

Draft National Action Plan on Neurological Conditions

Analysis of Responses

December 2019

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Executive Summary

The Scottish Government and the National Advisory Committee for Neurological Conditions (NACNC) developed a draft National Action Plan on Neurological Conditions (NAPNC), setting out a vision for driving improvement in the care, treatment and support available to people and their carers who live with neurological conditions.

On 13 November 2018, the Scottish Government published its National Action Plan on Neurological Conditions (draft for consultation) setting out a five-year Plan. The National Action Plan defines 'neurological conditions' to include a wide range of conditions, disorders and syndromes affecting the brain, spinal cord, nerves and muscles. A consultation to gather views on this Plan ran from 13 November 2018 until 8 February 2019. The final Plan was published on 18 December 2019 and has been retitled 'Neurological Care and Support in Scotland – A Framework for Action 2020-2025'.

Respondent Profile

In total, there were 145 replies to the consultation, of which 49 were from organisations (broken down as below) and 96 were from individuals.

Table 1: Respondent Groups

	Number
Health and Social Care Partnerships	2
NHS / Health	11
Pharmaceutical / manufacturing	2
Representative organisation	7
Third sector	24
Other	3
Total organisations	49
Individuals	96
Total respondents	145

Key Themes

A number of key themes were evident across questions as well as across respondent groups and these are summarised below.

- While there were high levels of support for the Vision, Scope, Approach, Aims and Commitments, there were some concerns that the Plan is too ambitious and it may be difficult to achieve, particularly in the current economic climate.

- Respondents noted the importance of partnership working across all stakeholders, including third sector organisations who are seen to have built up a great deal of expertise and knowledge about different neurological conditions. It was also seen as important to include individuals with neurological conditions, as they have lived experience of the impact of these conditions.
- Linked to the importance of partnership working, there were also calls for integrated service delivery and co-operation between different services and Health Boards, so as to ensure a truly multi-disciplinary approach.
- Respondents identified a need for appropriate funding and resources to be made available so as to be able to offer the wide range of services that are needed; some also pointed to the need for this funding to be long term so that services can be planned properly and sustained in the future.
- Linked to this latter point, there were requests for parity in services across the whole of Scotland; rather than the fragmented services seen at present; and some references to the inconsistent implementation of self-directed support as well as inconsistency across Health Boards in terms of the services available.
- There were calls for a workforce with the necessary skills, expertise and knowledge to deal with a wide range of different neurological conditions, with some references to existing problems in relation to recruitment and retention within the health and social care sector.
- While there was support for the Plan, there were also some calls for all age groups to be included in this, so that there is consistency in service offerings for all ages. At present, there are concerns that services available to Children and Young People are not then necessarily available within Adult Services.
- There were also requests for timescales for the introduction of the NAP to be provided, particularly given the need to increase the size and expertise of the workforce to enable the wide range of services to be available to all individuals with neurological conditions.
- While there was support for increased use of technology, there were some concerns that current systems are unable to communicate with each other and that there is a need for interoperability across all systems so as to be able to meet the aims and commitments laid out in the NAP.
- In a number of instances, respondents requested further detail and information on aspects of the NAP.

Consultation Questions

The following paragraphs summarise the main findings from each of the consultation questions.

Main Findings: Vision, Scope and Approach

Almost all respondents agreed with the vision; a majority agreed with the scope, and a large majority agreed with the approach. Some respondents wanted to see a

list of specific conditions so as to ensure all individuals with neurological conditions are represented and to ensure there is a consistent approach to appropriate services and treatment for all. There were also some requests for further detail.

Some respondents felt that children and young people should be included in the Plan to ensure parity in services across all age groups, and well co-ordinated progression for children and young people to adult services as well as effective transition for service development and configuration.

While a large majority agreed that the most important priorities have been included in the Plan, there were some comments of a need for partnership working, improved pathways and creating higher awareness levels of all neurological conditions.

Main Findings: Aim A and Commitments 1-3

A majority of respondents supported Aim A and Commitments 1-3, although there were some comments of the need to follow through on these.

Commitment 1: There were some requests for a definition of ‘self-management’; additionally, there were some comments that self-management will not work for individuals with rapidly progressing conditions. In order to deliver on this commitment, there were requests for the specialist neurological workforce to be expanded; as well as ensuring this workforce has the necessary skills and expertise. There was also reference to the need for partnership working across the sector.

Commitment 2: There were some requests for clear signposting and access to information; and for information to be provided via a range of different channels and in different formats. Comments about A Local Information System for Scotland (ALISS) were that the presentation of information needs to be more accessible and user-friendly, as well as up-to-date.

Commitment 3: There were comments of a need for partnership working across the health sector and third sector organisations so as to ensure that training, support and best practice is consistent, and there is no disconnect in service provision, advice and support.

Main Findings: Aim B and Commitments 4-10

Almost all respondents were supportive of Aim B and Commitments 4-10. Some respondents commented on the need to ensure there is commitment from all stakeholders and providers to work together to ensure services are joined up across Scotland, offering consistency of care to all individuals with neurological conditions. Across the Aim and Commitments, there were calls for funding, for the provision of good practice and queries on how success will be measured.

Commitment 4: There were requests for funding and guidance for Integrated Authorities and Health and Social Care Partnerships, as well as a need to review eligibility criteria.

Commitment 5: There were again concerns over the effectiveness of transition from Children and Young People Services to Adult Services with some respondents suggesting that the National Action Plan should include individuals of all ages.

Commitment 6: Respondents focused on the need to include a broad range of stakeholders, organisations and individuals so as to improve available services. There was also a focus on ensuring third sector organisations have an active role as key partners so as to make use of their expertise and experience of neurological conditions. There were also some concerns that self-directed support (SDS) has been implemented inconsistently across local authorities and that individuals with neurological conditions are unable to access some services as they are not included within SDS parameters.

Commitment 7: While there was broad agreement on the need to use technology to improve services, there was reference to the need to make better use of advancing technologies and improve the existing IT infrastructure and its operability so that all systems can communicate with each other. It was felt that this would allow for the delivery of fully integrated services that are intelligence-led and support the provision of seamless services.

Commitment 8: Again, there was reference to a need for adequate and sustained funding as well as fully trained care professionals who can offer a flexible service. There were some queries as to the mixture of expertise, skills and knowledge that would be needed to provide support in an integrated manner.

Commitment 9: There was reference to the need to include third sector organisations and individuals with neurological conditions so as to ensure the necessary specialist skills exist within multi-disciplinary teams.

Commitment 10: The key theme was of a need to work with third sector organisations to make use of their specialist expertise and advice.

Main Findings: Aim C and Commitments 11-13

All respondents supported Aim C; almost all supported Commitments 11-13. Once again, there were references to the need for funding, monitoring and scrutiny, and the need for a holistic service with multi-disciplinary teams delivering effective, safe and person-centred care.

Commitment 11: There were some requests for more definition in some of the terminology used and the need for commitment to scrutiny and accountability.

Commitment 12: There were calls for robust scrutiny as well as a commitment to review and assess performance so as to ensure accountability, along with requests

for key performance indicators (KPIs) that are easily measurable. There were also requests for guidance on pathways on how to access and use information at a local level to influence the development of services.

Commitment 13: There were comments on the need to include third sector organisations as many currently contribute to research.

Main findings: Aim D and Commitments 14-15

There was almost universal support for this Aim and its related Commitments.

Commitment 14: Again, there were references to the need for funding and resources, the need to consider workforce requirements and to see how different networks can work together. There were some requests for rapid access neurology clinics to be extended to conditions other than epilepsy; and some reference to the need for treatment-specific protocols rather than generic protocols.

