

## Note of Meeting – Cross- Party Group on Epilepsy, 26 September 2019

### In Attendance:

Alasdair Allan MSP	Helen MacDonald – Lanarkshire Epilepsy
Jeremy Balfour MSP	Ian Morrison – NHS Tayside
Fliiss Blades - LivaNova	Darren McCarthy – LivaNova
Helen Bongard – MSP staff	Ross Nisbet – Office of Alex Cole-Hamilton
Jan Campbell - UCB	Emily Ord - Eisai
Dr Richard Chin	Louise Phillips - UCB
Ian Forbes - UCB	Derek Robertson – NHS Lothian
Kenneth Gibson MSP	Phil Robinson – Lanarkshire Epilepsy
Paul Gillon – Veriton Pharma	Brian Rocks – West Dunbartonshire Epilepsy Support Group
Craig Heath – NHS Greater Glasgow & Clyde	Anas Sarwar MSP
Andrena Hughes - Observer	Graham Sheppard - UCB
Raymond Hussain - WDSG	Sarah Silk – ESN NHS Lothian
Chris Jeans – SUDEP	Anissa Tonberg – Epilepsy Scotland
Rona Johnson – Epilepsy Scotland	Sam Whitmore
Jude Kilbee – Bial Pharma	Eunis Jassemi Zarganis – Office of Anas Sarwar MSP
Rachel Lloyd – ESN NHS Lothian	

### Apologies:

	Dr Ailsa McLellan – NHS Lothian
Jean Barclay - Observer	Dr Jay Shetty
Pat Graham	Jane Stuart – NHS Lothian
Jennifer Irvine – NHS Lanarkshire	John Thomson – NHS Lanarkshire
Lorraine Mackenzie	Lesslie Young – Epilepsy Scotland
Anne Maxwell OBE - MMT	
Dr Clare Mills - Headway	
Michael & Barbara McCulloch	

1. Convener Alasdair Allan MSP welcomed attendees to today's Meeting and gave an update since the last meeting in March:
  - NICE have published draft guidance on the use of medicinal cannabis to treat severe treatment resistant epilepsy in children. The committee were unable to make a recommendation on its use for this group. The draft guidelines instead recommend significantly more research to support the effectiveness of the drug.
  - The consultation on the Scottish Government's new approach to delivering Social Security Disability Assistance received over 200 responses. The first payments for the new PIP system are expected to start in early 2021.
  - Epilepsy Scotland have launched a national petition as part of their social security campaign. The petition calls on the UK Government to review how people with epilepsy are assessed for PIP. It has been signed by 5,000 people so far and covered widely in the media. The policy team at Epilepsy Scotland welcomes members to add their signature to the petition which can be found on Epilepsy Scotland's website and social media.
2. AGM Business and the election of Office Bearers was undertaken. Anissa Tonberg, CPG Secretariat, expressed sincere thanks to Kenneth Gibson MSP for his convenorship and dedicated service to the CPG on epilepsy for the past eleven years. Alasdair Allan MSP was elected Convener, David Torrance MSP and Richard Lyle MSP were elected Deputy Co-Convenors. Members also agreed for Epilepsy Scotland to carry on providing the Secretariat on behalf of Epilepsy Consortium Scotland. Alasdair Allan MSP read the annual financial statement for the CPG and the minutes of the last epilepsy CPG were approved.

3. Alasdair Allan MSP introduced Dr Ian Morrison, a consultant neurologist based in NHS Tayside and Dr Craig Heath, a consultant neurologist based in NHS Greater Glasgow and Clyde. They discussed the development of an epilepsy register, which included the following points:

**Dr Ian Morrison:** Epilepsy is the most common chronic neurological condition; it is ten times more common than Multiple Sclerosis. Epilepsy does not get as much attention as other conditions, it is still very stigmatised, and people continue to experience prejudice. Epilepsy can kill up to 1 in 400 people, this increases to 1 in 100 if someone does not take their medication as prescribed.

NHS Tayside received funding from a bereaved family who wanted to further epilepsy research. The clinicians decided to start a database that could be used for research purposes but would also improve clinical outcomes. They decided to establish a non-linear structure with the intention of identifying people who had been in the NHS Tayside epilepsy service in the last five years. They developed an app which patients used and updated the database in real time. In future, they are intending to use artificial intelligence to try and improve data input.

One area of the register where patients have directly benefited is in the prescribing of sodium valproate. In 2014 EU Medicines Agency advised that clinicians must be more aware of the impact of sodium valproate, led to MHRA advice in 2018 that sodium valproate could not be prescribed to women of childbearing age unless they were compliant with the Prevent Programme. If a woman on sodium valproate falls pregnant, there is a 10% chance the child will have a physical defect and 30-40% chance the child will have developmental issues.

This advice increased the risk of GPs not prescribing sodium valproate to patients. For a woman of childbearing age to be prescribed sodium valproate they have to be seen by an epilepsy specialist, have to get effective contraception and have to be seen on yearly basis. The database allowed clinicians to see, via one click of a button, how many patients have been prescribed sodium valproate, figure out who was female, see their age and contact them directly. Without the database this would have taken weeks or months.

Out of 153 people who they approached, only 28 came to clinic. Many patients did not want to switch drugs as they had achieved seizure freedom, had no desire to extend family or were in a same sex relationship. Only two came to clinic because they had thought about starting a family.

To populate the database was severely labour intensive, this works in NHS Tayside but might not work in other centres as it is too much work. Said they are looking at other options to make it a national project.

