January 2021

## Via Zoom

### Attendance

Rona Jonson	Epilepsy Scotland (Chair)
Ian Williams	Quarriers (Vice Chair)
Scott Johnstone	Lanarkshire Epilepsy
John Bruce	Individual
Anna de Vries	Epilepsy Connections
Chris Jeans	SUDEP Action
Paul Gillon	Veriton Pharma
Norma Crawford	Quarriers
Annette Parker	Sense Scotland
John Thomson	Eisai

### Apologies

Shirley Maxwell	Epilepsy Connections
Lesley Perkin	UCB

### 1. Welcome and apologies

RJ welcomed everyone to the meeting and shared apologies.

### 2. Minutes of meeting held on 28 October 2020

The minutes were reviewed and were agreed as accurate.

### 3. Matters arising

- The consultation on the draft regulations for Adult Disability Payment has been [published](#), the consultation itself will close 15<sup>th</sup> March. RJ asked present members if the Consortium should submit a response and it was agreed that a response from the Consortium would add extra weight. RJ suggested using the comment box at the end of the consultation for this.

**Action:** RJ to send an email to members to organise what should be included in the Consortium's response.

- A letter was sent to Her Majesty's Courts and Tribunals Service regarding the impact of telephone appeals on people with epilepsy. They are now aware of the issues that have been put forward. As the situation has not deteriorated, RJ sees no need to submit another letter at this point but would be happy to pick this up again if needed.
- The wording of the consultation on the Patient Safety Commissioner is being finalised. This role is coming into force after the Cumberlege Report and aims to ensure no more avoidable harm is suffered by medical devices/medications.

**Action:** RJ to circulation information once this is released.

#### 4. Member Updates

Member organisations each gave an update on current work and how they are continuing to adapt to operating during the pandemic.

#### 5. Neurological Framework Round 2 Funding

Funding for the second round of the Neurological Framework Funding is now open. The Scottish Government attended a recent meeting of the Neurological Alliance of Scotland on the topic. For this round, £1 million is available with no limit to how much projects can put a bid in for. Projects will need to be delivered between April 2021 and April 2022 (or September 2022) and need to be high quality, collaborative, robust and realistic. The original deadline for Monday 15<sup>th</sup> February has been extended until 1<sup>st</sup> March. Projects need to be relevant to the framework, transferable, transparent, and clear about their aims; evaluation should be possible. An example of a successful Round 1 project is the Epilepsy Database. Clinicians applied for funding to role out this database to NHS GGC, Tayside and Lanarkshire. The database provides information and alerts to clinicians about their patients. The team are hoping for success in Round 2 and hope to roll this system out to other Health Board areas.

#### 6. Parliamentary and CPG update

The most recent CPG meeting, which took place virtually, was a joint one with the MS Society. It focused on the new Adult Disability Payment system run by Social Security Scotland and was attended by the Cabinet Secretary for Social Security and Older People, Shirley-Anne Somerville.

The next CPG meeting will take place on Friday 26 February via Zoom and will focus on the video sharing platform VCreateNeuro with Professor Zuberi. This is an exciting and positive project that has come out of the pandemic. It allows patients to take videos and share them with their neurologist so that they can instantly see and react to the content. It bridges the gap in between appointments and has been rolled out very quickly due to COVID-19. This CPG meeting will be the last before the group will be disbanded ahead of the Scottish elections. It will be reconstituted in September.

**Action:** RJ to circulate the information on the upcoming CPG meeting.

#### 7. Financial Report

As financial documents were only received last minute they could not be circulated ahead of the meeting. The Consortium currently has £4517.68 available. There has not been much activity over the last year apart from income through annual membership subscriptions, a small interest, a payment to Epilepsy Connections for administrative support and a payment for refreshments for the last face-to-face CPG meeting in 2020. There are a few outstanding invoices from numerous organisations from last year's fees. PG clarified that the invoice received by Veriton Pharma was dated incorrectly and could not be actioned. After several inquiries for a correct invoice, this was not provided by Engage. If all outstanding invoices are correct, this will leave the Consortium with around £6000 which can be used to commission a piece of research as discussed at the previous meeting. It was suggested to wait until the next meeting when more members will be present to discuss this further.

**Action:** IW to send the financial report to AdV for circulation with the minutes. IW to contact Engage to issue correctly dated invoices to organisations with outstanding invoices.

**8. AOCB**

None.

**9. Date of Next Meeting**

Wednesday 28 April, 10.30am via Zoom