Commitment 15: There were requests for a realistic timeframe to be stated as well as comments that the The Scottish Atlas of Variation should not just be limited to NHS services.

Main Findings: Aim E and Commitments 16-17

Again, there was almost universal support for this Aim and Commitments.

Commitment 16: There were references of a need to ensure overall access to services, as well as timely access to services. There were also requests for reference to the need for a wider range of professionals in order to deliver the necessary services to individuals with neurological conditions.

Commitment 17: There were references to the need to ensure the provision of information and appropriate training for all staff, and the need to consider barriers to recruitment and retention in the sector.

Main Findings: Implementation of the Plan

A number of key themes emerged at this question. These included some comments that while there is support for the Plan, there were concerns that it is too ambitious as it stands and that there needs to be further detail; for example, what funding and support will be available, clarity in timescales and what services would look like.

Introduction

Background

1. The Scottish Government recognises the need to support improvements in healthcare for everyone and wants to ensure that people living with neurological conditions have access to the best possible care and support. The National Advisory Committee for Neurological Conditions (NACNC) was established in 2016 to drive improvements in the care, treatment and support available for people living with neurological conditions.
2. Subsequent to this, the Scottish Government and NACNC developed a draft National Action Plan on Neurological Conditions, setting out a vision for driving improvement in the care, treatment and support available to people – and their carers – living with neurological conditions. The Plan’s vision is that everyone with a neurological condition will be able to live independently with care and support as needed.
3. On 13 November 2018 the Scottish Government published its National Action Plan on Neurological Conditions (draft for consultation), setting out a five-year plan with a vision that everyone with a neurological condition in Scotland is able to access the care and support they need to live independently, on their own terms. This is focused on adults aged 16+ and there is separate work being conducted, which considers how best to support disabled children and young people and their families. There are separate strategies already in place for stroke, dementia and learning disabilities, so these are not specifically considered within the National Action Plan (NAP).
4. The NAP defines ‘neurological conditions’ to include a wide range of conditions, disorders and syndromes affecting the brain, spinal cord, nerves and muscles.
5. The consultation opened on 13 November 2018 and closed on 8 February 2019.

Respondent Profile

6. In total, there were 145 responses to the consultation, of which 49 were from organisations and 96 from individuals.
7. Respondents were assigned to respondent groupings in order to enable analysis of any differences or commonalities across or within the various different types of organisations and individuals that responded.
8. A list of all those organisations that submitted a response to the consultation and agreed to have their name published is included in Appendix 1.

Table 2: Respondent Groups

	Number
Health and Social Care Partnerships	2
NHS / Health	11
Pharmaceutical / manufacturing	2
Representative organisation	7
Third sector	24
Other	3
Total organisations	49
Individuals	96
Total respondents	145

9. As Table 2 shows, the two largest organisation sub-groups were third sector organisations and those in the NHS / Health sector.

Methodology

10. Responses to the consultation were submitted using the Scottish Government consultation platform Citizen Space, or by email or hard copy.

11. It should be borne in mind that the number responding at each question is not always the same as the number presented in the respondent group table. This is because not all respondents addressed all questions. This report indicates the number of respondents who commented at each question.

12. Some of the consultation questions contained closed, tick-boxes with specific options to choose from. Where respondents did not follow the questions but mentioned clearly within their text that they supported one of the options, these have been included in the relevant counts.

13. In undertaking analysis of responses to this consultation, the researchers took into account the full range and nature of views provided by respondents, while ensuring that responses from individuals were balanced against responses from different types and sizes of organisation, some of which were representing thousands of individuals. The report summarises the main themes and issues emerging and reflects the full range of views submitted.

14. The researchers examined all comments made by respondents and noted the range of issues mentioned in responses, including reasons for opinions, specific examples or explanations, alternative suggestions or other comments. Grouping these issues together into similar themes allowed the researchers to identify whether any particular theme was specific to any particular respondent group or groups.
15. When considering group differences however, it must also be recognised that where a specific opinion has been identified in relation to a particular group or groups, this does not indicate that other groups did not share this opinion, but rather that they simply did not comment on that particular point.
16. While the consultation gave all who wished to comment an opportunity to do so, given the self-selecting nature of this type of exercise, any figures quoted here cannot be extrapolated to a wider population outwith the respondent sample.

Vision, Scope and Approach

The Vision

17. The vision laid out in the National Action Plan noted ‘*Everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms*’. Question 1 of the consultation asked ‘Do you agree with this overall vision?’

18. As shown in Table 3, almost all respondents who answered this question supported the vision.

Table 3: Q1 Do you agree with this overall vision?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9		2
Pharmaceutical / manufacturing (2)	2	-	-
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	3	-	-
Total organisations (49)	44	-	5
Individuals (96)	87	3	6
Total respondents (145)	131	3	11

19. A total of 19 respondents made general comments about the National Action Plan (NAP), most of whom noted their support for the Plan. Very small numbers of respondents also noted:

- A need for appropriate resources to enable implementation of the Plan; as well as a need for appropriate resources to be provided for different neurological conditions.
- Services are currently too fragmented.
- A need for references to Community Pharmacists and Occupational Therapists.
- A need for more detailed information.

20. Only a small number of respondents made specific comments about the Vision. There was a request for inclusion of an ambition to improve our understanding of

neurological conditions and for the words ‘with support as required’ to be incorporated to ensure that individuals who lack mental capacity are included.

21. Within the National Action Plan, the term ‘neurological conditions’ is used to include a wide range of conditions, disorders and syndromes affecting the brain, spinal cord, nerves and muscles. Question 2 asked, ‘Do you agree with the decision to maintain a broad view of neurological conditions rather than include every neurological condition by name in the plan?’ As Table 4 shows, a higher number of respondents agreed with this decision than disagreed. The organisation sub-group showing the highest level of disagreement was third sector organisations.

Table 4: Q2 Do you agree with the decision to maintain a broad view of neurological conditions rather than include every neurological condition by name in the plan?

	Number		
	Yes, agree	No, disagree	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	6	1	4
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	5	1	1
Third sector (24)	14	7	3
Other (3)	2	1	-
Total organisations (49)	30	10	9
Individuals (96)	55	34	7
Total respondents (145)	85	44	16

22. A number of respondents made comments specific to the scope of the Plan, with some of these welcoming this part of the Plan. That said, some respondents outlined conditions they felt should be specifically referred to and these included MS, ME, dystonia, MND, fibromyalgia and myasthenia gravis, and a small number of respondents also suggested there is a need to define what is (and what is not) included or to illustrate the range of conditions encompassed by the Plan. The key reasoning behind this was that this will ensure all individuals with neurological conditions will be represented or that inclusion of a range of conditions will ensure a consistent approach, reduce barriers and improve equity so that all individuals will be able to access appropriate treatment. A small number of these respondents felt that failure to include a range of specific neurological conditions could lead to generic criteria that would mask their complex needs. One third sector organisation noted that the current approach does not reflect the variety of neurological conditions in terms of their symptoms, the complexity of health and care support required or the way in which these can impact on peoples’ lives.

23. A small number of third sector organisations suggested the Plan needs to differentiate between static neuropathies and progressive neurological conditions.

24. A small number of respondents – primarily representative organisations – suggested a need for a more detailed Implementation Plan as this would provide more detail on specific programmes of work for specific conditions.

25. There were also comments that there is a need to work with, and link into, other policy areas such as dementia and mental health.

26. The National Action Plan is focused on adults aged 16 or older, as there is separate work within the Scottish Government considering how best to support children and disabled young people and their families. There are already separate strategies in place for stroke, dementia and learning disabilities so, although these are neurological conditions, they are not specifically considered within the NAP.

