

**Note of Meeting – Cross-Party Group on Epilepsy, 26 February 2021**

Held virtually via Zoom

**In Attendance:**

Rona Johnson, Epilepsy Scotland	Anna Telfer, Epilepsy Scotland
Kenneth Gibson, MSP	Elaine Collard, NHS Highland
Jay Shetty, NHS Lothian	Jan Campbell, UCB Pharma
Michael McCulloch	Jude Kilbee, Bial Pharma UK
Helen MacDonald	Jennifer Mutch, NHS Lothian
Sylvia Lawrie	Stuart Mulheron, Arvelle Therapeutics
Ian Williams, Quarriers	Colleen Wilson, Epilepsy Connections
Mary Keenan, Epilepsy Connections	Raymond Hussain
Barbora Jones, Epilepsy Connections	Paul Gillon, Veriton Pharma
Chris Jeans, SUDEP Action	Jen Irvine, NHS Lanarkshire
Rebecca Marshall, Salvensen Mindroom Centre	Sameer Zuberi
Patricia Graham, PAMIS	Heather Davies, Epilepsy Connections
John Thomson	Derek Robertson, NHS Lothian
Andrew Boyle, NHS Lothian	Audrey Noble, GW Pharma UK

**Apologies:**

Lesslie Young, Epilepsy Scotland	Eleonora Saturmo, NHS Fife
Michelle Small, NHS Lothian	Jo Campbell, NHS Grampian
Jean Barclay	Ailsa McLellan, NHS Lothian
Lorraine Mackenzie	Alasdair Allan MSP
Eleonora Saturmo, NHS Fife	

1. Convener Kenneth Gibson MSP welcomed attendees to meeting and gave an update since the last meeting in December:
  - The Association of British Neurologists (ABN) have published guidance on COVID-19 vaccines and neurological conditions. The guidance states that all COVID-19 vaccines are safe for those living with neurological conditions. In Scotland, people with epilepsy are in priority group 6 to receive the vaccine.
  - Epilepsy Consortium Scotland have become aware of a couple of cases where people with epilepsy have been knocked back from receiving their COVID-19 vaccine at their appointment on account of their epilepsy. ECS are monitoring the situation and contacting Health Boards where necessary.
  - Round two of funding to support the implementation of Scotland's Neurological Care and Support Framework is open, the deadline for applications is 1<sup>st</sup> March.
  - The Scottish Government is currently consulting on the draft regulations for Adult Disability Payment, the Scottish replacement for PIP. The consultation closes 15<sup>th</sup> March. Please get in touch with the Secretariat if you would like to contribute to Epilepsy Consortium Scotland's response.

2. Kenneth Gibson MSP welcomed Professor Sameer Zuberi, Consultant Paediatric Neurologist. He presented vCreate Neuro, a patient and carer recorded video service which is used for the diagnosis and management of epilepsy.

**Professor Sameer Zuberi:** New video technologies for epilepsy diagnosis and care

We use video synchronous communication in epilepsy diagnosis (in real time, eg, phone calls, video clinics) which is a fast and dynamic with interactive discussions. But also, you can have interruption, distractions, and it might not allow you to do very detailed analysis. So, there are other asynchronous tools that we use. These are things that happen over a longer period, like pre-recorded video, phone messages, emails, so you can then you can take some time to consider and analyse a communication. There is no need to schedule, it can be done at your own pace and it allows for discussion with colleagues, helping in making a permanent record.

One of the challenges of the pandemic has been seeing patients (physically), and the need to find other ways to communicate. Historically, you make a diagnosis of epilepsy by speaking to a witness. But, as we have got more accessibility to video, recordings on mobile phones have become really important in epilepsy diagnosis. The reason videos are so important is because most of what they see in a first seizure clinic, is not epilepsy. There is a big mixture between epileptic and non-epileptic attacks and most of the things in first seizure clinics are faints and other episodes. Because of this, there are high levels of misdiagnosis and unconfirmed epilepsy.

We have used video in paediatric neurology for many years, but there are many challenges: hospital systems are not set up for this, they cannot cope with the sizes of videos and the clinical governance around sending videos into a hospital email system and security around this is a real challenge.

