

Cross-Party Group on Epilepsy

25th November 2021

Minute

Present

MSPs

Alasdair Allan MSP
David Torrance MSP

Invited guests

Anissa Tonberg, Scottish Government
Frauke Hunter, Scottish Government
Pauline Bennett, Scottish Government

Non-MSP Group Members

Alex Wilson
Andrea McKenna, Salvesen Mindroom Centre
Ann Greenall, NHS Lothian
Anna Telfer, Epilepsy Scotland
Audrey Nobel, Angelini Pharma
Charlie Bethune, Valporate Scotland
Christine Jeans, SUDEP Action
Collen Wilson, Epilepsy Connections
Derek Robertson, NHS Lothian
Elaine Collard, NHS Highland
Elanora Saturno, NHS Fife
Fiona Burton
Graeme Aitken
Helen MacDonald, Lanarkshire Epilepsy
Hillary Mounfield, Scottish Epilepsy Centre
Jan Campbell, UCB Pharma
Jen Irvine, NHS Lanarkshire
Jenny Hunt
John Campbell, Neuraxpharm UK
John Thomson, Eisai Ltd
Jude Kilbee, Bial Pharma
Katie Russell
Lesley Perkin, UBC Pharma
Norma Crawford, Quarriers
Pat Graham, PAMIS

Paul Gillon, Veriton Pharma
Philip Robinson, Lanarkshire Epilepsy
Rona Johnson, Epilepsy Scotland
Shirley Maxwell, Epilepsy Connections
Dr Susan Duncan
Victoria Burns, Epilepsy Scotland
Will Wood

Apologies

John Toland, NHS Fife
Jean Barclay
Jay Shetty, NHS Lothian
Kirsten Watson, GCHC
Lesslie Young, Epilepsy Scotland

Agenda item 1. Convenor Alasdair Allan MSP welcomed attendees

No matters arose from the minutes of the previous meeting. Minutes were approved, Rona Johnson proposed, Anna Telfer seconded.

Alasdair Allan gave an update since the last meeting in September.

- Round three of funding, worth £1 million, to support the implementation of Scotland's Neurological Care and Support Framework is due to open very soon, the deadline for applications is 31st January. More information can be found on the Scottish Government's website.
- The Neurological Alliance of Scotland have launched, in partnership with the other UK Neurological Alliances, the UK-wide "My Neuro Survey". This survey aims to capture the experiences of people living with neurological conditions across the UK, with the intention to identify areas for service improvement. The survey will run until 14th January 2022. This is the first time Scotland has taken part in the My Neuro Survey, it is important the voices of those living with neurological conditions in Scotland are captured. The survey has Scottish Government support, and the results will be shared directly with key decision-makers.
- Child Disability Payment has now launched nationally across Scotland. Child Disability Payment provides support for the extra costs that a disabled child might have. More information on eligibility and how to apply can be found on Social Security Scotland's website.
- New research has been published about epilepsy-related deaths in Scotland. The Edinburgh University study found that as many as 80% of young adult epilepsy-related deaths in Scotland could have been prevented. The Scottish Government are meeting with the research team to discuss the research further.

Agenda item 2. Alasdair Allan MSP welcomed the Scottish Government to provide an update on the Patient Safety Commissioner in Scotland and an update on the implementations of the Cumberlege recommendations in Scotland.

Pauline Bennett, Senior Policy Advisor within the Quality and Safety Team in the Scottish Government.

Today I will give you an overview of the work our team have been doing on the establishment of a Patient Safety Commissioner in Scotland (PSC). This area of work came about off the back of the review carried out by Baroness Cumberlege.

The review focused on the harm caused through the hormone pregnancy test Primodos, Sodium Valproate, and pelvic mesh. The Scottish Government has committed to implement all of the recommendations in the review as far as devolved competence allows.

Our team is responsible for the appointment of a PSC who would be an independent public leader with statutory responsibility. The commissioner would champion the value of listening to patients and promoting user perspectives in seeking improvements to patient safety around the use of medicine and medical devices.

The establishment of the PSC is a programme for government commitment, and will require primary legislation.

We conducted a public consultation on the role of a PSC which has been analysed and will be published in coming days. During the drafting of the consultation, we sought input across Scottish Government policy areas as well as from the two stakeholder groups we established – the Patient Reference Group and the Specialist Reference Group.

The Patient group was made up of people with lived experience. Its main function was to advise on the development of proposals for the appointment of the PSC. The Specialist group was made up of key organisations with the remit to map out the current patient safety landscape to help identify what exists and if there are any gaps.

