

# **National Action Plan on Neurological Conditions**

*(Draft for consultation)*

**2019-2024**

**November 2018**

The Scottish Government is committed to equality and diversity. This draft plan is intended to support improvements in healthcare for everyone, regardless of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socio-economic status or any other status. Suggested aspects to consider and recommended practice throughout the draft plan should be interpreted as being inclusive of everyone living in Scotland. We have assessed this draft plan for likely impact on the nine equality protected characteristics as stated in the Equality Act 2010, including the Fairer Scotland Duty. A copy of the impact assessment is available upon request.

## **Executive Summary**

We want to ensure that people living with neurological conditions have access to the best possible care and support. To achieve this goal, we have developed this plan in partnership with the National Advisory Committee for Neurological Conditions (NACNC) and wider Neurological Community. It sets out a vision for driving improvement in the care, treatment and support available to people living with neurological conditions – and their carers - in Scotland.

Throughout we have used '*Neurological Community*' to mean people living with neurological conditions, their families and carers, those who provide care and support, practitioners, clinicians, academics, NHS Boards, Integration Authorities, third sector and independent care providers.

## **Our Vision**

Everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms.

## **Our Aims**

- Ensure people with neurological conditions and their carers are partners in their care and support
- Improve the provision of co-ordinated health and social care and support for people with neurological conditions
- Ensure high standards of effective, person-centred, and safe care and support
- Improve equitable and timely access to health and social care and support across Scotland
- Build a sustainable neurological workforce for the future

## **We will do this by working with national, regional and local services to:**

- Support people to manage their condition as appropriate to their needs
- Develop integrated and co-ordinated models of care and support with the Neurological Community
- Support HSCP's to embed mainstream models of care that ensure personalised support in every case, and options over the level of control the individual and their family chose to take, in accordance with the Social Care (Self-directed Support) (Scotland) Act 2013
- Test and introduce innovative ways of delivering health and social care and support
- Improve our understanding of the neurological population in Scotland
- Improve ways of measuring quality of care and outcomes via better data collection and use of outcome measures
- Use technology to enhance care.
- Support participation of all members of the Neurological Community in research and quality improvement

We will meet the aims above through commitments which we have identified for implementation, these can be found throughout the plan and at **Annex A**.

## Introduction

1. The Scottish Government aims to help people sustain and improve their health, independence and wellbeing.
2. In 2003, it was estimated that there were about one million people in Scotland living with a neurological condition, of whom at least 10% were disabled as a result (*Neurological Alliance of Scotland report, 2003*)<sup>[1]</sup>. Neurological conditions account for up to 10% of acute hospital admissions<sup>[2]</sup>, and 10% of the overall burden of disease in Scotland, as measured by disability-adjusted life years<sup>[3]</sup>. In this plan we have attempted to maintain as broad a view of neurological conditions as possible, accepting that it is unrealistic to specifically include every condition in which neurological symptoms might be expressed. **Therefore this plan, and its commitments, are not condition-specific.**
3. As part of our ambition to help people improve their health and wellbeing, we want everybody with a neurological condition to live well. In September 2017, the First Minister announced that, following discussion between the Minister for Public Health and Sport and the National Advisory Committee for Neurological Conditions, the Scottish Government had started work to develop Scotland's first ever National Action Plan on Neurological Conditions.
4. We invited the NACNC<sup>[4]</sup> to undertake preparatory work and evolve the National Action Plan.

## Scope

5. The National Action Plan On Neurological Conditions is focused on adults (16 years and older), as there is separate work within Scottish Government considering how best to support children and young people with disabilities and their families. However, we recognise the importance of the transition period when young people move into adult services. This is an issue considered by the Ministerial Advisory Group for Disabled Children and Young People. Transition is also an issue for adults as they move to become users of services for older people, or move from their own home to residential or nursing care.
6. There are separate strategies already in place for stroke<sup>[5]</sup>, dementia<sup>[6]</sup>, and learning disability<sup>[7]</sup>, so whilst these are neurological conditions, they are not specifically considered within this plan; although there are clear linkages especially in relation to access to care and support, short breaks, options to residential care, and a need for rehabilitation care and support to live well in the community.
7. We recognise the importance of other policy areas such as welfare, education, housing and employment to drive independence, health and wellbeing for people living with long term conditions including neurological. These issues are addressed in other government policy and are not within the scope of this plan.

## What are neurological conditions?

8. In this plan we use '*neurological conditions*' to include a wide range of conditions, disorders and syndromes affecting the brain, spinal cord, nerves and muscles.

9. Well known conditions include migraine, multiple sclerosis, epilepsy, and Parkinson's disease. Neurological conditions are caused by a range of diverse pathologies. These may be congenital (e.g. cerebral palsy), hereditary/genetic (e.g. Huntington's disease), neoplastic (e.g. brain tumours), degenerative (e.g. motor neurone disease), infective (e.g. meningitis). Neurological conditions range from the common (headache/migraine, functional neurological disorders) to the very rare (e.g. Creutzfeldt-Jakob disease and other prion disorders). The cause of many common conditions remains uncertain (e.g. functional neurological syndromes, migraine).

10. **Annex B** provides some examples of the more common neurological conditions and their prevalence within the Scottish population.

### **Impact of neurological conditions**

11. Some neurological conditions present as an abrupt "one off" event with life changing consequences (e.g. traumatic brain injury). Other conditions may evolve over many years, either in a relapsing remitting manner (e.g. multiple sclerosis), or in a relentlessly progressive way (e.g. motor neurone disease). Some neurological conditions are more readily identified and defined (e.g. Parkinson's disease) than others (e.g. ataxia), and some generic headings mask enormous variation in how symptoms affect people's lives (e.g. epilepsy, myalgic encephalomyelitis, cerebral palsy, functional neurological symptoms).

