Epilepsy Consortium Scotland (ECS) Secretariat **DRAFT**
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Note of Meeting – Cross- Party Group on Epilepsy, 8 September 2016

In Attendance:

Jeremy Balfour MSP	Carsen Mandt, SPEN Programme Manager
Celia Brand, ESN NHS Lothian	Pamela Martis, NHS Lothian
John Bruce, Epilepsy Connections	Shirley Maxwell, Epilepsy Connections
Donald Cameron MSP	Dr Ailsa McLelland, NHS Lothian
Dr Susan Duncan, NHS Lothian	Hilary Mounfield, Scottish Epilepsy Centre
Yasmin Erginsoy. PA to Kenneth Gibson MSP	Alan Moir, Epilepsy Scotland
Ines Ezzeddine, Asst to Kenneth Gibson MSP	Allana Parker, Epilepsy Consortium Scotland
Mary Fee MSP	Gil Paterson MSP
Kenneth Gibson MSP	Susan Riddell, ESN, NHS Fife
Rhoda Grant MSP	Derek Robertson, ESN NHS Lothian
John Heaney, West Dumbartonshire Support Group	Brian Rocks, West Dumbartonshire Support Group
Joanne Hill, ESN Scottish Epilepsy Centre	Dr Aline Russell, Scottish Epilepsy Centre
Gerard Gahagan, ESN Scottish Epilepsy Centre	Dr Eleonora Saturno, NHS Fife
Gillian Horsburgh, NHS GG&C	Sharon Thinn, NHS Fife
Andrena Hughes, Observer	Anissa Tonberg, Epilepsy Scotland
Fiona Hughes, ESN NHS Fife	Margaret Wilson, ESN NHS GG&C
Chris Jeans, SUDEP Action Scotland	Sam Whitmore, Epilepsy Connections
Lorraine Mackenzie, Observer	

Apologies:

Claire Baker MSP	Peter Martin, Observer
Miles Briggs MSP	Lewis Macdonald MSP
Dr Ruth Brotherstone, NHS Lothian	Donald McIntosh, ESN Highlands
Jo Campbell, ESN NHS Grampian	Stuart McMillan MSP
Jane Cassidy, Observer	Anas Sarwar MSP
Rosanne Cassidy, Observer	Michelle Small, ESN NHS Lothian
Suzanne Cameron-Neilson, Royal Pharmaceutical Society	Brian Whittle, MSP
Alex Cole-Hamilton MSP	Lesslie Young, Epilepsy Scotland
Clare Haughey MSP	

1. Convener Kenneth Gibson MSP welcomed MSPs and attendees to the re-registration meeting

2. The draft note of the January 2016 meeting has been circulated. There were no amendments and it was approved. An update was given by the Convener on activities since May:

- The Scottish Parliament's first session coincided with National Epilepsy Week 2016. Kenneth Gibson MSP thanked colleagues in the room who signed his Members Motion in support of improved healthcare and raising awareness to end the stigmatisation of epilepsy
- The Convener has also agreed to sponsor a 2017 epilepsy exhibition in the Scottish Parliament for the Epilepsy Consortium Scotland (ECS). A decision and possible date is expected shortly.

3. Next were nominations for and the election of the Office Bearers. Allana Parker read out the nominations to date: Kenneth Gibson MSP for Convener and David Torrance MSP and Mary Fee MSP as Deputy Conveners. No other nominations were offered by MSPs in the room. Gil Paterson MSP and Jeremy Balfour MSP formally seconded the nominations which were then endorsed by Donald Cameron MSP and Rhoda Grant MSP. The Convener asked attendees about Epilepsy Scotland continuing to provide the Secretariat. This was unanimously agreed.

4. Attendees were asked to set provisional dates and times for future meetings pending the Standards Committee approval of the Cross-Party Group on Epilepsy re-registration. It was agreed meetings take place at lunchtime and on the last Thursday of January, April and September. Proposed dates for the remainder of this session are 26 January and 27 April 2017.

5. Suggestions were also invited for topics for these remaining two sessions. Attendees were asked to contact the Secretariat with ideas by Friday 30 September for the office bearers to consider.