In Glasgow, the neonatal unit worked with vCreate to set up a system where nurses could take a video of a baby and send it to parents. This was a really positive experience and became a part of family integrated care. But from the epilepsy perspective, the important thing was that that system went through all the clinical governance, and all the security requirements, for transferring video from a video from a hospital to a family. They asked if they could establish a system where they could get videos sent the other way, into the hospital, from families. They submitted a couple of unsuccessful grant applications in 2019/early 2020, but then the pandemic occurred, and the video system spread to all paediatric and adult ICUs in Scotland and beyond. The system has now sent more than 100,000 videos from ICUs out to families to help support care.

They put in an application to the Scottish Government Technology Enabled Care, for a pilot of vCreate Neuro. Initially in four university hospitals (Glasgow, Edinburgh, Dundee and Aberdeen), four paediatric and four adult neurology services. Glasgow and Edinburgh pilots commenced in early May 2020 and now they have many district general hospitals on board and some English centres. They have more than 1,600 families using the system and almost 4,000 videos uploaded.

Demonstration of live system: it is a cloud-based system, where people are invited to log in and give the relationship to the patient (patient themselves, parent, welfare guardian etc), so the system is also appropriate for adults with learning disability and their carers. People can upload videos through an easy pathway, with a few standard questions which would be asked in a normal epilepsy history. Within the system, clinicians can classify what they are seeing, if

it is an epileptic event, what type of episode it is, classify the aetiology, classify the syndrome etc. They can also communicate directly with the families messages through the system. They can use the system for second opinions as well.

*Demonstration video of a baby having an infantile spasm*, a sign of a very severe epilepsy which needs treatment very rapidly to avoid significant, lifelong, learning disability. From the video, they were able to organise an urgent assessment for an EEG and get started on medication which made the seizures well controlled, and the baby is doing well.

vCreateNeuro has been incredibly successful throughout Scotland. Most of the patients are paediatric but they have some adult patients. Most of the events that they are seeing are non-epileptic which is really important because in many patients with established epilepsy, when they start having more episodes, often the assumption is that they are having more seizures so their medication gets put up or changed. They have had positive feedback from patients and carers - 95% recording a positive experience. Clinical users are finding it really helpful for diagnosis in 98% of cases and making treatment decisions and it reduces time to diagnosis and therapy in 97% of cases, taking about 5 minutes to review and classify videos. It is preventing clinical appointments, in person clinical review, hospital admissions, and saving lots of investigations. So far, they are getting the impression that they are using less medication and making less medication changes. Scottish government health economists are looking at detail at this project and so will have a full health economic investigation of this soon.

In parallel to the clinical database, they are building a neurological video research database. They have national research ethics approval for both adults and paediatrics and for adults with incapacity as well. This could be helpful for future research because they will have the biggest library of seizure videos in the world and this is building rapidly. They are looking at artificial intelligence to try and help with diagnosis. There are pathways of traditional epilepsy referrals (from a GP or other service) where you go to the first clinic, with this system before the patient is even seen you get the video and are able to triage the patient as to whether they need to be seen urgently, or if at all. In the future, if they have artificial intelligence looking at these videos, then it might streamline the process even further.

There are lots of exciting developments:

- Going international, working with Toronto Sick Kids and various US centres for example
- Creating a clinician-to-clinician pathway, so videos taken in the emergency department for example can send the video to the clinician, saving time.
- Building seizure diary and seizure passport into it
- Will have a universal language capability very soon
- Many other clinical pathways and uses too – remote diagnosis of autism, ophthalmology, respiratory, cardiac services etc
- They have a low and middle income country project, through collaboration with the International League Against Epilepsy and WHO. In many parts of the world there are very few/no neurologists. Using systems like this, in a world where smartphones are so ubiquitous, may really help with epilepsy diagnosis. They are beginning projects in certain African and South American countries and the University of Austin with some small Caribbean Islands.

This was built rapidly over the last year, from a project starting in Glasgow, spreading across Scotland and now has an international reach. They received the Scottish Health Innovation award in December 2020.

3. Kenneth Gibson MSP thanked Professor Zuberi for his presentation and opened the meeting to question from members.

**Rona Johnson:** How do you see this changing the pathway of epilepsy care post Covid. Will this be central paediatric and adult epilepsy care within Scotland going forward?