12. Neurological conditions affect people and their families in different ways. We know that for some people and their families a neurological condition is a life changing diagnosis, affecting the person's ability to live independently, achieve personal ambitions, sustain their personal identity or life roles, work, or drive. For others their condition may affect their ability to communicate, walk, think, swallow or breathe. Any of these factors can cause stress, anxiety and depression for the person and their family/carers, increasing isolation, and dependency on local support.

13. While developing a plan for all of these diverse groups, we recognise the challenges this presents. We acknowledge that while in some areas care and support for people with neurological conditions work well, across Scotland there is scope for improvement.

14. We have developed this plan with the expectation that it will stimulate the evolution of new ideas that can be further tested and evaluated. The plan aims to build on what already works well, challenge the more traditional models in some areas that may not be providing the best solutions for people living with a neurological condition, and introduce innovative ideas to improve standards of care and support.

### **Developing the National Action Plan**

15. In preparation for the plan, NACNC advised Scottish Government to commission several overlapping pieces of work, **Annex C**. NACNC was determined to have people with lived experience and their families and carers at the centre of the plan; as such their engagement as key stakeholders has been paramount. The work commissioned included the following:

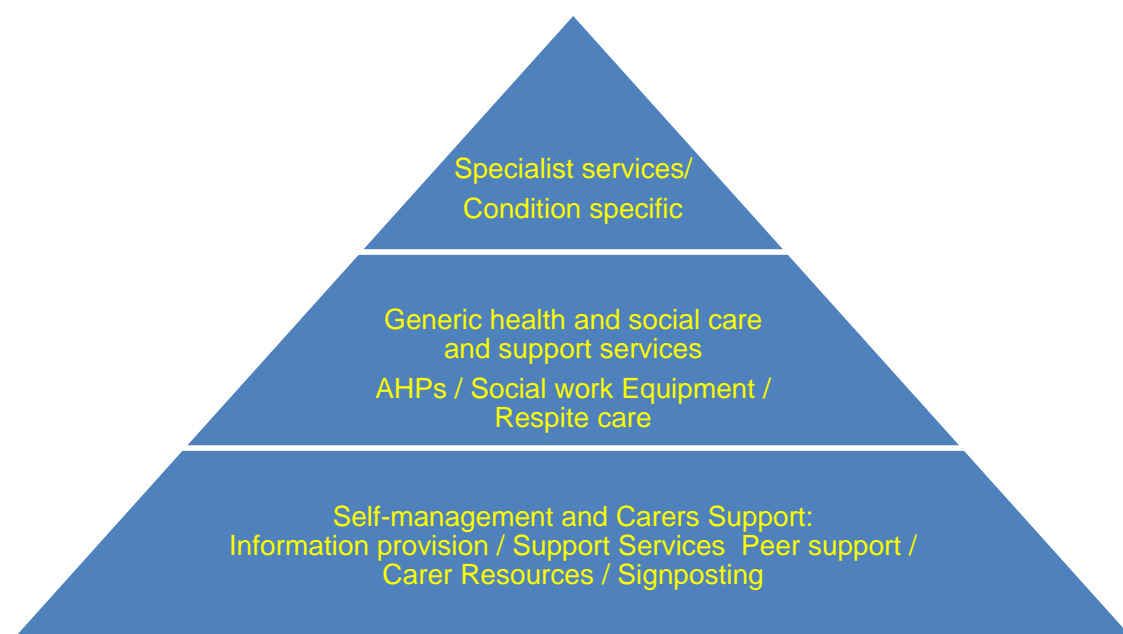
- I. NACNC asked the Health and Social Care Alliance and the Neurological Alliance of Scotland to work together to gather the views, and priorities, of people living with neurological conditions, and their families and carers. The Health and Social Care Alliance presented the report *Priorities from the Lived Experience Project*<sup>[8]</sup> to NACNC.
  - II. NACNC needed to know more about how many people in Scotland are living with different neurological conditions, so commissioned NHS Information Services Division (ISD) to investigate, and provide data relating to use of NHS Services. ISD provided a report on the complexities of determining prevalence estimates for neurological conditions - *NACNC briefing on estimating prevalence of neurological disorders in Scotland from the Scottish Burden Of Disease study*.<sup>[9]</sup>
  - III. NACNC wanted to understand what care and support are currently available, and what innovative models of care there might be, either already in action or in development. NACNC conducted a survey *Mapping Neurological Services in Scotland 2017/18*<sup>[10]</sup>. This survey described current care and support services and existing gaps in provision as well as identifying examples of good practice and priorities for improvement.
  - IV. NACNC considered the available evidence found through literature reviews on *Establishing Best Practice in Neurological Service Delivery and the Ideals of an Action Plan*<sup>[11]</sup> and *Person Centred Care and Self-Management*.<sup>[12]</sup>
16. The NACNC convened a National Action Plan Project Team, **Annex D**, to lead on the development of this plan. To evolve the plan, the project team also considered a logic model, and used the findings of the work commissioned, to develop the Vision and Aims of this plan.
17. NACNC considered existing frameworks such as the *House of Care Model* for long term conditions<sup>[13]</sup>, the *National Care Framework for Huntington's Disease*<sup>[14]</sup>, the *Active and Independent Living (AILIP) Logic Model Version 7*<sup>[15]</sup>, and some of the models described in *Improving Care for People with Long Term Conditions: a review of UK and International Frameworks*<sup>[16]</sup>. Furthermore, Scottish Government officials, who also sit on the NACNC, visited the Welsh Government to learn about their *Neurological Conditions Delivery Plan*<sup>[17]</sup>.
18. NACNC organised a series of national engagement events involving key stakeholders from across the Neurological Community; people living with neurological conditions, their families and/or carers, clinicians and practitioners from health and social care and support, third sector organisations, researchers and industry.
19. At all three engagement events the feedback highlighted the need for change. People felt treatment is “done to them” and want to be partners in their care. This requires support, both for health and social care professionals and individuals, to be able to shift the balance to a more equal relationship, good communication, and improvement in how care and support are delivered - if we are to meet the need to provide truly person centred care.