6. The Convener was aware that the Secretariat had notified attendees asking if they wished to be listed on the Cross-Party group re-registration form. Copies of the draft form were available from Allana Parker. The final form will be submitted later this month and attendees notified afterwards. On behalf of the Epilepsy CPG, the Convener thanked everyone for their continued support.

7. He then welcomed guest speaker, Dr Aline Russell, a consultant clinical neurophysiologist at the Scottish Epilepsy Centre, who outlined EEG and videotelemetry provision in Scotland.

- Dr Russell explained that an EEG records electrical activity from the brain and is an important diagnostic procedure. The recording of seizure activity, and successfully capturing a typical clinical attack with video co-registered with EEG - known as videotelemetry (VT)) - can guide diagnosis, treatment and prognosis. Misdiagnosis of epilepsy (around 20%) is common. EEGs also assist planning for epilepsy surgery and for the diagnosis and treatment of status epilepticus (continuing non-convulsive seizures). Long term monitoring VT or just ambulatory EEG can be recorded at home over several days or in hospital in dedicated VT beds.

- During 2015, former CPG on Epilepsy Deputy Convener Dr Richard Simpson MSP sent an FOI questionnaire to all Scottish health boards. This provided an overview of EEG services and Dr Russell has since collected further data from her colleagues around Scotland including some extra questions on in-patient VT provision in dedicated beds.

- EEGs are carried out for newly diagnosed epilepsy. Emergency EEGs are used for diagnosis and treating status epilepticus cases while VT helps with diagnosis and epilepsy surgery assessment. There are eight EEG departments in Scotland excluding the Scottish Epilepsy Centre. This residential assessment unit for complex epilepsy carries out diagnostic videotelemetry only on in-patients admitted to the centre. A highly skilled neurophysiology technician (health care scientist) takes 60 minutes to set up, perform and provide an initial technical review of a standard EEG. Recordings made over several days may take many hours to review. Medical staff trained in clinical neurophysiology usually provide the final interpretation so that the report is clinically useful to the referring doctor.

- During the week (9am-5pm) most centres manage to offer emergency EEGs that working day or within 24 hours, except NHS Fife and Forth Valley which take up to 48 hours. This is because the staff work part time or are single handed at those two small sites. Routine EEGs for new cases of epilepsy can range from 2 weeks for adult patients in Glasgow to 10 weeks in NHS Fife where the department has been single handed. This data was collected in September 2016 and will fluctuate month to month depending on demand and staff availability. There is no EEG availability during the week after the end of the working day. At weekends emergency EEGs are only available at the Queen Elizabeth University Hospital (QEUH), mainly due to the small staffing pool in all Scottish centres other than Glasgow.

- NHS Borders and Dumfries have ITU (Intensive Care Unit) beds but lack on-site EEG staff. EEG departments linked to these hospitals - Edinburgh and Crosshouse - are too far away to provide a portable EEG service to them given current staffing resource at these centres. VT is available at fewer hospital centres, where waiting times for diagnosis and epilepsy surgery assessment vary for the same reasons: demand, staff and the availability of dedicated nursing support and beds. Recent waiting time figures went from three months (NHS Grampian) to 18 plus months (NHS Lothian) where just one VT bed was available due to a 50 % reduction in the EEG staff pool.

- Clinical neurophysiologists (CN) can be divided into two groups. Health care scientists (HCS) (known in the past as neurophysiology technicians) who set up, record EEG/VT and review data. Consultant clinical neurophysiologists, along with consultant neurologists with a special interest and expertise (Edinburgh) and very highly trained senior HCSs (Aberdeen), will report and interpret recordings which make sense of these useful diagnostic tests.

- Clinical neurophysiology is under huge service pressures and EEGs are not the only thing CNs do. Other tests such as nerve conduction studies (NCS) and EMGs come with waiting list targets. Increasing demands are made from surgical colleagues for intra-operative work (including brain tumours) and specialities like neurology and orthopaedic services have expanded faster than clinical neurophysiology in terms of consultant staffing and extended role practitioners.