27. Question 3 then asked, ‘There is separate work by the Scottish Government considering how best to support children and young people with disabilities and their families, so we decided to consider the needs of people who are 16 years and older in the Plan. Do you agree with this decision?’ As Table 5 demonstrates, a large majority of respondents across all sub-groups were supportive of this decision. Once again, the largest number of organisations who disagreed with this question was in the third sector.

Table 5: Q3 There is separate work by Scottish Government considering how best to support children and young people with disabilities and their families, so we decided to consider the needs of people who are 16 years and older in the Plan. Do you agree with this decision?

	Number		
	Yes, agree	No, disagree	Not answered
Health & Social Care Partnerships (2)	1	1	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	5	-	2
Third sector (24)	14	6	4
Other (3)	2	-	1
Total organisations (49)	31	7	11
Individuals (96)	80	9	7
Total respondents (145)	111	16	18

28. A total of 18 respondents opted to provide commentary in support of their response to question 3. The key theme was that children should be included in the

Plan as their exclusion will not address the current disparity in the provision of services. There were also comments that this will result in a disconnect between children and adult services or that there could be duplication across programmes.

29. Some other respondents, while they were supportive of the approach outlined, noted the importance of ensuring a well co-ordinated progression for young people from child to adult services and effective transition for service development and configuration so that young people do not receive a different service and support. A few respondents highlighted the need to ensure co-ordination of planning, policy and services to ensure smooth transitions as well as a need to ensure all neurological conditions have equal access to support and services.

30. The NAP then explained that the Scottish Government commissioned several overlapping pieces of work so as to ensure that people with lived experience and their families and carers were placed at the centre of the Plan. Question 4 asked, 'Developing the National Action Plan involved a range of activities to make sure we identified the right priorities. Do you think we included the most important priorities in the plan?' As shown by Table 6, a large majority of respondents agreed with this question. Once again, it was primarily third sector organisations who disagreed.

Table 6: Q4 Developing the National Action Plan involved a range of activities to make sure we identified the right priorities. Do you think we included the most important priorities in the plan?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	6	2	3
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	5	-	2
Third sector (24)	15	6	3
Other (3)	3	-	-
Total organisations (49)	32	8	9
Individuals (96)	63	19	14
Total respondents (145)	95	27	23

31. A total of 16 respondents chose to provide additional commentary in support of their response at question 4 and outlined a number of other priorities that should be included in the Plan. These included a need for:

- More education on neurological conditions, with some specific reference for the need for GPs to be able to recognise conditions.

- A commitment to identifying and delivering curative treatments.
- Clarification on how organisations would be supported to develop innovative ideas.
- Reference to individuals living in care homes that are not suitable for their needs and the importance of addressing their needs.
- Stronger focus on partnership working and improved pathways to ensure specialist knowledge is shared; with some reference to the need for a pan-neurological condition information resource; greater consideration of service delivery integration and co-ordination between specialities and services.
- Greater priority for mental health services and support.
- Commitment to report on progress on an annual basis.
- Greater focus on premature mortality.
- Acknowledgement of the greater numbers of individuals who will have a neurological condition in the future.
- Greater prominence for social care.
- Greater focus on rehabilitation.
- Greater focus on individuals who are physically able but who have complex cognitive difficulties, which are not immediately evident.
- Gap analysis and needs assessment to identify what level of support and focus will be needed by organisations for each neurological condition.
- Reference to palliative end of life care.

32. The National Action Plan outlined five aims, each of which contained a number of commitments. The following chapters outline responses to each of the Aims and their corresponding commitments.

In summary:

Almost all respondents agreed with the vision; a majority agreed with the scope, and a large majority agreed with the approach. Some respondents wanted to see a list of specific conditions so as to ensure all individuals with neurological conditions are represented and to ensure there is a consistent approach to appropriate services and treatment for all. There were also some requests for further detail.

Some respondents felt that children and young people should be included in the Plan to ensure parity in services across all age groups, and well co-ordinated progression for children and young people to adult services as well as effective transition for service development and configuration.

While a large majority agreed that the most important priorities have been included in the Plan, there were some comments of a need for partnership working, improved pathways and creating higher awareness levels of all neurological conditions.

Aims A and Commitments 1-3

33. Initial discussions showed that individuals wanted the National Action Plan to focus on personal outcomes and for them to be partners in their care and support. Data from the *Lived Experience*¹ showed that while some people may feel listened to, others perceived a lack of understanding on the part of clinicians, practitioners and other staff.

Aim A

Ensure people with neurological conditions and their carers are partners in their care and support.

34. Respondents were asked whether they agreed with Aim A. As the following table shows that the vast majority of those answering this question agreed with Aim A.

Table 7: Q6 Do you agreed with Aim A?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	3	-	-
Total organisations (49)	43	-	6
Individuals (96)	85	3	8
Total respondents (145)	128	3	14

35. A total of 59 respondents, across all sub-groups, opted to provide a response to Qs 6-10 in relation to Aim A and Commitments 1-3. Some of these provided general comments, while others referenced the Aim or a specific Commitment. The following paragraphs outline general comments.

36. The key theme emerging from a few respondents who made general points was that the Aim and Commitments are commendable but, while these look good in theory, there is a need for follow through in practice. A small number of

¹ Alliance Scotland et al. 2018. Priorities from the Lived Experience Project. Unpublished.

respondents felt the language used was rather vague. A few respondents also outlined a number of conditions they felt should be included in the A to Z list of common illnesses and conditions; these included Mysathenia Gravis, ME, Dysautonomia, Small Fibre Neuropathy and EDS.

37. The key comment in relation to Aim A, albeit only made by a small number of respondents was support for this Aim, with comments that there is a need to include people with neurological conditions in their care and support or that they should be central to decision making. One third sector organisation noted that there needs to be a focus on the rights of people with neurological conditions in line with commitments given in 'A Fairer Scotland for Disabled People'. Other issues raised by very small numbers of respondents included a need:

- For independent trained advocacy to ensure all views are well represented.
- To consider guardianship and incapacity.
- For health and social care workers to have condition specific knowledge and to work closely with organisations in the third sector.

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.

38. Question 7 asked if respondents agreed or disagreed with this Commitment and the following table shows that almost all answering this question agreed with this commitment. The only disagreement came from two third sector organisations and three individuals.

Table 8: Q7 Do you agree or disagree with Commitment 1

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	7	-	4
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	19	2	3
Other (3)	3	-	-
Total organisations (49)	37	2	10
Individuals (96)	85	3	8
Total respondents (145)	122	5	18

39. A total of 27 respondents opted to provide commentary in relation to Commitment 1; support came from all sub-groups. The key theme emerging, albeit by a relatively small number of respondents, was welcome for this Commitment, with comments such as the importance of ensuring that shared decision making is at the centre of care or the need to involve carers. A small number of these respondents made qualifying comments including a need to provide a definition of self-management or that not all individuals with neurological conditions will have an ability to self-manage.

40. A few respondents focused on services for individuals with neurological conditions, with comments such as a need for the specialist workforce to be expanded, that access to specialist staff can be difficult, that there is a lack of services at present or that there is a lack of people with the appropriate knowledge to understand neurological conditions and invisible impairments. These comments came primarily from organisations within the third sector. Allied to this point, a small number of respondents noted that it can be difficult to recruit and retain care workers and that financial resources need to be improved in order to offer the services that are required by individuals with neurological conditions.

41. While a small number of respondents also noted their support for the involvement of individuals with neurological conditions or their carers, a small number also noted concerns that this commitment places an onus on the individual or their carer to identify their own needs and access the necessary services and support.