## Approach

20. People told us that they want to be able to live well, and play a full role in making decisions about their care and support. People asked for appropriate advice and support for them and their carers so that they could do this on their own terms.

21. We recognise that many people do not need, or want, to access hospital based services. The actions detailed later in this plan are considered based on a pyramid of support (Figure 1) which defines levels of support and care dependent on the needs and choices of the person living with a neurological condition.

**Figure 1. Pyramid of support**



22. In the first tier of the pyramid, people living with neurological conditions are self-managing their condition effectively within their communities, with shared decision making, including resources to promote a self-management approach to their care.

23. In the second tier people have a need for access to more generic neurological care and support delivered within the local community (e.g. paid carers from the local authority or a social care provider, personal assistants, social workers, speech or occupational therapy).

24. In the smallest tier are people who require specialist, often condition specific support, frequently available through regional or national services. Such individuals may require complex, highly tailored packages of care and support.

25. People may move between these levels of support, or access all levels at the same time, depending on their needs. Social care delivered in any tier will be accessed through self-directed support, Scotland's mainstream approach to social care. This ensures that support is personalised, and allows people to take control of their support if they wish to.

26. Scotland's Health and Social Care Standards<sup>[18]</sup> set out what standards of care everyone can expect when using health, social care or social work services in Scotland. The standards seek to provide better outcomes for everyone, and we have developed our approach in accordance with the principles of Dignity and Respect, Compassion, Inclusion, Responsive Care and Support, and Wellbeing.

## **Aims and commitments**

### **A: Ensure people with neurological conditions and their carers are partners in their care and support**

27. People told us they wanted to focus on personal outcomes and to be partners in their care and support. Some people gave good examples of personalised care from clinical nurse specialists, therapists, and their GP. Others found helpful information and support from charities or online. Others described receiving excellent support from community carers. People described positive experiences when they found information, were involved in decision making, or were helped to achieve their goals.

28. Data from the *Lived Experience* showed that while some people may feel listened to, other people perceived a lack of understanding on the part of clinicians, practitioners and other staff. People described lack of understanding of their condition, a lack of information on what care and support are available for them and their carers, and a lack of consideration of what matters most to them.

#### **Commitment 1**

We will support the development of shared decision making and personalised models of care and support for people with neurological conditions and their carers, including self-management support where appropriate in all services; and work with the Health and Social Care Alliance to identify shared learning from projects funded through the Self-Management Fund.

#### **Commitment 2**

We will work with NHS Inform, and stakeholders across the Neurological Community to improve the information available on neurological conditions, awareness of the NHS 24 Care Information Scotland resource, and support the further development of a local Information System for Scotland (ALISS) as a national resource for sign-posting people with neurological conditions to care and support.

29. People also told us that staff were sometimes reluctant to share information with peoples' families and carers and that their carers were not given the information or help they needed. People and their carers asked for training in using equipment and carrying out more technical interventions such as using hoists, feeding through a tube, and non-invasive ventilation.

30. We acknowledge the key role of unpaid carers and the need to support their health and wellbeing.



The Carers (Scotland) Act 2016<sup>[19]</sup> introduced new rights for carers to support, information and advice, designed to make caring more sustainable.

**Commitment 3**

We will work with stakeholders including third sector organisations and local carer information and advice services to develop approaches to enable improved access to training materials that will support carers as required under the Carers Act, in addition to working to make carers of people with neurological conditions aware of their new rights to support. We will work with stakeholders, including carers and local carer information and advice services to explore the need and potential delivery routes for further support to carers in the use of equipment and interventions to support those with neurological conditions, for example through the development of guidance on the content and delivery of training programmes for unpaid carers. We will encourage the involvement of people with neurological conditions and their carers in the development of Integration Authorities' local carer strategies.

**B: Improve the provision of co-ordinated health and social care and support for people with neurological conditions**

31. We know that the current model of primary, secondary and tertiary care works well for some people with neurological conditions, who are able to be referred to specialist teams, and can benefit from new therapies and medicines.

32. However, for others the current structure creates barriers to people accessing care and support when and where they need it, whether due to waiting times for appointments, the need to travel long distances to attend a specialist neurology clinic, or differences between referral and prioritisation criteria for housing adaptations, respite care, and provision of specialist, personalised equipment.

**Commitment 4**

We will work to ensure legislation, policy and guidance recognises the complex needs of those living with disabilities due to neurological conditions, and those of their carers. This should enable Integration Authorities - taking account of local accountability and priorities - to reduce inequalities and variation in the provision of care and support services, prioritisation of referrals, respite care and provision of bespoke equipment.

33. Through the *Lived Experience*<sup>[8]</sup> project and the national engagement events, we heard that some people experienced a lack of “joined up” care. People described a lack of co-ordination between different teams, and disjointed care between care providers, statutory, third and independent sectors. There was a clear message that we should improve communication among care and support professionals and between professionals and others.

34. We also heard from young adults with neurological conditions, and their families, about the difficulties experienced when moving/transitioning from Children and Young Peoples services to Adult Services.

We were given examples of less frequent review appointments, lack of access to therapy, and the need to establish relationships with a new care team. For older adults, moving into a suitable care home was difficult - as residential care for people with a complex neurological condition was not always available locally.

