

Note of Meeting – Cross- Party Group on Epilepsy, 20 September 2018

In Attendance:

George Adam MSP	Angela McCormack - Observer
Stacy Adam (office of George Adam MSP)	Colin McFarlane – Indigo
Alasdair Allan MSP	Iain Morrison – Revive MS
Mary Antcsak – Epilepsy Connection People’s Forum	Tanith Muller – Parkinson’s UK
Matt Barclay – Community Pharma Scotland	Mairi O’Keefe – Leuchie House
Robert Bennett – West Dunbartonshire Support Group (WDSG)	Ronnie Prentice - WDSG
Andrew Boyle – NHS Fife	Jenny Preston – NHS Ayrshire & Arran
John Bruce – Epilepsy Connection People’s Forum	Elizabeth Quigley - Observer
Claire Cairns – Coalition of Carers in Scotland	Keith Robson – MS Society
Donald Cameron MSP	Brian Rocks - WDSG
Jan Campbell – UCB Pharma	Derek Robertson – NHS Lothian
Heather Davies – Epilepsy Connections	Kelly Robinson - WDSG
Jacqui Downs – NHS Ayrshire & Arran	Caroline Rooks – Community Pharmacy Scotland
John Finnie MSP	Alastair Ross - Observer
Joe Fitzpatrick MSP	Shona Scott – NHS Lothian
Ian Forbes – UCB Pharma	Morna Simpkins – MS Society
Stephanie Fraser – Bobath Scotland	Niall Sommerville – MS Society
Gerard Gahagan - Quarriers	Kamath Tallur – NHS Lothian
Kenneth Gibson MSP	Sharon Thinn – NHS Fife
Paul Gillon – Veriton Pharma	John Thomson – NHS Lanarkshire/Eisai Ltd
Anne Gray - WDSG	Anissa Tonberg – Epilepsy Scotland
Raymond Hussain - WDSG	Colin Urquhart – Scottish Government
John Heany - WDSG	Helen Walsh – Merck Group
Fiona Hughes – NHS Fife	Sam Whitmore – Epilepsy Connections
Lorraine Hunter – Leuchie House	
Jen Irvine – NHS Lanarkshire	
Elinor Jayne – Sue Ryder	
Chris Jeans – SUDEP Action Scotland	

Apologies:

Lynne Allan – NHS Lanarkshire	Lorraine Mackenzie - Observer
Jean Barclay - Observer	Hilary Mounfield - Observer
Celia Brand – NHS Lothian	Barbara McCulloch - Observer
Jo Campbell – NHS Grampian	Michael McCulloch - Observer
Eugine Chizooma – Eisai Ltd	Dr Ailsa McLellan – NHS Lothian
Yasmin Fraser - Biogen	Gail Patrick - Observer
Alex Cole-Hamilton MSP	Dr Aline Russell - Quarriers
Gillian Horsburgh – NHS Greater Glasgow & Clyde	Eleonora Saturno – NHS Fife
Andrena Hughes - Observer	Dr Jay Shetty – NHS Lothian
Sylvia Lawrie - Observer	Dr Linda Stephen – NHS Greater Glasgow & Clyde
Yvonne Leavy – NHS Lothian	David Torrance MSP
	Lesslie Young – Epilepsy Scotland

1. Convener Kenneth Gibson MSP welcomed attendees to today's Joint Meeting.
2. AGM Business and the election of the Office Bearers was undertaken for both groups. Kenneth Gibson MSP was re-elected Convenor of the CPG on Epilepsy and David Torrance MSP and Alasdair Allan MSP were elected Deputy Co-Convenors. Members also agreed for Epilepsy Scotland to carry on providing the Secretariat on behalf of Epilepsy Consortium Scotland. Kenneth Gibson MSP read the annual financial statement for the CPG and the minutes of the last epilepsy CPG were approved.

John Finnie MSP conducted the AGM business for the CPG on MS. George Adam MSP was re-elected Convenor and Donald Cameron, John Finnie and Neil Findlay were re-elected Deputy Convenors. John Finnie MSP read the annual financial statement for the CPG and the minutes of the previous meeting were approved.