42. Some respondents commented on the issue of self-management, with a small number noting that the concept of self-management will not work for individuals

with rapidly progressing conditions. Others referred specifically to the Self-Management Fund and felt this is limited in terms of the projects it can support, that some of the projects it supports are too short-term, or that it is limited in the change that it is able to deliver and that some services offered under this are not specific to some neurological conditions.

43. A small number of organisations in the third sector referred to the need for partnership working across the health service in the provision of support.

44. Other comments made, each by only one or two respondents included:

- The need to reach individuals who may not identify as a carer.
- The need to conduct an annual review to ascertain what changes have been brought about and to identify any issues that need to be addressed.
- Requirements for further information, for example, how the Scottish Government would make shared decision making and personalised models of care and support a reality.
- A need to use technology to help meet this commitment.

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.

45. Question 8 asked if respondents agreed or disagreed with this Commitment and table 9 shows almost all those answering this question agreed with this commitment.

Table 9: Q8 Do you agree or disagree with Commitment 2?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	19	2	3
Other (3)	2	-	1
Total organisations (49)	37	2	10
Individuals (96)	86	3	7
Total respondents (145)	123	5	17

46. 19 respondents then chose to provide commentary in support of their response to question 8. Most comments were made by only small numbers of respondents. Once again, some of these respondents noted their support for this Commitment but a small number reiterated the importance of clear signposting and access to information.

47. A small number of organisations also pointed out the need for information to accommodate different abilities and for information to be provided via a range of different channels and in different formats.

48. Some respondents commented specifically on ALISS (A Local Information System for Scotland), with reference to the need for the presentation of information to be more accessible and user-friendly. A small number of respondents suggested improvements to ALISS and these included an improved search function and presentation of information by place name rather than postcode. There were also queries on how information is checked to ensure it is up-to-date and what guarantees there are for funding to continue.

49. One organisation in the NHS / Health sector suggested reference could be made to existing and development of new evidence-based SIGN guidelines, in relation to identifying and informing good practice.

50. Reiterating comments made in relation to Commitment 1, there were comments that:

- There is a need for greater resources.
- Care services and support are too fragmented across Scotland.
- Technology should be better utilised.
- There is a need to reach those who may not identify as a carer.

51. The draft NAP went on to note that staff are sometimes reluctant to share information with peoples' families and carers and that their carers were not given the information or help they needed. It also noted the key role of unpaid carers and the need to support their health and wellbeing.

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.

52. Question 9 asked if respondents agreed or disagreed with this Commitment and table 10 shows almost all of those answering this question agreed with this Commitment.

Table 10: Q9 Do you agree or disagree with Commitment 3

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	21	1	2
Other (3)	3	-	-
Total organisations (49)	40	1	8
Individuals (96)	87	2	7
Total respondents (145)	127	3	15

53. 19 respondents then chose to provide commentary in support of their response to question 9. Most comments were made by only small numbers of respondents.

54. Three key themes emerged in response to this question. First, a number of organisations, mostly in the third sector and NHS / Health organisations noted their support for this commitment. Second, there were references of a need to ensure partnership working across the health service and third sector organisations to ensure that training, support and best practice is consistent and there is no disconnect in advice and support. Linked to this latter point, the third key theme was that there will need to be additional training and access to training for carers, with some suggesting condition-specific training and others noting the relevance of training beyond conditions to encompass mental and emotional health and wellbeing.

55. A small number of respondents also noted the need to consider carers and their needs and to ensure they can access training in a variety of ways and not just through digital technology.

56. Other comments, each made by only one or two respondents included:

- A need for training and planning for service staff.
- The need for resource to ensure appropriate training can be delivered.
- A need for clear signposting to training and support.
- The importance of involving carers so they can support individuals with neurological conditions.
- A need for explicit reference to respite care that is age-appropriate.
- Concern that Local Integration Authority Carer Strategies will not consider the involvement of patients and carers with specific neurological conditions and are likely to have a much broader based approach to carer support.

In summary:

A majority of respondents supported Aim A and Commitments 1-3, although there were some comments of the need to follow through on these.

Commitment 1: there were some requests for a definition of 'self-management'; additionally, there were some comments that self-management will not work for individuals with rapidly progressing conditions. In order to deliver on this commitment, there were requests for the specialist neurological workforce to be expanded; as well as ensuring this workforce has the necessary skills and expertise. There was also reference to the need for partnership working across the sector.

Commitment 2: there were some requests for clear signposting and access to information; and for information to be provided via a range of different channels and in different formats. Comments about A Local Information System for Scotland (ALISS) were that the presentation of information needs to be more accessible and user-friendly, as well as up-to-date.

Commitment 3: there were comments of a need for partnership working across the health sector and third sector organisations so as to ensure that training, support and best practice is consistent, and there is no disconnect in service provision, advice and support.

Aim B and Commitments 4-10

57. The National Action Plan then noted 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. However, for some individuals 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 adaptation, respite care, and provision of specialist, personalised equipment.

Aim B

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

58. In the first instance, respondents were asked whether they agreed with Aim B. As the following table shows, all bar one individual agreed with Aim B.

Table 11: Q11 Do you agree with Aim B?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	-	3
Other (3)	3	-	-
Total organisations (49)	42	-	7
Individuals (96)	91	1	4
Total respondents (145)	133	1	11

59. A total of 75 respondents, across all sub-groups, opted to provide a response to Qs 11-19 in relation to Aim B and Commitments 4-10. Some of these provided general comments, while others referenced the Aim or a specific Commitment.

60. Only a small number of respondents opted to provide any comments about Aim B. Most welcomed this aim, although there were some qualifying comments in terms of the need to ensure there is a commitment from all stakeholders and providers to work together so there are joined up services across Scotland, offering consistency in care.

61. There were a few comments on the need for this aim to be more ambitious or that the wording is too vague. One third sector organisation noted the need for more accurate prevalence data given the role this plays in service planning.

62. A total of 30 respondents opted to provide general comments in relation to these Commitments. A key theme was support for the Commitments although, once again, there were some qualifying comments. These included queries on how success will be measured, and on how parity will be achieved across all the NHS Boards, as well as the need for funding as the NHS is overburdened and under-resourced. An HSCP welcomed the links to other strategies and their application to individuals with neurological conditions.

63. Another key theme which emerged was the need for funding to be able to achieve these commitments, with one NHS respondent noting that this should not be at the expense of existing primary care and acute sector services. This theme was cited by NHS / Health Boards, third sector organisations and individuals.

64. Other themes noted by small numbers of respondents included:

- A need for clear signposted pathways to access information, care and support. Two third sector organisations also commented that access to care at present is too inconsistent.
- A need for more education, specialisation and understanding of neurological conditions, with some specific reference to increasing knowledge for GPs, with some noting the need for increased knowledge of ME specifically.
- A need for specialist roles for specific conditions.
- A need to ensure individuals with neurological conditions can have access to a wide range of services such as therapeutic services, preventative therapies and so on.
- Requests for more information or detail such as how different services will be integrated to offer a high quality of care to individuals with neurological conditions; or more clear definition for some of the terminology used.

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.

65. The next question asked respondents to provide their agreement or disagreement with Commitment 4. As the following table demonstrates, almost all respondents agreed with this Commitment.

Table 12: Q12 Do you agree or disagree with Commitment 4?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	20	1	3
Other (3)	3	-	-
Total organisations (49)	39	1	9
Individuals (96)	86	2	8
Total respondents (145)	125	3	17

66. A total of 24 respondents opted to provide commentary in relation to Commitment 4, with a key theme being support for the commitment, although again there were a number of qualifying comments. There were references to the need for funding, a need for guidance for Integrated Authorities and Health and Social Care Partnerships and a need to review eligibility criteria.