**Commitment 5**

We will work with key partners such as the Disabled Children and Young Peoples Advisory Group and other stakeholders to develop policies and procedures for good transitions for people living with neurological conditions.

35. We value the critical role of third sector organisations as key partners in developing, delivering and trialling new services and look to actively support them in creating a sustainable environment, particularly in areas where these organisations may be best placed to deliver services and support.

**Commitment 6**

We will work with COSLA; local partners in social services, the wider health and social care landscape and in housing; communities; people with care needs and carers; and others to support local reform of adult social care. We are currently developing a national programme for this work together, which will include publishing a refreshed implementation plan for self-directed support. We will also look to actively support third sector organisations as key partners by striving to create a sustainable environment for the care and support they provide.

36. We recognise the need to harness digital technology as a means of improving communication and overall care for people with neurological conditions. This ranges from better use of technology across care and support services, to improving the availability of information to people with neurological conditions, their families and carers, whether through shared records, person-held records or other initiatives to improve communication. There has been significant progress across services in the development and roll-out of innovative approaches to video-appointment systems such as *Attend Anywhere*, and out-patient booking systems that allow people to book an appointment at a time that suits them. We want to encourage the extension of these approaches in services for people with neurological conditions.

**Commitment 7**

We will support the use of technology and the exchange of digital information between people with neurological conditions and those who provide care and support, and within and between Integration Authorities and Boards, through the extension of the national initiatives described above.

37. We also heard about the need to share information between members of care teams, and the importance of anticipatory care plans<sup>[20]</sup> for some people with neurological conditions. A national programme that supported the implementation of anticipatory care plans and the development of an infrastructure concluded in June 2018, and an anticipatory care planning approach is now being embedded across all areas of work in Healthcare Improvement Scotland and the Living Well in Communities Programme.

**Commitment 8**

We will work with Healthcare Improvement Scotland to promote the development of anticipatory care planning approach by NHS Boards and Integration Authorities, to ensure these are widely available to people with neurological conditions.

38. Many people with neurological conditions experience deterioration in their condition over time. Services need to develop a more proactive approach to offering information, care, support and rehabilitation to people that enables them to maintain their independence, health and wellbeing. There is a need to develop and test different community based neurological rehabilitation models with expertise in neurological (rather than disease specific) rehabilitation and therapy, that can proactively provide care and support to people with a wide range of neurological conditions. Model teams could include generic neurology keyworkers as well as clinicians and practitioners with advanced skills, and need to be tested in both rural and urban settings.

39. Some neurological symptoms (e.g. headache, tingling hands/feet, dizziness) are extremely common and rarely caused by serious underlying disease. Yet they cause concern and anxiety for people, and represent a significant proportion of primary to secondary care referrals, either routinely or urgently. It is questionable whether this is the best way to support people with these symptoms, and so we propose to test projects that assess and support people with common neurological symptoms. Similar models already exist for other conditions (e.g. integrated back pain services led by Advanced Physiotherapy Practitioners).

**Commitment 9**

We will support Integration Authorities to improve services and support for people with neurological conditions, with a commitment to evaluation and testing of generic / neurology community based multi-disciplinary team models and testing of innovative ways of delivering health and social care to people with neurological conditions, including new roles and new arrangements for co-ordinating care and support.

We will work with Healthcare Improvement Scotland's Improvement Hub to review neurological rehabilitation care and support across Scotland, identifying aspects of good practice and integrated models of care.

40. There is also potential to explore whether existing community based models of care and support such as those used in some specialist neurological services, acquired brain injury, stroke and dementia could be enhanced and extended to those with other neurological conditions.

**Commitment 10**

We will work with the Neurological Alliance of Scotland, and other stakeholders, to explore the potential of National Care Frameworks - such as that used by the Scottish Huntington's Association<sup>[21]</sup> - and how these can inform neurological care.

## **C: Ensure high standards of effective, person-centred, and safe care and support**

41. Healthcare Improvement Scotland have recently revised its 2009 Neurological Services Clinical standards. The new publication *Healthcare Improvement Scotland General standards for neurological care and support: Draft Standards September 2018*<sup>[22]</sup> supports the development of joined-up health and social care, and reflect the National Health and Social Care Standards<sup>[23]</sup>.

42. The new standards for neurological care and support apply to anyone living with a neurological condition in Scotland. Organisations will use the standards to demonstrate that they are delivering high quality services. The standards set out the same high level of care and support for all adults regardless of condition, geographical location, service provider, or an individual's personal circumstances.

43. Scottish Government has worked with Healthcare Improvement Scotland to support the development of the standards through a shared ethos in bringing the greatest benefit to all people living with neurological conditions, regardless of their diagnosis.

### **Commitment 11**

We will promote and support the implementation of the Healthcare Improvement Scotland General Standards for Neurological Care and Support 2019.

44. The Scottish Burden of Disease<sup>[24]</sup> project ranked neurological conditions as fifth in terms of years lost owing to early death or living in less than ideal health (disability-adjusted life years, DALYs), representing 10% of the overall DALY score in Scotland.

45. However, through our work with NHS Information Services Division we concluded that it is not currently possible to identify exactly how many people there are in Scotland living with a neurological condition. We have a series of estimates for some (but not all) conditions, some more accurate than others; thus we do not underestimate the challenge we face regarding basic epidemiological data.

46. Neurological conditions affect everyone in different ways, and, also cause differences in health, independence and wellbeing over time. These differences make it difficult to find a way of measuring what type of treatment, care and support works best.

47. However, we know the use of outcome measures that are meaningful to everyone is paramount in the case of people with neurological conditions, so that they can decide what treatment, care and support will work best for them. The choice of measures for monitoring the outcomes of the implementation of the national action plan is similarly complex.