**Dr Craig Heath:** The primary aim of the register is to improve the care and outcomes in people with epilepsy.

There are many challenges that people with epilepsy face which the register may be able to improve. One third of patients will never achieve seizure freedom, despite advances in pharmaceutical medicine. Mortality rate for people with epilepsy is two to five times higher compared to the general population, life expectancy is ten years shorter. Finally, 23% of people with epilepsy do not take their medication as prescribed. Women's health provides significant difficulty as mentioned by Ian Morrison, maternal outcomes are poorer for people with epilepsy.

They want to have more than a list of names; they need to create an active NHS embedded infrastructure that can be used to improve outcomes. The epilepsy dashboard allows clinicians to be made aware of any adverse events which have happened to their patients. By the end of the year the three dashboard alerts will be admissions, deaths and pregnancy.

Recognised that the register will not improve mortality in the short term. However, it will ensure that clinicians are made aware when one of their patients die. This will allow them to follow protocols and ensure families are supported as well as reviewing and improving their practice.

If people with epilepsy do not take their medication as prescribed, their risk of death is two to three times higher. Dispensing information is already available to the health board, it is clear when people are not regularly renewing their prescriptions. Therefore, clinicians can pinpoint people who are not adhering to their medication, are at a higher risk of death and take steps to

reduce that risk. By Summer 2020 the next flag on the dashboard will be poor adherence, if patients are not picking up their scripts 80% of the time they will appear on the dashboard.

There are 6,600 patients on the register at present, have five years' worth of data on admissions and deaths. The areas which are missing at present is EEG and radiology data. Hopes the data from the register will be able to answer the question of why a third of people with epilepsy do not achieve seizure freedom.

The first output from the dataset is a study on people with epilepsy who are taking methadone and whether they have higher rates of mortality. An individual with epilepsy who has an addiction is 25 times more likely to die compared to the general population. The aim of the study was to understand if epilepsy or its care contributes to mortality. One in twenty people who attend an epilepsy clinic take methadone. This is almost certainly underestimating the problem as this is of those who attend clinic. If a person has epilepsy and takes methadone, they are four times more likely to die than those who have epilepsy alone. These individuals are less likely to engage with neurology services. Despite these individuals attending a pharmacy every day for their methadone, one third do not take their epilepsy medication. Their outcomes might be improved by dispensing their anti-convulsant medication alongside their methadone.

The two speakers thanked a number of supporters including; UCB Pharma, Eisai, Cyberonics, Universities of Dundee and Glasgow.

Alasdair Allan MSP thanked the speakers for their presentations and opened up to questions from members.

**Anissa Tonberg, Epilepsy Scotland** – asked what is needed to support national roll out of the epilepsy register.

**Dr Ian Morrison** – said there is no reason why this could not be a national project in the space of a couple of months. IT issues are stopping them from supporting the national roll out.

**Dr Craig Heath** – said IT departments are faced with several databases and are under pressure. They need to show to the IT departments how the register will affect clinical outcomes and has been successful in other areas. Scottish Government could help encourage local IT departments and show it is something worthwhile to support.

**Alasdair Allan MSP** – said he was happy to write a letter to the Scottish Government asking what can be done to facilitate the national roll out. Asked if there were any legal issues regarding data sharing.

**Dr Ian Morrison** – said the clinical aspect of the register exists within current NHS systems and are subject to strict board and ethics approval. Additionally, all details within Safe Haven are anonymised.

**Paul Gillon, Veriton** – asked if the dashboard would flag acute and A&E patients.

**Dr Craig Heath** – said it picks up both. Said it is about identifying epilepsy related admissions and they hope to manage that in the future, with IT help.

**Andrena Hughes, Observer** – asked if the alerts on the dashboard will only appear to clinicians if they go in and look at individual patients.

**Craig Heath** – said the alerts comes up automatically. Said this leads on to other issues of what clinicians then do with the information alerts but said knowing what is happening is a good start.

**Andrena Hughes** – clarified that the dashboard will be monitored by someone who will then alert the clinician that an adverse event has taken place.

**Craig Heath** – said yes that is the aim.

**Richard Chin** – asked if the register is an active or passive alert system. Asked how clinicians become aware of these adverse events.

**Craig Heath** – said that clinicians have to click on the dashboard and the alert is there.

**Richard Chin** – said he understands it is a passive system which clinicians log onto and see a list of their patients, rather than something that sends you a flag.

**Craig Heath** – said yes but the dashboard is updated every hour.

**Richard Chin** – asked if the onus would be on the clinician to have the dashboard up.

**Craig Heath** – said yes, at the moment.

**Alasdair Allan MSP** – asked how the register can be used to analyse the genetic aspect to drug resistance.

**Craig Heath** – said drug resistance research has traditionally assumed that people are adhering to their medication. The register will be the first to bring all the factors together to pinpoint areas that affect drug resistance.

**Alasdair Allan MSP** – asked if anywhere in the world was doing this.

**Ian Morrison** – said no one has ever done a national study like this and it would be groundbreaking to have full country population data of people with epilepsy.

**Anissa Tonberg** – asked if there are any plans for dual dispensing AEDs alongside methadone and if there are any other upcoming pieces of research.

**Craig Heath** – said the next study will be factors responsible for persistence, looking at various factors to see if patients continue to take their medication for longer than twelve months. Additionally, want to look into whether people who take enzyme inducers are more likely to have cardiovascular endpoints e.g. stroke and heart disease. Said the problem is trying to find time to carry out the research.

**Ian Morrison** – said they are considering to look at whether first seizures could be a risk factor for stroke. Then use this to prevent strokes in the future.

**Alasdair Allan MSP** thanked the speakers for their presentations and said he hopes to take up the issues presented to try and see what can be done at national level.

The Convenor stated that:

- The next CPG on epilepsy will be held in 7<sup>th</sup> November and the subject will be the new paediatric SIGN Guidelines.

He thanked all for their attendance and closed the meeting.