**Professor Zuberi:** Yes, I think this will become part of the embedded care now, because its really coming into their regular pathways of care. When neurologists/epilepsy specialist nurses get referrals for new patients, they will ask the families to register for vCreate, even before they have seen them. They can look at the videos and prioritise patients and save time. It will speed up diagnosis and for established patients it is helping because they can see what seizure types are, and if they are changing, and whether new events are epileptic or not.

**Ian Williams:** As an independent healthcare provider who provides services to the NHS, the ability to have a platform where either patients or clinicians out with the NHS can talk to the NHS in a secure system with up to date technology is really innovative. They have patients send them videos, so the ability to share video footage with clinicians for collaborative consultation on a secure platform will be a huge step forward for them.

**Professor Zuberi:** Once a video is in a system with consent, then you can share the link with any clinician, and they will only get access to only that one video. It is a much more secure platform than currently used. Having a secure method protects everyone.

**Anna Telfer:** Have you come across any barriers around digital inclusion, and do you envision this being an issue going forward.

**Professor Zuberi:** Digital inclusion has a broad meaning. People can be excluded because of their social-economic status, or maybe because of learning disability etc. They have done a project where they have looked at the postcodes of users against the Scottish deprivation categories, and they found they matched the deprivation categories. It didn't look like it was only people from lower deprivation categories who were using this. In terms of support, the epilepsy nursing teams are often critical to the rollout of this service, so for adults with learning disability or parents who don't have access to support, they can provide support for them registering. Most people have smartphones in the UK and have video accessibility. Where people don't have laptops or computers, often they do have smartphones. Even in low income parts of the world, they believe this has to potential to be a very useful platform.

**Pat Graham:** Expressed her personal experience of how this platform could made an enormous difference in terms of diagnosis and treatment. It is wonderful to think of the many people and their families that this will beneficially affect. Thanked Professor Zuberi, expressing how appreciated this is in her community (learning disability).

**Professor Zuberi:** Thanked Pat. Noted how important time is particularly for young children with epilepsy, if you can control the epileptic seizures and make a diagnosis rapidly, then you can allow that child to develop, preventing delays which have lifelong impacts. This is making diagnosis much more rapid and accessible for people.

**Colleen Wilson:** Has recently adopted vCreate Neuro as a parent/carer, and it is making a difference to people with epilepsy and their families and carers. Thanked the teams in Scotland who have pushed this ahead and used the opportunity of the pandemic to make a difference to care.

**Christine Jeans:** Believes this is probably going to prevent a lot of SUDEP deaths. Asked if all GPs will have this facility.

**Professor Zuberi:** At the moment, it is about giving GPs awareness of the system so they can talk to people as they refer them. They are doing this now in clinical practice, telling them about the system and asking the family to register. Eventually, since there are so many clinical uses for this beyond neurology, there may be an integrated national system for video transfer that will need to be developed. The SUDEP issue is really important because treatment can be sped up.

**Jen Irvine:** Questioned confidentiality in relation to one of their current inpatients signed up to vCreate.

**Professor Zuberi:** At the moment, they are just working on the clinician-to-clinician pathway and how perhaps a clinician for an inpatient might be able to send a video into the system. These are the sort of issues they are looking at – it is very simple from a family to a hospital, but they are wanting to move to the next step where they are using it between even schools or respite care for example.

**Rona Johnson:** What research can we expect as a result of vCreateNeuro?

**Professor Zuberi:** There are lots of potential aspects of research. They will have a library of videos which they can look at and compare different seizure types and presentations of particular types of epilepsy to see how epilepsy evolve. They can also look to see whether they can diagnose epilepsy through using machine learning techniques, looking at artificial intelligence. Other things they want to do is look at on a national basis at outcomes for epilepsy, and if they can use this system as a diary system for recording seizure frequency and potentially linked to medication too. Because its use is so widespread across Scotland, it will give us really strong data.

4. Kenneth Gibson MSP thanked the Professor Sameer Zuberi for taking the time to talk and answer questions. Noted how informative and enlightening it was, and that it is tremendous that Scotland is leading such globally significant research in epilepsy.

This will be our last meeting before the Scottish Parliament election. The group will be re-formed and the next meeting will be in September, which allows plenty of time for members of the Cross Party Group to network in the interlude and send any issues they want to be discussed in the next meeting in September.

Previous meeting minutes were approved.

Kenneth Gibson MSP thanked all for attendance and closed meeting.