48. The development of linked data to support Health and Social Care Partnerships is a key project for NHS Information Services Division Scotland<sup>[25]</sup>.

We have some data available for the neurological population in Health and Social Care Partnerships, and further data will be available in the next year from the Scottish Care Home Census.

49. We will be better able to understand people's interaction with services as the data develops. This will inform future planning of services based on need, and provide a way of measuring performance and outcomes.

**Commitment 12**

We will work with NHS Information Services Division and others to:

- understand the gaps in prevalence, and how best to improve the data.
- enhance capture of already routine collected data.
- further develop systems and processes that support service planning and workforce development based on this information.
- explore the feasibility of developing a national reporting framework that includes key performance indicators for neurological care and support and measures improvements in care and support.
- explore the feasibility of developing effective measures of experience and outcome of person centred care and support, for people with neurological conditions.

50. Health and social care and support need to be effective. Ensuring effectiveness implies a willingness to learn from user feedback and service reviews, participation in development and improvement activities, a willingness to consider new paradigms, and apply new findings from research. Scotland has a proud history of research, and we wish to encourage ongoing research within the Neurological Community, alongside other development and improvement activities.

**Commitment 13**

We will support the neurological research agenda, promoting the work of the Chief Scientist Office and the Scottish Neuro-progressive and Dementia Research Network, and opportunities for people with neurological conditions to become involved in research trials; highlighting the need for further qualitative research on the impact of living with a neurological condition and on the identification of outcome measures that are meaningful to people who use care and support services that could be used across the Neurological Community.

**D: Improve equitable and timely access to care and support across Scotland**

51. Over the past 10 years there has been increasing demand on hospitals for neurology, neurophysiology, neurorehabilitation, neuropsychology and therapy services. There is also significant demand on care and support services provided by Integration Authorities.

52. Over the past 10 years there has been a 13% increase in the total number of residents in a care home for adults with physical disabilities <sup>[26]</sup>, against a backdrop of a slight reduction in registered care home places.

This suggests that there are challenges in providing care and support for people with physical disabilities, many of whom will have a neurological condition, and in enabling them to remain in their own home.

53. The Scottish Access Collaborative<sup>[27]</sup> is working to sustainably improve waiting times for patients waiting for non-emergency procedures and will shape the way services are provided in the future.

54. We have convened a Neurology group within the Scottish Access Collaborative, and this work, in conjunction with *The Modern Outpatient*<sup>[28]</sup> document, should lead to better referral guidelines and care and support pathways for people with neurological symptoms across Scotland.

#### **Commitment 14**

We will seek to improve access to Health and Social Care and Support by working with the Scottish Access Collaborative for Neurology to develop nationally agreed, regionally and locally applied guidelines for services and referral pathways for neurological conditions; and work with stakeholders on the development of a national or regional approach to access to services based on DCAQ (Demand, Capacity, Activity and Queue) for hospital neurology and neurophysiology services. In particular we will encourage NHS Boards and Integration Authorities to consider introducing/strengthening current provision for commonly accessed services including:

- open access clinics for suspected new epilepsy / first seizure patients, that accept referrals from patients, emergency departments and GPs
- rapid access neurology clinics
- pilots of community based teams for dealing with common neurological symptoms

55. *Mapping Neurological Services in Scotland 2017/18*<sup>[29]</sup> confirmed considerable variation in access to services depending upon local services, pathways and geography. We also heard from people with neurological conditions that the services they received varied depending on the condition they had, and on the types of services available in their local area. Some people reported that they received excellent care, however people with other conditions reported long periods of anxiety while waiting to access services and get a diagnosis, and a lack of support for managing their symptoms following diagnosis.

56. The *Scottish Atlas of Variation*<sup>[30]</sup> aims to highlight geographical variation in Scotland's population health, the provision of health services and associated health outcomes. The Atlas will facilitate discussion and raise questions about why differences exist and help to promote quality improvement through conversation. In time, the Scottish Atlas of Variation will be an important tool to help identify and eliminate unwarranted variation, and to support the reduction of harm and waste within healthcare.

#### **Commitment 15**

We will work with the Scottish Atlas of Variation Group to explore developing an Atlas on neurological conditions.

57. Variation in care is not confined to health services. We also heard about care and support services not being accessible to people in neighbouring localities because of partnership boundaries, of differences in funding essential equipment, and lack of access to therapy services due to place of residence. We need to remove barriers to improve access to care and support so that people can move easily between acute and community, and move in and out of services as appropriate to their needs, and at the right time.

## **E: Build a sustainable neurological workforce fit for the future**

58. The delivery of joined up and holistic services requires us to think more widely about 'workforce' and those who support the independence, health and wellbeing of people with neurological conditions. Care workers, practitioners and professionals are a huge asset to health and social care and support, therefore it is important to support them in their current roles and in developing new roles. As staff move into new roles we need to be able to model and predict the impact on the changing workforce and the services they provide.

59. During the mapping exercise and engagement events, we heard of gaps in the provision of adequately trained staff to deliver care and treatment. For example, vacancy rates in Consultant Neurologists exceeded 10% of the funded establishment, impacting on services' ability to deliver timely access to care and support.

### **Commitment 16**

We will discuss a national or regional approach to workforce planning with stakeholders, to test the extension of existing workforce planning tools and their application to the wider neurological workforce in Integration Authorities and NHS Boards; supporting review of job plans for Consultant Neurologists and Neurophysiologists to make posts more attractive, while recognising the national approach to consultant contracts. We will support a programme of innovation and the development of a phased approach to implementation where emerging evidence supports changing models of workforce, such as testing new roles of Advanced Practice for nurses, allied health professionals, general neurology keyworkers and healthcare scientists working in neurological care and support services.