So what do we plan to do next? We have secured a slot for the first stage of the bill in October 2022 and are working with our legal colleagues to develop the policy instructions for this. We are also doing some work mapping out the various policies and processes that exist to support the patient voice in Scotland in order to identify any gaps and areas that could be simplified.

We will also establish an overarching advisory group by the end of the year to assist us in developing the principals of the legislation and to build on the outputs of the consultation.

Alasdair Allan: Asked what areas of this work might be relevant for people with epilepsy.

Pauline Bennett: It is expected that initially the role will be focused in the three areas specified in the Cumberlege Review. However, we are anticipating that it might expand as the role develops.

Rona Johnson: Asked what themes emerged from the consultation responses.

Pauline Bennett: Most respondents agreed that the PSC should initially focus on the medicines and medical devices as recommended in the review, however it is clear that there is support for the role expanding at some point in the future. There was strong support for the role being independent of both the Scottish Government and the NHS and accountable to for example, the Scottish Parliament. There was also strong support for the PSC role being set out in legislation

Susan Duncan: Asked if clinicians should refer medicine concerns to the PSC or the MHRA and what should clinicians do if MHRA advice is different to the PSC.

Pauline Bennett: It is not entirely clear how that would work in practice. We are still at the early stages of trying to figure out what this role will look like.

Frauke Hunter: The MHRA is the UK regulator and also the UK agency responsible for safety in relation to medicines and devices and I don't see that changing in terms of what's been proposed.

Anna Telfer: Asked how the PSC role will feed into the National Care Service.

Pauline Bennett: We are still at the early stages. We need to consider what we have been learning from our stakeholder groups and what is coming out of the consultation, and then decide how the role might look going forward.

Charlie Bethune: In terms of the relevance of the PSC from an epilepsy point of view, although it is not exclusively the case, for the vast majority of the people that are affected by sodium valproate, it was a result of their mother being on sodium valproate before the child was born. One of the big issues that many of the people who have been affected by this, which has been going on for forty years, is that because of the difficulties they have as a result of epilepsy, they've really struggled to be listened to and heard. They are dealing with their own medical issues themselves and dealing with a child who has been affected by valproate. So a key part of the PSC is to act as their advocate.

The other comment is that the PSC is needed because over those forty years, the existing mechanisms through the NHS and MHRA have not been effective in

resolving this issue. The big thing the Cumberlege report looked at was to say, we've got all these mechanisms in place but they don't deal with it from a patient's perspective, it has always been dealt with from a government agency and NHS perspective. A PSC is vital in terms of representing the patient. That is the big difference. We are not expecting medical practitioners would be the people going to the PSC, it is the patient's themselves – its people who are identifying there are issues that are not being taken seriously by the existing medical establishment. Giving them a route that is independent and has some powers to make something happen.

Frauke Hunter, part of the Pharmacy and Medicines division within the Scottish Government

I will provide an update on Cumberlege recommendations and actions our team has an interest in.

Firstly, the recommendation on specialist centres. We remain committed to ensuring that patients in Scotland receive the best possible care and we are examining how to take forward this recommendation. As part of that we are considering the existing foetal alcohol advisory and support team as one potential option to coordinate and/or provide specialist services. And this is because there are similarities between valproate syndrome and foetal alcohol spectrum disorders. We are conscious of the fact that the service will need to deal with different challenges faced by those affected and their families across their whole life and we are working on this basis.

Secondly, the recommendation about support schemes. For that, we are examining ways in which we can improve the care received by those harmed by sodium valproate, including through any proposed specialist centres or services, and through work with the UK government on reserved issues.

Thirdly, the recommendation on medicines registries. Notably, for all women on anti-epileptic drugs who become pregnant. The report calls for mandatory reporting of patient identifiable data created over lifetimes. The epilepsy register has the potential to be linked to other available routine datasets, including for example, childhood developmental datasets. We are looking at how it may contribute to the work on UK wide medicines registries led by the MHRA. The purpose of these medicines registries is for safety and risk minimisation. In England, there is already a valproate registry under development by MHRA which had recently been extended to all anti-epileptic medicines following the Cumberlege report. We are therefore engaging on the development of this in relation to Scottish patients.

Rona Johnson: Asked if the medicines registry will be part of the epilepsy register.

Frauke Hunter: They started separately and independently. We are not looking to duplicate what the epilepsy register is doing, we are working closely with the team.

Yes, the intention is to have something that is the same UK wide, but this started of separately so any future proposals will be developed from the start to be joint ones.

Derek Robertson: Asked for more information on specialist centres and said these centres should not create a two-tier system.