1. John Finnie MSP thanked Epilepsy Scotland for assisting with the arrangements for this joint meeting and updated a few matters arising; George Adam MSP and Neil Sommerville from MS Society met on 12th September with the Minister of Public Health Joe Fitzpatrick MSP, regarding access to stem cell therapy in Scotland. Neil Somerville will provide the Group an update writing. Also the summary of Health and Staff in Scotland bill was circulated to CPG members as was Rachel Morris' presentation and there has been no further discussions taken place on the future work, that will be picked up on at further meetings.
2. Kenneth Gibson MSP introduced Stephanie Fraser, Chief Executive of Bobath Scotland and Vice Chairperson of the National Advisory Committee on Neurological Conditions (NACNC). Stephanie gave an overview of work with the Committee so far to produce a national action plan for neurology in Scotland, which included the following points:

The NACNC was formed in 2016, in 2017 the former Minister for Public Health announced that there would be a National Action Plan for Neurology and that the NACNC would develop it. In the Programme for Government there is a commitment that the draft National Action Plan for neurological conditions will be published for consultation. The publication date is set for early October for a draft, it will then go out to full consultation until after Christmas.

The scope, which was set by the Minister, is that it is a generic plan to cover all neurological conditions, and seeks to learn from approaches that have been used in other conditions or groups and to share the benefits of those amongst the vast umbrella that covers neurological conditions. The plan uses the World Health Organisation's definition of a neurological condition which includes functional disorders and is therefore a very wide range of conditions. The plan concerns adult services only, however it also includes the transition into adult services. It excludes conditions that have an existing national policy context or national strategy such as dementia, stroke, palliative or end of life care.

There have been a number of challenges; the spotlight is on neurological conditions at the moment and the committee wanted to grasp that opportunity, but knew it would not be perfectly right which is why it will be published in draft form for the full consultation process. Neurological conditions are a hugely vast and differing population and there isn't always consensus between all those groups, also there are a large number of people with undiagnosed functional, neurological symptoms. There are a wide array of stakeholders with an interest in the plan, including those from the NHS, integrated boards, third sector, families and carers, people with neurological conditions, academic and government institutions.

Following the appointment of the current Chair of the NACNC, neurologist Dr Richard Davenport, the committee decided there was a need to try and get an understanding of the scale of the problem; to understand not only the population of people in Scotland with neurological conditions but also what existed in terms of services, workforce and expertise. It was also important to understand people's lived experience of these services. There was a literature and policy review undertaken by the Scottish Government team and a programme of engagement events around the country.

The committee commissioned NHS Scotland's Information Services Division (ISD) to see what data is collected on the wide umbrella of neurological conditions. There were estimates for some,

but not all, conditions. There was no information on the use of care services – ISD Scotland could look only at hospital records. Even looking solely at hospital data, determining estimates for the prevalence of certain neurological conditions was extremely challenging and there was significant variation in the estimates for conditions such as epilepsy. Given the challenge with hospital data, the challenges are even greater in trying to look at social care data because people with neurological conditions may be cared for by generic services and so are not necessarily counted specifically. Information from the current ISD Scottish Burden of Disease study was also considered and shows that demand on services in Scotland is increasing as people with neurological conditions live longer.

The NACNC prepared a detailed questionnaire which was distributed to all NHS Boards, all integrated joint boards, and to third sector service providers. The idea was to establish a bench mark as best as possible. The returns suggested that at a very high level all NHS Boards have access to 24-7 neurology advice – however the actual nature of this varied greatly between boards, with wide variation in access of services. There were gaps in provision of neurology ward reviews. Neuro-Rehabilitation services were not available in all Board areas. The make-up of Multi-Disciplinary teams was inconsistent, and there was variation in waiting times across Boards. There are variations in accessibility both because of geography but also depending on what condition is involved; some pathways are clearer than others and the services are provided by varied diverse range of staff groups.

A Lived Experience survey was conducted with Health and Social Care Alliance Scotland and the Neurological Alliance Scotland, supported by a literature review and focus groups. The priorities identified for action were: care pathways, functional symptom support, family carers, information and resources. Some issues were outside the scope of the National Action Plan but will be fed into relevant policy areas. Engagement events were held at Hampden, Murrayfield and Pittodrie, they were well attended and provided strong feedback as to priorities for action. The draft plan will be out in October, and the NACNC looks forward to everyone's comments and input. The ultimate aim is to ensure we can help people to live well for longer.