67. Another key comment – primarily from individuals – was the need for access to all tiers of support services for individuals with ME (Myalgic Encephalomyelitis).

68. Other comments raised by only one or two individuals included:

- Queries over whether there will be any reviews to ensure inequalities are reduced.
- Queries over whether there will be a reporting and governance structure.
- A need for guidance to be provided to Integrated Authorities given their lack of experience with neurological conditions and to Health and Social Care Partnerships. That said, one third sector organisation noted that guidance can be interpreted in different ways or simply ignored.
- A need for stronger wording in the commitment that will reflect the narrative constructed in Aim B. One third sector organisation suggested inclusion of the words '*recognises*' and '*strives to meet*'. An individual wanted to see the words '*We will create legislation*' and '*This will enable integration authorities*'. A third sector organisation felt that this Commitment was non-specific and should outline the actions that will be taken forward to reduce variation in the quality of care and health inequalities.

- A need for services to work together and remove barriers to integrated service provision and support.
- A need for improved communication for all services, particularly at times of transition.
- A need to refer to technological solutions at this commitment.
- A separate commitment for residential care to explore this issue further; as well as reference to the differences of younger adults moving to care homes.

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.

69. The draft National Action Plan noted that that some individuals experience a lack of joined up care. The next question asked respondents to provide their agreement or disagreement with Commitment 5. As the following table demonstrates, almost all respondents agreed with this Commitment. Only three individuals disagreed.

Table 13: Q13 Do you agree or disagree with Commitment 5?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	7	-	4
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	2	-	1
Total organisations (49)	39	-	10
Individuals (96)	86	3	7
Total respondents (145)	125	3	17

70. A total of 16 respondents opted to provide commentary in relation to Commitment 5. Once again, a key theme was support for having a focus on transition, although again there were a number of qualifying comments.

71. A key theme was concerns over the effectiveness of transition from Children and Young People Services to Adult Services, with some comments on the need to

plan for transitioning very early and / or offering gradual transition. Moreover, it was noted that Adult Services are not as effective or widespread as those for Children and Young People (CYP) and for a need to improve Adult Services so they are in line with those offered to CYP. One individual pointed out that a neurological condition may impact on a child's development together with their potential for independence and that transition should be allowed to occur at an older age.

72. A small number of respondents felt the National Action Plan should include individuals of all ages.

73. Other issues raised by one or two respondents included:

- A need for more detail in this commitment, with specific reference to the complex needs of children and the inclusion of education to increase awareness of neurological conditions.
- Age-appropriate care provision is lacking in many areas.
- The importance of communication, particularly during the transition period, and the need to work with the young person, their carer and a range of stakeholders and services. One third sector organisation suggested reference to the Scottish Transitions Forum about transition planning.
- A need to include palliative considerations.

74. One third sector organisation suggested some alternative wording so that the commitment refers to '*We will work with the third sector and others to support local and national reform*'.

Commitment 6

75. The draft National Action Plan noted the value 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.

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.

76. The next question asked respondents to provide their agreement or disagreement with Commitment 6. As the following table shows, almost all respondents agreed with this Commitment.

Table 14: Q14 Do you agree or disagree with Commitment 6?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	21	1	2
Other (3)	2	-	1
Total organisations (49)	39	1	9
Individuals (96)	85	2	9
Total respondents (145)	124	3	18

77. A total of 27 respondents opted to provide commentary in relation to Commitment 6. The key theme was support for this Commitment, although again there were a number of qualifying comments. The key qualifying comment was of the need to include a broad range of stakeholders, organisations and individuals so as to improve services available. The primary emphasis was on inclusion of third sector organisations having an active role as key partners, rather than simply as providing a service, as these organisations have a great deal of specialist expertise in neurological conditions that should be used.

78. Another key theme referred to the provision of a broad range of services for all neurological conditions and the need to ensure they can be quickly accessed; with one respondent pointing to the need for information sharing across the NHS to improve upon service provision and reduce inequality of care.

79. Another key theme – mentioned by third sector organisations – was in relation to self-directed support (SDS), with comments that there has been inconsistent implementation across local authorities, that individuals need more control over their SDS budgets to be able to access specialist support and that most social care is not provided via SDS because of the choice allowed in personal budgets.

80. Once again, there were some references to the need for increased budgets and requests for further clarity or information.

81. A third sector organisation requested information on the timescale for this work and clarity on what this would mean in practice.

Commitment 7

82. The draft Plan then went on to note the need to harness digital technology as a means of improving communication and overall care for people with neurological conditions.

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.

83. Respondents were then asked to indicate their agreement or otherwise with Commitment 7; and almost all respondents noted their agreement.

Table 15: Do you agree or disagree with Commitment 7?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	7	-	4
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	-	3
Other (3)	3	-	-
Total organisations (49)	40	-	9
Individuals (96)	88	1	7
Total respondents (145)	128	1	16

84. A total of 18 respondents opted to provide commentary in relation to Commitment 7. Again, most of these respondents noted their support for this Commitment, although again there were a number of qualifying comments.

85. The key qualifying comment was in relation to the use of technology and the need to ensure that it is used to improve services to individuals with neurological conditions. There was also some reference to the need for better use of modern technologies, with support during diagnosis and support for individuals with mental health issues being cited as times when technology could be used.

86. There were also a small number of comments on the need to improve the existing IT infrastructure and its interoperability so that all systems can

communicate with each other. In this way, it should be possible to have integrated services that are intelligence-led and support the provision of seamless services.

87. A small number of respondents also noted a need for a degree of caution so that there is not an over-reliance on technology as some individuals will need access to non-digital support. Allied to this, there were some suggestions that services cannot be ‘digital by default’ as some impairments can create difficulties in using technology. Although digital technologies can help to support people to remain connected with video consultations, social media, social prescribing and access to social groups, there was some concern that an over-reliance on technology could lead to an increase in social isolation for some individuals with neurological conditions.

Commitment 8

88. The draft Plan outlined that some individuals noted the need to share information between members of care teams, and the importance of anticipatory care plans for some people with neurological conditions, and that 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.

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.

89. Respondents were then asked to indicate their agreement or otherwise with Commitment 8; and almost all agreed with this Commitment.

Table 16: Q16 Do you agree or disagree with Commitment 8?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	20	2	2
Other (3)	3	-	-
Total organisations (49)	39	2	8
Individuals (96)	85	2	9
Total respondents (145)	124	4	17

90. A total of 21 respondents opted to provide commentary in relation to Commitment 8. Some of these respondents noted their support for this Commitment, although again there were a number of qualifying comments, with references to the need for adequate and sustained funding, that care professionals need to be properly trained and offer a flexible service.

91. There were some queries on how health professionals would work together and what mixture of expertise, skills and knowledge would be needed so as to provide support in an integrated way, along with references to the need for good communication channels between neurological services and mental health services.

92. One NHS / Health sector organisation noted their concern that the wording of Commitment 8 could raise expectations of service delivery where there are not the resources to back this up.

93. Again there were references to the need:

- To ensure that a range of professionals provide input to any arrangements.
- For speed and accuracy in diagnosis and the implementation of individual plans.
- For this to be informed by the experience of individuals with neurological conditions in trying to access health services.
- For a greater focus on future care needs.
- To consider care at home as well as access to specialist services.
- To learn from current good practice.
- For progress to be assessed in relation to anticipatory care planning during organisational reviews of compliance with national neurological standards.