- Currently, there are five funded vacancies for health care scientists (HCS) which cannot be filled in Aberdeen, Dundee, Edinburgh and Glasgow. This does not include gaps in cover from long-term sick leave and maternity leave.

- HCS training in neurophysiology is a graduate course which takes four years. Glasgow Caledonian University (GCU) only offers the course every two years. There are usually 50-60 applications for each advertised HCS post. Normally, the NHS process is to wait for a qualified HCS vacancy in the department by someone who is retiring or leaving. If this post is unfilled, and it may be advertised several times, the hospital can either freeze the post to save money or release the funding for a trainee post. This process appears to be rarely planned for and with the university course only taking on new students every other September, opportunities to fill a vacancy are missed. The trainee receives practical training under the supervision of their department and with day release at GCU for the academic input. It can be difficult for small departments to train students and tricky for distant trainees, like those based in Aberdeen and Inverness, to attend GCU.
- There are presently eight consultant CNs in Scotland, of whom several are less than full time, with none currently in post in either Aberdeen or Edinburgh who are relying on locums. NHS Grampian has recently advertised its consultant CN post twice with no applicants. The vacancy rate for consultant CNs is 33%. Other than in Glasgow, where five of six posts are filled, all the other posts are single handed. Although Lothian has approval for two posts, they have been unable to fill even one for several years. Both posts need to be filled as the work load in Edinburgh is too much for one consultant and this has put off applicants. A post graduate specialty training course for a consultant CN takes four years. Scotland has three trainees, all doing their training in Glasgow, with just about enough staff to train – although the 9+1 contact for new consultants is limiting their time to train. Whether these trainees will take up single-handed posts in Scotland remains to be seen given many vacancies south of the border in better supported, larger centres with more generous consultant contracts.
- In summary, clinical neurophysiology is a small specialty, rarely on the agenda of health service planners. The main issues for EEG/VT services include staff shortages in most regions, access to trainee places and the capacity to train more HCS and consultants. For example, filling both Edinburgh consultant posts would allow a fourth medical CN trainee. In addition, the lack of ring-fenced money to replace aging equipment, and having to compete with other specialty wish lists such as neuro theatre and ITU which get priority; and increasing budget constraints for IT support are significant and increasing issues. There are huge pressures to meet waiting list targets for set procedures and increasing demands for intra-operative monitoring for our non-epilepsy patients. It is a struggle to provide a timely and equable service to patients with neurological disorders including people with epilepsy (one of our two main specialty users). Consultant CNs try to offer cross-departmental help where they can but everyone is under huge workload pressure, both in Glasgow and with single-handed consultants. Understandably, morale is low.
- A Scotland-wide review would reveal the need for more support to allow this small diagnostic specialty to meet the needs of patients more effectively. Consultant contracts will require more time for training while central funding for training HCS students would help significantly. Ring-fenced funding to procure new reliable EEG systems and replace out of date equipment is a way forward. This would include the potential for more home VT – currently only available in Inverness. Scotland-wide IT support for networking EEG would allow a uniform electronic system linking departments across regions. This would assist cross-cover arrangements for emergency work particularly for single-handed departments when consultants are on leave, and would provide a method of secure data transfer rather than the ad-hoc arrangements that exist just now, which makes discussion of EEG and VT recordings between colleagues almost impossible, and include multidisciplinary surgical planning discussions at national epilepsy surgery network meetings.

8. The Convener thanked Dr Russell for her presentation and invited questions.

   Anissa Tonberg asked what risks could result from the current situation? Dr Russell said younger patients with poorly controlled epilepsy referred for diagnosis or epilepsy surgery carried a risk of SUDEP (Sudden and Unexpected Death in Epilepsy). Status epilepticus also carries a high risk of death or brain damage and timely access to an EEG was very important.

   Margaret Wilson noted there were waiting list targets for nerve conduction studies and EMGs but none for EEGs. For some reason epilepsy was not given priority. Dr Russell said perhaps the reason was that high-volume procedures were more likely to attract targets and the numbers were relatively small for EEG and VT.