4. The Convener thanked Stephanie for her presentation and invited questions.

Brian Rocks, West Dumbartonshire Epilepsy Support Group – Asked the speaker's opinion on why epilepsy is so little understood .

Stephanie Fraser – Agreed that is something that is common to many different conditions, e.g. an unseen disability affecting people, but felt there is no clear answer.

Ian Morrison, Revive MS – wondered whether there is a move towards the statutory coming closer to the third sector; can we look forward to more collaboration there and greater recognition of the work, and the value of the work, that the third sector does?

Stephanie Fraser – hoped this is the case, and has been encouraged that all the way through this process the third sector has been very closely involved. SF thought it had been recognised that the third sector are really good at spotting needs, gaps in provision and going in quickly and efficiently to provide for those gaps. She is very keen to ensure that is recognised in a meaningful way and not just paid lip service. SF felt that there is a willingness at top level, and that the important thing is that people with neurological conditions have better support and services provided by whoever is the best equipped and able to do so.

Anissa Tonberg, Epilepsy Scotland – asked what more might happen to the information collected through the lived experience research which was outside the scope of the plan itself; it seems important it be used.

Stephanie Fraser – said the Health and Social Care Alliance are very keen to take the learning from that forward, the areas around say housing and benefits etc. are being fed back to the relevant government teams by the government officials on the NACNC.

Mairi O'Keefe - CE Leuchie House asked whether the NACNC had to resort to FOIs when it went to the local authorities for information, or was the information very happily given without waiting times etc.?

Stephanie Fraser – said they did not have to resort to FOIs, however it depended where the survey landed as to what results were received and some had to be chased.

Mairi O’Keefe – raised an issue about some guests at the consultation events struggling to communicate and be understood by the people who were hosting the groups. She asked what training was given to the facilitators?

Stephanie Fraser – said that the engagement events were organised collaboratively with the Neurological Alliance, there wasn’t specific training as such but what was very important was that the Lived experience of as many groups as possible was fed in, so the engagement events was one aspect and things like the focus groups at Leuchie House was another way of doing that.

5. The Convenor welcomed **Joe Fitzpatrick MSP**, Minister for Public Health, Sport and Well-being, who spoke about the talk National Action Plan for Neurology and included the following points:

The government’s intention is to ensure that everyone living with a neurological condition is able to access the best possible care and support, which why they have developed the National Action Plan. It was taken forward in partnership with the NACNC and neurological community – it is very much a partnership approach going forward.

It is the very first National Action Plan for Neurology, it is one of the centre pieces in this year’s programme for government, showing the government’s commitment to this work.

The plan is almost completed and will be shortly signed off to go out to consultation. It is really important that the neurological community gives its feedback, the government genuinely wants to hear any issues you have with the plan. It is about taking those actions in that plan forward to make a difference, it will make it easier for him to make any arguments he has to across government, to argue the case, if he knows the plan has the backing of the third sector.

The overall aim of the Plan is to ensure that we provide a more joined up service. This will include making sure that government agencies, NHS and local government are working with the third sector in a complementary way. There is no question that sometimes the third sector are the best people to deliver on the ground and we need to make sure that they are included in a joined up way rather than trying to overlap and competing for the same resources. It is the individual person that matters, we cannot have a blanket policy; the plan is to make sure we are focusing on that person centred care.

The government hopes it will be transformative, that it will make a difference in making sure that people with neurological conditions can live better lives. We also want to make sure that it is supported by the appropriate resources that we need to put in place.

As part of the work the Minister confirmed that the government is going to appoint a National Implementation Lead to make sure they are driving that forward right across Scotland. The plan is for a network of regional leads also in order to meet the different challenges of implementation across Scotland.

The Minister stated it is important to thank the NACNC and particularly to Stephanie for getting us to where we are. Also important to thank the third sector and partners who have played a very critical role in getting this to where it is and getting it into a good document, which he hopes everyone will feed back on.

Convenor – Thanked Joe Fitzpatrick MSP for his presentation and opened the floor to any questions or comments.

An unidentified attendee asked if there will be a statutory requirement on the action plan and also what legislative support will be given to the authorities to implement this?

Colin Urquhart, Scottish Government – has been leading on development of the plan and working with the NACNC. Statutory requirements around commissioning services for people with neurological conditions was discussed a lot and we are still tweaking some of the actions and the recommendations around that.