Commitment 9

94. It was noted that many people with neurological conditions experience deterioration in their condition over time and services will need to develop more proactive approaches to offering information, care, support and rehabilitation to people that enables them to maintain their independence, health and wellbeing. The draft Plan proposed to test projects that assess and support people with common neurological symptoms.

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.

95. Respondents were then asked to indicate their agreement or otherwise with Commitment 9. Once again, almost all respondents agreed with this Commitment.

Table 17: Q17 Do you agree or disagree with Commitment 9?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	7	-	4
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	21	1	2
Other (3)	2	-	1
Total organisations (49)	38	1	10
Individuals (96)	87	1	8
Total respondents (145)	125	2	18

96. A total of 21 respondents opted to provide commentary in relation to Commitment 9. Again, there were high levels of support for this commitment, although there were also references to the need to ensure the involvement of third sector organisations and individuals with neurological conditions to ensure that the necessary specialist skills exist within multi-disciplinary teams.

97. There were also a small number of comments of a need for models that can be adapted for specific needs such as ME and access to condition-specific specialists, with one NHS / Health organisation cautioning that there should not be a dilution of specialist condition-specific expertise.

98. A few respondents requested further detail such as which health professionals would constitute these multi-disciplinary teams and how they would operate.

Commitment 10

99. The draft Plan noted 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.

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 Huntingdon’s Association – and how these can inform neurological care.

100. Finally, in relation to Aim B, respondents were asked to indicate their agreement or otherwise with Commitment 10. As table 18 demonstrates, only one respondent – an individual – disagreed with this Commitment.

Table 18: Q18 Do you agree or disagree with Commitment 10?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	7	-	4
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	3	-	-
Total organisations (49)	41	-	8
Individuals (96)	86	1	9
Total respondents (145)	127	1	17

101. Only 8 respondents provided commentary in relation to Commitment 10. The key theme was a need to work with third sector organisations to make use of their specialist expertise and advice.

In summary:

Almost all respondents were supportive of Aim B and Commitments 4-10.

Some respondents commented on the need to ensure there is commitment from all stakeholders and providers to work together to ensure services are joined up across Scotland, offering consistency of care to all individuals with neurological conditions. Across the Aim and Commitments, there were calls for funding, for the provision of good practice and queries on how success will be measured.

Commitment 4: there were requests for funding and guidance for Integrated Authorities and Health and Social Care Partnerships, as well as a need to review eligibility criteria.

Commitment 5: there were again concerns over the effectiveness of transition from Children and Young People Services to Adult Services with some respondents suggesting that the National Action Plan should include individuals of all ages.

Commitment 6: respondents focused on the need to include a broad range of stakeholders, organisations and individuals so as to improve available services. There was also a focus on ensuring third sector organisations have an active role as key partners so as to make use of their expertise and experience of neurological conditions. There were also some concerns that self-directed support (SDS) has been implemented inconsistently across local authorities and that individuals with neurological conditions are unable to access some services as they are not included within SDS parameters.

Commitment 7: while there was broad agreement on the need to use technology to improve services, there was reference to the need to make better use of advancing technologies and improve the existing IT infrastructure and its operability so that all systems can communicate with each other. It was felt that this would allow for the delivery of fully integrated services that are intelligence-led and support the provision of seamless and preventative services.

Commitment 8: Again, there was reference to a need for adequate and sustained funding as well as fully trained care professionals who can offer a flexible service. There were some queries as to the mixture of expertise, skills and knowledge that would be needed to provide support in an integrated manner.

Commitment 9: There was reference to the need to include third sector organisations and individuals with neurological conditions so as to ensure the necessary specialist skills exist within multi-disciplinary teams.

Commitment 10: The key theme was of a need to work with third sector organisations to make use of their specialist expertise and advice.

Aim C and Commitments 11-13

102. The National Action Plan explained that Healthcare Improvement Scotland have recently revised the 2009 Neurological Services Clinical Standards, which support the development of joined-up health and social care, and reflect the National Health and Social Care Standards. The new standards apply to anyone living with a neurological condition in Scotland and set out the same high level of care and support for all adults regardless of their condition, location, service provider or their individual circumstances. Aim C and commitments 11-13 refer to these standards.

103. A total of 16 respondents provided general comments in relation to this aim and the related commitments. While some of these respondents noted their support for these, they also noted some concerns over available funding, the need for fully trained professionals and an adequate workforce, the need for guidance to ensure that standards are adhered to, and a need to include those with ME in the plan. One third sector organisation noted a need to conduct a comprehensive evidence-based scientifically verifiable epidemiological study of neurological conditions in Scotland. Two individuals also referred to their specific situation and lived experience with a neurological condition.

Aim C

Ensure high standards of effective, person centred, and safe care and support.

104. Respondents were asked to say if they agreed with this aim and the following table demonstrates that no respondents disagreed with this Aim.

Table 19: Q20 Do you agree with Aim C

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	3	-	-
Total organisations (49)	43	-	6
Individuals (96)	89	-	7
Total respondents (145)	132	-	13

105. A small number of respondents – mostly third sector organisations and individuals – made comments specifically in relation to Aim C. Again, comments tended to echo those seen at earlier questions. While there was general support for this aim, there were also some references to the need for funding, monitoring and scrutiny, and the need for a holistic service with multi-disciplinary teams delivering effective, safe and person-centred care. There were a small number of concerns including how this would be achieved in rural areas, how this would be implemented and the need to address workforce pressures. One third sector organisation requested stronger wording so that this reads ‘*we will implement*’

Commitment 11

106. The National Action Plan then went on to note that the 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.

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

107. Respondents were asked to indicate their agreement or otherwise with Commitment 11. As table 20 demonstrates, almost all respondents agreed with this Commitment.

Table 20: Q21 Do you agree or disagree with Commitment 11?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	20	1	3
Other (3)	3	-	-
Total organisations (49)	40	1	8
Individuals (96)	81	4	11
Total respondents (145)	121	5	19

108. A total of 15 respondents provided commentary in relation to Commitment 11 and the key comment was support for this, albeit there were some qualifying comments such as requests for more definition in some of the terminology used or the need for a commitment to scrutiny as well as information on how organisations who do not meet the standards will be held to account.

109. Other comments made, each by only one or two respondents included:

- The need to record data for ME in order to ascertain its prevalence and for the standards to be updated to recognise ME and remove Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) as recommended treatments.
- Current data is inconsistent as different Health Boards use different approaches.
- HIS standards need to be backed up with governance and leadership, together with a framework for improvement.
- There is a need for condition-specific standards. These should be considered before ratifying the general standards.
- The wording should be changed to include '*we will ensure the implementation*'

Commitment 12

110. The National Action Plan then explained that through work with NHS Information Services Division (ISD), it had been concluded that it is not currently possible to identify exactly how many people there are in Scotland living with a neurological condition. Commitment 12 noted,

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.

111. Respondents were asked to indicate their agreement or otherwise with Commitment 12 and almost all respondents agreed; only three individuals disagreed.

Table 21: Q22 Do you agree or disagree with Commitment 12?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	22	-	2
Other (3)	3	-	-
Total organisations (49)	42	-	7
Individuals (96)	85	3	8
Total respondents (145)	127	3	15

112. A total of 34 respondents provided commentary in relation to Commitment 12 with a number of comments in support of this commitment. These comments included the importance of gathering high quality population level data, the need to support research and the need for the development of meaningful outcome measures with measurement tools or standards and a reporting framework that allow for the capacity to have comparisons between different organisations.