   Gillian Horsburgh said young people faced a waiting time of seven months for surgery. Anissa Tonberg explained there was a six week NHS waiting time target for eight key diagnostic tests (e.g. endoscopy, colonoscopy), but not for a standard EEG. Dr Russell said they did not have the

clinical neurophysiology staff to deliver a target. Sharon Thinn said it would be very useful to have an EEG target. She provides a single-handed service for the whole of NHS Fife. Her colleague is on maternity leave and there is no cover even though there is a temporary part time vacancy. Patients are being sent to Edinburgh

Andrena Hughes picked up on the point about Scotland only having three trainees and whether there was any way to encourage these trainees to stay in Scotland on completion of their training. Dr Russell said consultant 9+1 contracts for Glasgow were not the norm in the rest of Scotland or UK and were a deterrent. Single-handed consultant contracts needed to be significantly generous to include time out of service for networking and supporting other single handed colleagues, and for time to travel to Glasgow for CPD, clinical governance and to maintain super specialty interests. Dr Russell is currently mentoring a new consultant CN in Dundee. Eleonora Saturno said that having time to consult and exchange opinions with fellow colleagues was important. Dr Russell agreed, and it might be possible to consider neurology trainees who could be trained in clinical neurophysiology to ease the pressure of a mountain of work.

Allana Parker asked Dr Russell about the value of home EEG and video telemetry. Dr Russell replied that this kind of service had been audited in England and was economically cheaper than the costs for a neurology bed. Ailsa McLellan said that while it might save costs for neurology beds, there were still staffing issues as people had to read and interpret the EEG/VT results. There was a hidden waiting list here with people not getting quick access to tests. She asked if this matter could be raised with the Scottish Government? The Convener said he would write to the Health Minister and ask directly what help they and health boards would give in this situation. He would feedback the response in due course.

Kenneth Gibson MSP also suggested inviting the Cabinet Secretary for Health and Sport to the January CPG meeting. The point of the Group was that MSPs are here to improve life for people with epilepsy. Attendees can email, write or send ideas for Parliamentary Questions at any time. Usually he has a debate each year on an epilepsy topic so send suggestions to him or Allana.

9. The Convener asked if there were any other issues anyone wished to share?

Lorraine Mackenzie raised the issue of protective headwear. The free service she previously used has been withdrawn by her health board. It now cost £150 to have a helmet made privately for her adult son who has complex epilepsy. Lorraine explained that the need for special head wear involves taking individual measurements and can be costly. She understood the need for protective headwear affects a small number of people. Fortunately, she had the means to pay for this helmet and a spare but other parents and carers may not.

Margaret Wilson explained the service was provided by NHS orthotics for adult and paediatric epilepsy centres. Some NHS boards still do it, others are not. Anissa Tonberg gave an update on the situation. The issue for orthotists is that epilepsy headwear is not safety tested and standardised by a Kite mark as required under EU legislation. Rugby players and cyclists, for example, wear helmets designed to protect against soft tissue injuries. Currently there is no manufacturer making approved headwear that orthotists can supply to people with epilepsy that meets EU health and safety regulations The Convener asked what happens elsewhere in the UK and EU? Margaret Wilson agreed that while this situation affected only a small number of patients, no-one was asking for a guarantee on safety helmets. Kenneth asked how to take this issue forward. Lorraine said she got her son's helmet from a private orthotics company and didn't look for a guarantee. The company used a hat her son wore before as the template model. It was created by an NHS orthotics team and was better than the new one. The safety of the child or adult with uncontrolled epilepsy is important and her view is protective headgear is helpful.

10. The Convener reminded attendees that MSPs sit on a whole host of committees and can look at many different issues. Epilepsy is not going to be a Cinderella service. This Group gives it a voice that is loud and clear so that the condition is not neglected or forgotten about. He also mentioned the potential value of arranging a site visit to the Scottish Epilepsy Centre.

11. The Convener thanked everyone for attending today and details of future meetings will be circulated in due course (potentially Thursday 26 January and 27 April 2017).