## **Medical Staffing**

60. Medical training is managed at a UK level, the *Shape of Training* <sup>[31]</sup> review proposed an important evolution in the development of specialties and their role within provision of healthcare, particularly in the acute sector. The impact of the review on specialties like neurology, and the number of doctors in training in this specialty will not be clear for some time.

61. Meantime, our analysis of consultant vacancy rates and the age profile of the current consultant workforce and neurology training numbers have led us to give active consideration to recruitment; particularly in acute neurology and neurophysiology services.

62. Innovative ways of encouraging applications at consultant level need to be considered. This need not be financially driven - improving study leave provision and training budgets may be one way to enhance the attractiveness of working in Scotland.

### **Wider workforce**

63. It would be helpful for staff working in services that do not provide specialist neurological care and support, such as other medical specialties, community teams, or care homes to receive training in understanding the needs of people with neurological conditions and this should be available. There is no national framework for the development of non-medical staff working with people with neurological conditions, whether knowledge or competence based.

64. We support the critical role of third sector organisations in providing services and support. There needs to be consideration as to the sustainability of this workforce, while still recognising the independence of the sector.

65. Feedback from the Neurological Community at our national engagement events identified a need to develop guidance on the use of equipment and interventions e.g. hoists, enteral feeding, non-invasive ventilation, by appropriately qualified staff.

66. Employers are responsible for ensuring their staff have the skills and knowledge to carry out their roles. This responsibility is set out in the *Codes of Practice for Social Service Workers and Employers*<sup>[32]</sup> and the Care Inspectorate use the codes in their inspections of services. The National Health and Social Care Standards are also relevant, in setting out what a person can expect from their service provider.

67. Part 2 of the *National Health and Social Care Workforce Plan: Part 2 - a framework for improving workforce planning for social care in Scotland*.<sup>[33]</sup> proposes the development of a Framework for Practice in Social Care. This is being led by the Scottish Social Services Council, and will work with stakeholders to consider how such a framework will contribute to ensuring that there are clear routes identified that reflect the development of appropriate expertise in the social services workforce, including for management of specialist conditions.

#### **Commitment 17**

We will work with stakeholders, in the context of the work taking place under the National Health and Social Care Workforce Plan, to explore how best to further support the development of appropriate expertise in the health and social care and support workforce for those working with people with neurological conditions.



## **Implementation of the plan**

68. This draft plan is ambitious and challenging. It has the potential to significantly improve the independence, health and wellbeing of people with neurological conditions across Scotland. However, to achieve our vision we need co-ordinated action across the Neurological Community.

69. We will consult members of the Neurological Community on the content of this draft plan, to make sure there is wide support for the commitments.

70. The National Action Plan on Neurological Conditions has a 5 year timescale and will be supported by an implementation plan that will identify key delivery partners such as Scottish Government Departments, Integration Authorities, NHS Boards and other organisations.

### **We will:**

- i. Consult the Neurological Community on the commitments in this plan.**
- ii. Develop a implementation plan to support delivery of the commitments over a 5-year period.**
- iii. Appoint a National Implementation Lead who will work to develop a national network of Local Implementation Leads in Integration Authorities and NHS Boards to help deliver the plan across Scotland.**
- iv. Invite proposals for testing new models of care and support from Integration Authorities, NHS Boards and third sector organisations.**
- v. Align the role of the National Advisory Committee for Neurological Conditions, to support the implementation of the National Action Plan.**

### List of commitments

#### **Commitment 1**

We will support the development of shared decision making and personalised models of care and support for people with neurological conditions and their carers, including self-management support where appropriate in all services; and work with the Health and Social Care Alliance to identify shared learning from projects funded through the Self-Management Fund.

#### **Commitment 2**

We will work with NHS Inform, and stakeholders across the Neurological Community to improve the information available on neurological conditions, awareness of the NHS 24 Care Information Scotland resource, and support the further development of a local Information System for Scotland (ALISS) as a national resource for sign-posting people with neurological conditions to care and support.

#### **Commitment 3**

We will work with stakeholders including third sector organisations and local carer information and advice services to develop approaches to enable improved access to training materials that will support carers as required under the Carers Act, in addition to working to make carers of people with neurological conditions aware of their new rights to support. We will work with stakeholders, including carers and local carer information and advice services to explore the need and potential delivery routes for further support to carers in the use of equipment and interventions to support those with neurological conditions, for example through the development of guidance on the content and delivery of training programmes for unpaid carers. We will encourage the involvement of people with neurological conditions and their carers in the development of Integration Authorities' local carer strategies.

#### **Commitment 5**

We will work key partners such as the Disabled Children and Young Peoples Advisory Group and other stakeholders to develop policies and procedures for good transitions for people living with neurological conditions.

#### **Commitment 6**

We will work with COSLA; local partners in social services, the wider health and social care landscape and in housing; communities; people with care needs and carers; and others to support local reform of adult social care. We are currently developing a national programme for this work together, which will include publishing a refreshed implementation plan for self-directed support. We will also look to actively support third sector organisations as key partners by striving to create a sustainable environment for the care and support they provide.

#### **Commitment 7**

We will support the use of technology and the exchange of digital information between people with neurological conditions and those who provide care and support, and within and between Integration Authorities and Boards, through the extension of the national initiatives described above.

### **Commitment 8**

We will work with Healthcare Improvement Scotland to promote the development of anticipatory care planning approach by NHS Boards and Integration Authorities, to ensure these are widely available to people with neurological conditions.

### **Commitment 9**

We will support Integration Authorities to improve services and support for people with neurological conditions, with a commitment to evaluation and testing of generic / neurology community based multi-disciplinary team models and testing of innovative ways of delivering health and social care to people with neurological conditions, including new roles and new arrangements for co-ordinating care and support.