113. The key comment, across all sub-groups, was support for this, albeit there were again qualifying comments. These qualifying comments included the need for:

- Robust scrutiny and a commitment to review and assess performance against the standards so as to ensure accountability.
- Baselines to be set and areas for improvement identified.
- The need for KPIs which are easily measurable to provide useful data.
- Guidance on pathways of how to access and use information at a local level to influence the development of services.

114. A range of other comments were made, each by small numbers of respondents. These included reference to the need to record the numbers of individuals with ME, the need to refer to specific conditions by name, and the need for electronic health records to be robust and person centred to enable the collection of data.

115. A small number of respondents referred to other links or developmental work being undertaken by different organisations. These included reference to the Personal Outcomes Network and the developmental work being undertaken and Cancer Registry work.

116. A small number of respondents also noted a need for references to palliative care, the need for qualitative data as well as quantitative data, and reference to psychological function.

117. A similar number of respondents also referred to the need to strengthen this commitment so that effective measures will be implemented.

Commitment 13

118. The National Action Plan then noted that health and social care and support need to be effective and a need 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. Commitment 13 noted,

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.

- Explore the feasibility of developing effective measures of experience and outcome of person centred care and support, for people with neurological conditions.**

119. Respondents were then asked to indicate their agreement with Commitment 13. Once again, there was almost universal agreement, and only two respondents disagreed with this Commitment.

Table 22: Q23 Do you agree or disagree with Commitment 13?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	1	2
Other (3)	3	-	-
Total organisations (49)	41	1	7
Individuals (96)	85	1	10
Total respondents (145)	126	2	17

120. A total of 22 respondents provided commentary in relation to Commitment 13. As with the previous commitments, the key comment was support for this commitment and acknowledgment of the need for research and clinical trials. A small number of respondents commented on the importance of including third sector organisations as many are currently key contributors to research; others noted the importance of including those who live with a neurological condition and who have multiple and complex needs.

121. A few individuals commented on the importance of having research trials to ascertain the causation of ME.

122. Other comments, each made by only one or two respondents included a need:

- For referral guidelines.
- To ensure this informs development and improvement in services.
- To conduct research that considers the roles and contributions of all team members.

123. A third sector organisation suggested inclusion of the wording *'improve equitable and timely access to care and support across Scotland'*.

In summary:

All respondents supported Aim C; almost all supported Commitments 11-13.

Once again, there were references to the need for funding, monitoring and scrutiny, and the need for a holistic service with multi-disciplinary teams delivering effective, safe and person centred care.

Commitment 11: there were some requests for more definition in some of the terminology used and the need for commitment to scrutiny and accountability.

Commitment 12: there were calls for robust scrutiny as well as a commitment to review and assess performance so as to ensure accountability, along with requests for key performance indicators (KPIs) that are easily measurable. There were also requests for guidance on pathways on how to access and use information at a local level to influence the development of services.

Commitment 13: there were comments on the need to include third sector organisation as many currently contribute to research.

Aim D and Commitments 14-15

124. The National Action Plan explained that there are many challenges in providing care and support for disabled people, many of whom will have a neurological condition, and in enabling them to remain in their own home.

125. A total of 15 respondents provided general comments in relation to this aim and the related commitments. One third sector organisation felt there is a need for these commitments to be more wide ranging as the two commitments are more narrow in scope than the aim and will not on their own deliver the aim. Another third sector organisation commented that Commitment 14 does not meet the aim as it is based on a medical model which Aim D is not and suggested an additional commitment on how equitable access to social care and support will be improved. Two individuals also felt the Commitments look good on paper but noted the need for services to be in place before they can be improved upon and queried how these will be achieved given the current shortage of experienced staff in the workforce.

126. A small number of respondents suggested that workforce planning needs to be undertaken to ensure that specialist staff are available; MS (multiple sclerosis) and ME were both cited as examples of neurological conditions where the required staff are not accessible at present.

Views on Aim D

Improve equitable and timely access to care and support across Scotland.

127. Respondents were asked to say if they agreed with this aim and the following table demonstrates there was almost universal agreement with this Aim.

Table 23: Q25 Do you agree or disagree with Aim D

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	-	3
Other (3)	3	-	-
Total organisations (49)	42	-	7
Individuals (96)	90	1	5
Total respondents (145)	132	1	12

128. A small number of respondents made comments specifically in relation to Aim D, most of whom welcomed this Aim although there were some comments of the need for funding to be able to achieve this.

Commitment 14

129. The National Action Plan then went on to note that the Scottish Access Collaborative 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. The Scottish Government has convened a Neurology Group within the Scottish Access Collaborative and this work, in conjunction with the Modern Outpatient document, should lead to better referral guidelines and care and support pathways for people with neurological symptoms across Scotland.

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 for 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

130. Respondents were asked to indicate their agreement or otherwise with Commitment 14. As table 24 shows, there was very little disagreement with this Commitment.

Table 24: Q26 Do you agree or disagree with Commitment 14?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	6	-	5
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	19	1	4
Other (3)	2	-	1
Total organisations (49)	35	1	13
Individuals (96)	85	2	9
Total respondents (145)	120	3	22

131. A total of 47 respondents provided commentary in relation to Commitment 14. As with the previous commitments, the key theme was support for this or for elements of this although again there were some qualifying comments. These comments included the need for funding and resources, the need to consider workforce requirements and ascertain what staff groups are required, and the need to see how different networks can link into each other.

132. Allied to the issue of funding and where services are needed, some respondents commented that DCAQ work should provide insight into demand in each area as well as considering all specialities.

133. A few respondents wanted to see rapid access neurology clinics extended to other conditions and there were a small number of queries as to why there is reference to epilepsy but not to other conditions, with one third sector organisation suggesting that open access clinics need to be extended and include other conditions such as MS. There were also a small number of comments on the need for treatment specific protocols rather than generic protocols. Once again, there were also references to ME specifically, with respondents noting the need for setting up a specialist centre of excellence for the diagnosis and management of ME and for the provision of equitable service for those with this neurological condition.

134. Other comments made by very small numbers of respondents included the need:

- For rapid access to rehabilitation services, including vocational rehabilitation.
- To include respite services within the scope of the new guidelines.
- For the NAP to have consistency between national, regional and local guidelines to ensure equity in provision.
- To ensure the NAP is informed by the experience of individuals with neurological conditions.
- To recognise that emergency access to a neurological team may be outwith normal hours.
- For priorities to be set under these Commitments.
- For a proactive approach on the part of agencies, authorities and health practitioners in identifying and engaging with individuals with a neurological condition.
- For a transition pathway between adult and older adult services.
- For support to help develop generic staff to give appropriate advice and support.

Commitment 15

135. The National Action Plan then explained that there is considerable variation in access to services, and that the services received can be varied. The Scottish Atlas of Variation aims to highlight geographical variation in Scotland's population health, the provision of health services and associated health outcomes.

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

136. Respondents were asked to indicate their agreement or otherwise with Commitment 15. As the following table shows, only four individuals disagreed with this Commitment.

Table 25: Q27 Do you agree or disagree with Commitment 15?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	-	3
Other (3)	3	-	-
Total organisations (49)	42	-	7
Individuals (96)	79	4	13
Total respondents (145)	121	4	20

137. Only 9 respondents commented specifically on Commitment 15, with most of these noting their support of this commitment. Other comments noted the need for a realistic timeframe to be stated under this commitment and that this Atlas should not just be limited to NHS services.

In summary:

There was almost universal support for this Aim and its related Commitments.

Commitment 14: Again, there were references to the need for funding and resources, the need to consider workforce requirements and to see how different networks can work together. There were some requests for rapid access neurology clinics to be extended to conditions other than epilepsy; and some reference to the need for treatment-specific protocols rather than generic protocols.