Frauke Hunter: The work is ongoing, particularly around delivery and implementation. The delivery of that would not be led by my team necessarily and so we haven't yet determined the most appropriate way forward but we have looked at the overlap with the foetal alcohol spectrum disorders and valproate syndrome. We cannot answer your question in detail yet until we've looked at how exactly it is going to be delivered.

Charlie Bethune: You need to be careful about the use of the term 'specialist centre'. It is not about providing a centre that is extra special for people who have been affected by valproate, it is about providing services that, at the moment, are not available in Scotland. The difficulty we have with people affected by valproate is that there is no one that can provide that diagnosis. In Scotland, there are very few people that have a formal diagnosis of sodium valproate syndrome and so many of them have great difficulty accessing existing services. It is not about a specialist service, it is about providing a service that we should be providing in Scotland because of the condition we have got.

Agenda item 5. Action Points/AOCB

Alasdair Allan: Asked for more information on the epilepsy deaths research.

Susan Duncan: I was the principal investigator on this research. Over a seven-year period we looked retrospectively at epilepsy related deaths in Scotland.

The take home message is that between ages 16 and 24, you are 2.5-3 times as likely to die prematurely if you have epilepsy than the background population.

20- 40% of these deaths were SUDEP, the rest were not. We found that well over 60% of the people who died had attended or been admitted to hospital at some point in the seven-year period before their death because of their epilepsy but only 27% were referred onto their specialist neurology clinic afterwards.

For the first time ever, this study used amenable (preventable) deaths analysis. We found that about 76% of deaths were amenable – we excluded the SUDEP deaths because we believed they were not amenable, they were deaths directly due to seizure – but the rest, we felt could have been preventable if the person had had had some intervention to perhaps alter drugs or been given even basic safety advice. We think with a rejig of our epilepsy services, we feel we could prevent a lot of deaths and improve the patient experience.

As an aside, talking about a register, I kept an epilepsy register when I was a full time NHS consultant. We developed an algorithm and ran it through the public available databases of hospital admissions and prescriptions and we found that we could quite easily identify well over 90% of people who had epilepsy. I wonder if that might be a better way forward of identifying people than constantly updating prospect registers.

Alasdair Allan: It might be useful for the group to write to the Health Secretary to ask what the government is learning from this.

Susan Duncan: This would be very useful. Our research group is having a meeting in December with the Scottish Government. We do have some proposals about how we could take this research further.

Anissa Tonberg: When you are talking about analysing preventable deaths, you excluded the SUDEP deaths. In the study I saw the next most common preventable cause was cardiovascular and addiction related deaths – so were those also preventable because of underlying conditions or was all of the cohort considered preventable by virtue of the fact they had epilepsy?

Susan Duncan: Biggest preventables were people who had epilepsy, but also had cardiovascular disease and then we got onto people who had addictions and mental health conditions – they were the next big cohort along with respiratory disease. What you see looking at that and with the multiple cause of death is to say that in Scotland it is an issue of these people's epilepsy, but it is also a background issue of public health. We know people with epilepsy don't take as much exercise, they are likely to be lower status jobs, and we also found that the general practice cohort that 50% of them had mental issues, which would feed into perhaps not taking medication regularly. These are things that we felt, if addressed, would have contributed to better epilepsy control but also longer life. It is a complex picture of epilepsy causing decline in social economic status because people don't get educational opportunities and don't get jobs and that then feeds into lifestyle choices. We felt if we could have got these people when they first came to hospital and got them into specialist neurology clinics, we might have been able to ameliorate their seizures, and then in turn, many other things improve as well, like mental health.

Rona Johnson: Asked what the next steps are for the epilepsy register regarding national roll out.

Anissa Tonberg: Things are going well. Things are very functional in Glasgow and Lanarkshire, and things are rolling into Tayside. They have got somebody working with the project collecting data. Once they have about six months of data, they are going to be using that to approach a number of other health boards.

There is clinical support. I think the difficulty has been around the IT, and the fact that all the boards have different systems. The intention and commitment around roll

out is very much there and I would expect to see some movement within the next six months.

In terms of the epilepsy deaths study – one of the features of the register is that if someone with epilepsy has an admission into hospital then an alert goes to their clinician.

Susan Duncan: One of the things that came out our study as something called the 'Death Tool'. We looked at our data found three questions to give a risk of death score. They are related to socioeconomic class, number of seizure related admissions in the last six months and anti-epileptic drugs. Depending on the score it says within how much time the person should be seen. We are currently trialling it in another part of UK. From my experience looking after people with epilepsy and as a consultant, I believe that is probably more useful than a red flag popping up on my desktop.

Agenda item 6. Close

Date and topic of next meeting are still to be confirmed. Members were encouraged to contact the Secretariat to suggest topics for future meetings.

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