We will work with Healthcare Improvement Scotland's Improvement Hub to review neurological rehabilitation care and support across Scotland, identifying aspects of good practice and integrated models of care.

### **Commitment 10**

We will work with the Neurological Alliance of Scotland, and other stakeholders, to explore the potential of National Care Frameworks – such as that used by the Scottish Huntington's Association<sup>[21]</sup> – and how these can inform neurological care.

### **Commitment 11**

We will promote and support the implementation of the Healthcare Improvement Scotland General Standards for Neurological Care and Support 2018.

### **Commitment 12**

We will work with NHS Information Services Division and others to:

- understand the gaps in prevalence, and how best to improve the data.
- enhance capture of already routine collected data.
- further develop systems and processes that support service planning and workforce development based on this information.
- explore the feasibility of developing a national reporting framework that includes key performance indicators for neurological care and support and measures improvements in care and support.
- explore the feasibility of developing effective measures of experience and outcome of person centred care and support, for people with neurological conditions.

### **Commitment 13**

We will support the neurological research agenda, promoting the work of the Chief Scientist Office and the Scottish Neuro-progressive and Dementia Research Network, and opportunities for people with neurological conditions to become involved in research trials; highlighting the need for further qualitative research on the impact of living with a neurological condition and on the identification of outcome measures that are meaningful to people who use care and support services that could be used across the Neurological Community.

**Commitment 14**

We will seek to improve access to Health and Social Care and Support by working with the Scottish Access Collaborative for Neurology to develop nationally agreed, regionally and locally applied guidelines for services and referral pathways for neurological conditions; and work with stakeholders on the development of a national or regional approach to access to services based on DCAQ (Demand, Capacity, Activity and Queue) for hospital neurology and neurophysiology services. In particular we will encourage NHS Boards and Integration Authorities to consider introducing/strengthening current provision for commonly accessed services including:

- open access clinics for suspected new epilepsy / first seizure patients, that accept referrals from patients, emergency departments and GPs
- rapid access neurology clinics
- pilots of community based teams for dealing with common neurological symptoms

**Commitment 15**

We will work with the Scottish Atlas of Variation Group to explore developing an Atlas on neurological conditions.

**Commitment 16**

We will discuss a national or regional approach to workforce planning with stakeholders, to test the extension of existing workforce planning tools and their application to the wider neurological workforce in Integration Authorities and NHS Boards; supporting review of job plans for Consultant Neurologists and Neurophysiologists to make posts more attractive, while recognising the national approach to consultant contracts. We will support a programme of innovation and the development of a phased approach to implementation where emerging evidence supports changing models of workforce, such as testing new roles of Advanced Practice for nurses, allied health professionals, general neurology keyworkers and healthcare scientists working in neurological care and support services.

**Commitment 17**

We will work with stakeholders, in the context of the work taking place under the National Health and Social Care Workforce Plan, to explore how best to further support the development of appropriate expertise in the health and social care and support workforce for those working with people with neurological conditions.

### Definition of neurological conditions

The most simple definition of neurological conditions might be any condition which leads to neurological symptoms. Such a broad definition is problematic, as neurological symptoms are so common, and many entirely compatible with normal health. Restricting the definition to specific conditions is too narrow, as many patients with disorders of the nervous system remain undiagnosed with a specific entity. In addition there are many developmental disorders (e.g. dyslexia, dyspraxia) which result in neurological symptoms, but are not traditionally thought of as neurological disorders. There are significant areas of crossover with mental health disorders (unsurprising given both areas share the same organ, the brain), and many neurological conditions commonly lead to mental health symptoms (e.g. anxiety in Parkinson's disease). Neurological symptoms are commonly encountered in other diseases and disorders primarily arising from other systems (e.g. sleepiness/fatigue due to obstructive sleep apnoea).

The World Health Organisation (WHO) defined neurological conditions as follows (2016): *Neurological disorders are diseases of the central and peripheral nervous system. In other words, the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles. These disorders include epilepsy, Alzheimer disease and other dementias, cerebrovascular diseases including stroke, migraine and other headache disorders, multiple sclerosis, Parkinson's disease, neuroinfections, brain tumours, traumatic disorders of the nervous system due to head trauma, and neurological disorders as a result of malnutrition. Many bacterial (i.e. Mycobacterial tuberculosis, Neisseria meningitides), viral (i.e. Human Immunodeficiency Virus (HIV), Enteroviruses, West Nile Virus, Zika), fungal (i.e. Cryptococcus, Aspergillus), and parasitic (i.e. malaria, Chagas) infections can affect the nervous system. Neurological symptoms may occur due to the infection itself, or due to an immune response. Hundreds of millions of people worldwide are affected by neurological disorders. More than 6 million people die because of stroke each year; over 80% of these deaths take place in low- and middle-income countries. More than 50 million people have epilepsy worldwide. It is estimated that there are globally 47.5 million people with dementia with 7.7 million new cases every year - Alzheimer's disease is the most common cause of dementia and may contribute to 60–70% of cases. The prevalence of migraine is more than 10% worldwide.*

Thus defining what constitutes a neurological condition is less straightforward than it might at first appear, and may explain why many different specialties overlap in the care of people with such conditions.

Table: Examples of common neurological conditions and prevalence in Scotland based on Scottish Burden of Disease project

<b>Condition*</b>	<b>SBOD prevalence**</b>
Alzheimer's disease and other dementias	66,300
Migraine	1,075,029
Tension Type headache	1,400,722
Epilepsy	43100
Multiple sclerosis	9700
Parkinson's disease	12,600
Motor neurone disease	730

\*This list is not exhaustive and reflects limitations of current data.