Minister – confirmed that it is within his Public Health Budget and is reasonably sizeable.

Elinor Jayne (Sue Ryder) – asked how much partnership there would be between whatever implementation actions are taken in relation to the action plan and the new General Standards for Neurology, to make sure that they are complimentary and that the standards are actually useful in practice.

Colin Urquhart – said that the consultation will be 3 months so we hope to launch the plan early next year and during the consultation period we will be thinking a lot about implementation including identifying the national lead. Yes, the action plan and standards need to be seen together, need to be read together as a sort of set in policy direction for the next 4-5 years. We are still trying to figure out the best way that they complement each other and how they can help to make a change on the ground.

Neil Sommerville (MS Society) – felt very encouraged about the action plan and implementation, however expressed concern about the experience of colleagues in Wales; whilst the content of the action plan introduced there was good it didn't have any outcomes or resource behind it. Can we expect to see anticipated outcomes detailed within the plan?

Minister – said yes, one of the advantages of being behind Wales in terms of doing the action plan before us is learning lessons, if other people have done something and it has not made the difference on the ground then you understand why; it is really important that we do know that we are going to deliver the actual action points that we could be challenged on.

Colin Urquhart – mentioned that the team visited Wales to learn about their action plan, it has been part of the development of this.

Kamath Tallar, Neurologist, Edinburgh – was very pleased to hear about the plan, however he looks after children with neurological conditions, and wanted to know why children were not included within the scope of the plan?

Colin Urquhart – replied that the NACNC had a lot of debate about this and decided to look at adults from 16 years up, however will also be looking at transition from children services to adult services which we know is an issue.

Stephanie Fraser – shared Kamath's concern, remarking that it is sometimes a ridiculous distinction, however said that things are divided into children's and adults services and felt that what is really important in the plan is the focus on transitions because the challenges associated with this came out in the engagement work. She commented that there are other areas that are being worked on with the Minister for Children and Young People, so parts of this plan are being fed in to other government policies.

Kamath Tallar, Neurologist – felt that if you look at a child who is 1,2,3,4 to 14, 15 you are going to look after them and give them a life for 90 years, and urged the Committee not to forget that.

Brian Rocks – asked about the potential rescheduling of cannabis oil

Minister – remarked that the Scottish Government has supported the UK Government's decision to make cannabis based medicines available on prescription, that there appears to be a growing amount of evidence that cannabis based medicines work for some people. It is a reserved matter, however the Scottish Government has been a supporter of the argument and the line that the UK government has decided to take.

Brian Rocks – asked if there are any time lines for this.

Kenneth Gibson – answered that there wasn't, however also added that he felt it important to recognise it was only helpful to some people, that the recent presentation about cannabinoids at the CPG on Epilepsy made it clear that for the majority of people it is not actually helpful and it can be harmful.

Anissa Tonberg – asked about measuring the success around the plan, is there going to be indicators, albeit broad ones, or anything associated with the plan to measure on?

Colin Urquhart – answer that yes, the NACNC will take on a key role doing a sort of yearly check of progress and actions, it is a 5 year plan so we will be looking to have the immediate wins of

things to be imposed straight away and some longer term actions. The implementation is still being thought through, however the plan has been approached in such a way that we can show some progress.

Minister – reminded attendees that if they see the published plan and think some specific things have been missed which would give a good measure of progress, to make sure they feed that back in.

Fiona Hughes, ESN Fife – asked whether the NACNC condition-specific work groups will be asked to become active again; these groups had been active prior to the work to develop the plan and had been out on hiatus for a year.

Stephanie Fraser – answered that the hope is to publish the draft plan for consultation and then to have a look at the role of the NACNC; she was not sure yet, however said that the structure is there if it is seen that that is the right way forward.

6. The Convener thanked the Minister, Stephanie Fraser and Colin Urquhart for their input and thanked everyone from both Cross Party Groups for attending, remarking that it had been a really interesting session.

He mentioned for members of the CPG on epilepsy that if there are issues relating to epilepsy they wished to raise to please take them up directly with their own MSP, himself as Convener or Anissa the Secretariat, and that similar arrangements applied within the CPG on MS and its work with MSPs.

The Convener stated that:

- The next CPG on MS will be held in early December.
- The next CPG on epilepsy will be held in January and the subject will be PIP and Social Security.

He thanked all for their attendance and closed the meeting.