\*\* *Scottish Burden of Disease study, 2015*. NHS Health Scotland and NHS Information Services Division <http://www.scotpho.org.uk/media/1474/sbod2015-overview-report-july17.pdf>

### Supporting pieces of work

- *Priorities from the Lived Experience Project*, The Health and Social Care Alliance and the Neurological Alliance of Scotland.
- *NACNC briefing on estimating prevalence of neurological disorders in Scotland from the Scottish Burden Of Disease study*, NHS Information Services Division.
- *Mapping Neurological Services in Scotland 2017/18*, NACNC.
- *Establishing Best Practice in Neurological Service Delivery and the Ideals of an Action Plan*, Dr Sophie Ilson.
- *Person Centred Care and Self-Management*, Dr Sophie Ilson.

These documents are available on request.

## Members of the National Action Plan Project Team

### Membership

Dr Richard Davenport*	Specialty Advisor to the Chief Medical Officer / NACNC Chair
Susan Walker*	Consultant Neurologist, NHS Lothian NACNC Deputy Chair General Manager, NHS Greater Glasgow and Clyde
Stephanie Fraser*	NACNC Deputy Chair Chief Executive Officer, Bobath Scotland
Colin Urquhart*	Policy Team Leader, Scottish Government
Kirsty Forsyth*	NACNC Project Co-ordinator, Scottish Government
Dr Jenny Preston MBE*	Consultant Occupational Therapist, East / North / South Ayrshire
Gerard Gahagan*	Chair, Neurological Alliance of Scotland
Gregory Hill-O'Connor*	Our Voice Coordinator, Health and Social Care Alliance Scotland
Donna O'Rourke	Programme Manager - Standards and Indicators, Healthcare Improvement Scotland
Dr Sophie Ilson	Intern and PhD student, Scottish Government

Key: \* also member of the NACNC, listed in Annex E



**National Advisory Committee for Neurological Conditions  
membership**

Dr Richard Davenport	NACNC Chair / Specialty Advisor to the Chief Medical Officer / Consultant Neurologist, NHS Lothian
Susan Walker	NACNC Deputy Chair / General Manager, NHS Greater Glasgow and Clyde
Stephanie Fraser	NACNC Deputy Chair / Chief Executive Officer, Bobath Scotland
Colin Urquhart	Policy Team Leader, Clinical Priorities, Scottish Government
Kirsty Forsyth	NACNC Project Coordinator, Scottish Government
Professor Siddarthan Chandran	MacDonald Professor of Neurology, University of Edinburgh / Director Anne Rowling Regenerative Neurology Clinic
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Gerard Gahagan	Acting Chair, Neurological Alliance of Scotland
Gregory Hill-O'Connor	Our Voice Coordinator, Health and Social Care Alliance Scotland
Sandra Larkin	Lead Nurse, NHS Tayside
John Paul Leach	Honorary Professor, University of Glasgow
Alison Love	Representative of people with neurological conditions
Annie Macleod	Scotland Director, Parkinson's UK
Dr Ed Newman / Dr Craig Heath (Alternates)	Consultant Neurologists representing the Scottish Association of Neurological Sciences
Irene Oldfather	Director, Health and Social Care Alliance Scotland

Dr Jonathan O’Riordan	Consultant Neurologist, NHS Tayside
Dr Jenny Preston MBE	Consultant Occupational Therapist, East / North / South Ayrshire
Claire Ritchie	Director of Allied Health Professionals NHS Greater Glasgow and Clyde (formerly NHS Lanarkshire)
Jane-Marie Stobie	Head Occupational Therapist, NHS Lanarkshire
Alison Swierkot	Representative of people with neurological conditions
Rebecca Duff	Chair Neurological Alliance of Scotland (on maternity leave)

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## **Responding to this Consultation**

We are inviting responses to this consultation by 8<sup>th</sup> February 2019.

Please respond to this consultation using the Scottish Government's consultation hub, Citizen Space (<http://consult.gov.scot>). Access and respond to this consultation online at <https://consult.gov.scot/healthcare-quality-and-improvement/neurological-conditions>.

You can save and return to your responses while the consultation is still open. Please ensure that consultation responses are submitted before the closing date of Friday, 8<sup>th</sup> February 2019.

If you are unable to respond using our consultation hub, please complete the Respondent Information Form to:

Strategic Planning and Clinical Priorities Team  
Scottish Government  
GER  
St Andrew's House  
Edinburgh  
EH1 3DG

## **Handling your response**

If you respond using the consultation hub, you will be directed to the About You page before submitting your response. Please indicate how you wish your response to be handled and, in particular, whether you are content for your response to be published. If you ask for your response not to be published, we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

If you are unable to respond via Citizen Space, please complete and return the Respondent Information Form included in this document.

To find out how we handle your personal data, please see our privacy policy: <https://beta.gov.scot/privacy/>

## **Next steps in the process**

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public at <http://consult.gov.scot>. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us. Responses will be published where we have been given permission to do so. An analysis report will also be made available.

## **Comments and complaints**

If you have any comments about how this consultation exercise has been conducted, please send them to the contact address above or at [Clinical\\_Priorities@gov.scot](mailto:Clinical_Priorities@gov.scot).

## **Scottish Government consultation process**

Consultation is an essential part of the policymaking process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

You can find all our consultations online: <http://consult.gov.scot>. Each consultation details the issues under consideration, as well as a way for you to give us your views, either online, by email or by post.

Responses will be analysed and used as part of the decision making process, along with a range of other available information and evidence. We will publish a report of this analysis for every consultation. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.



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The Scottish Government  
St Andrew's House  
Edinburgh  
EH1 3DG

ISBN: 978-1-78781-350-2 (web only)

Published by The Scottish Government, November 2018

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA  
PPDAS475506 (11/18)

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