Commitment 15: There were requests for a realistic timeframe to be stated as well as comments that the Atlas should not just be limited to NHS services.

Aim E and Commitments 16-17

138. The National Action Plan explained the need to consider the workforce and those who support the independence, health and wellbeing of people with neurological conditions.

139. A total of 10 respondents provided general comments in relation to this aim and the related commitments, with the key comment being of a need for better integration of services and for workforce planning to deliver joined up services that focus on anticipatory and preventative care which respond to peoples' needs. Once again, the need for appropriate funding and resources was referred to. A small number of organisations referred to work which had been undertaken and one third sector organisation outlined its view of how an ideal person centred model would work. An organisation in the NHS / health sector noted the need for partnership between NHS boards and local authority social care workforce plans.

Aim E

Build a sustainable neurological workforce fit for the future.

140. The following table shows that all who answered this question definitively supported Aim E.

Table 26: Q29 Do you agree or disagree with Commitment 16?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	9	-	2
Pharmaceutical / manufacturing (2)	1	-	1
Representative organisation (7)	6	-	1
Third sector (24)	21	-	3
Other (3)	3	-	-
Total organisations (49)	42	-	7
Individuals (96)	90	-	6
Total respondents (145)	132	-	13

141. A small number of respondents made comments specifically in relation to Aim E, most of whom welcomed this Aim, although there were some comments of the need for funding and resources to be able to achieve this; as well as support for people to access the relevant services at the point of need.

Commitment 16

142. The National Action Plan then went on to note that there are currently gaps in the provision of adequately trained staff to deliver care and treatment.

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.

143. Respondents were then asked to indicate their agreement or otherwise with Commitment 16. As table 26 shows, almost all those answering were supportive of this commitment.

Table 26: Q30 Do you agree or disagree with Commitment 16?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	6	1	4
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	19	1	4
Other (3)	3	-	-
Total organisations (49)	36	2	11
Individuals (96)	85	3	8
Total respondents (145)	121	5	19

144. A total of 48 respondents, across all sub-groups, provided commentary in relation to Commitment 16. As with the previous commitments, the key theme was support for this either in part or wholly, although there were some qualifying comments such as the need to include mental health services in workforce planning.

145. A few respondents commented on the current lack of support available in terms of overall access to services as well as timely access to services. Allied to this, a number of respondents commented on the need to have a wider range of professionals referred to, including the full range of neurological specialists such as neurology nurses, neuro immunologists and neuropsychologists, and GPs, pharmacists and any others who would form part of the integrated care team. One Health and Social Care Partnership noted the need for this to cover all staff groups and to identify the roles needed to deliver pathways, as well as to identify the knowledge, skills and experience needed for each role. There was reference to the need for the Scottish Government to be realistic about how it aims to meet the potential additional need that will be brought about by the implementation of this Plan.

146. There was also some reference to the need for a full list of all neurological conditions, with ME being cited specifically by a few respondents.

147. A few respondents referred to specific roles that should be created. These included:

- Consultant neurologists with responsibility for each condition to ensure leadership.
- Key worker co-ordinator.
- Advanced neurological AHP / nurses who can assess and order tests and prescribe medicine.
- General neurology key workers.
- Posts within acute neurology services that link patients with appropriate services across sectors including health and social care, and benefit services.

148. A few comments were made, each by only very small numbers of respondents. These included:

- Commitment 16 on its own is not sufficient in that there is also a need to create conditions to attract staff to the sector.
- This commitment needs to be more explicit to provide clarity of certainty for Aim E to be met effectively.
- There needs to be an overarching national development strategy.
- There needs to be a national workforce in order to have a level playing field.
- There is a need to consider how plans for improving neurology can provide flexible models of care; for example, community-based models of care would be suitable for some individuals and would in turn alleviate some of the pressure on other services.
- Workforce planning should include rehabilitation services.
- The NAP needs to connect with the AHP Specialist and Advanced Practice short life working group at HIS.

Commitment 17

149. The National Action Plan then explained that the Scottish Government has been giving consideration to consultancy vacancy rates and the age profile of the current consultant workforce and to recruitment, particularly within acute neurology and neurophysiology services. It also noted that there is no national framework for the development of non-medical staff working with people with neurological conditions, whether knowledge or competence based; and that there needs to be consideration as to the sustainability of this workforce, while still recognising the independence of the sector.

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.

150. Respondents were then asked to indicate their agreement or otherwise with Commitment 17. As the following table shows, almost all respondents agreed with this commitment; and only two respondents disagreed.

Table 27: Q31 Do you agree or disagree with Commitment 17?

	Number		
	Yes	No	Not answered
Health & Social Care Partnerships (2)	2	-	-
NHS / Health (11)	8	-	3
Pharmaceutical / manufacturing (2)	-	-	2
Representative organisation (7)	6	-	1
Third sector (24)	20	1	3
Other (3)	3	-	-
Total organisations (49)	39	1	9
Individuals (96)	89	1	6
Total respondents (145)	128	2	15

151. A total of 23 respondents commented specifically on Commitment 17, with most of them noting their support of this commitment. Other comments noted the need to ensure the provision of information and appropriate training for all staff, with a small number of references to specific neurological conditions such as ME or MS.

152. There were a small number of references to the need to consider barriers to recruitment and retention within the sector. One third sector respondent felt this commitment lacked the necessary detail to underpin how the sustainability of the workforce would be considered; another that this needs to address the shortage of care staff and not just their shortage of expertise.

In summary:

Again, there was almost universal support for this Aim and Commitments.

Commitment 16: There were references of a need to ensure overall access to services, as well as timely access to services. There were also requests for reference to the need for a wider range of professionals in order to deliver the necessary services to individuals with neurological conditions.

Commitment 17: There were references to the need to ensure the provision of information and appropriate training for all staff, and the need to consider barriers to recruitment and retention in the sector.

Implementation of the Plan

153. The draft plan noted that there is a need for co-ordinated action across the Neurological Community in order to achieve its vision. It is intended that the Scottish Government will consult members of the Neurological Community on the content of the draft plan to ensure there is wide support for the commitments. It noted,

We will:

- 1. Consult the Neurological Community on the commitments in this plan.**
- 2. Develop an implementation plan to support delivery of the commitments over a 5-year period.**
- 3. 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.**
- 4. Invite proposals for testing new models of care and support from Integration Authorities, NHS Boards and third sector organisations.**
- 5. Align the role of the National Advisory Committee for Neurological Conditions, to support the implementation of the National Action Plan.**

154. A total of 94 respondents, across all sub-groups, took the opportunity to answer this question, and a number of key themes emerged. To an extent, many of these comments echoed elements of the plan.

155. Some respondents commented generally on the plan and the commitments, and a few noted their support for the plan, its aims and commitments, although a similar number also noted the need for further detail such as what funding and support will be available, or more clarity in timescales or what services should look like.

156. A few respondents noted the plan is too ambitious and needs to be more realistic, or that the commitments will need to be strengthened. One or two respondents were cynical as to whether this will actually be implemented. As at some previous questions, there were requests from a small number of respondents for a list of all neurological conditions.

157. A key theme was on consultation and communication over the plan. A significant number of respondents noted the need to include the views of those living with a neurological condition, their carers or their family members, with some requests for them to be involved in not simply providing feedback but to also be involved in implementation of the plan. A number of these respondents referred specifically to the need to include individuals with ME.

158. A few respondents – mostly third sector organisations – noted the need to include the views of third sector organisations, in the detail of the implementation plan. Small numbers of respondents also made reference to including the views of professionals, decision-makers and purse-holders.

159. Other suggestions relating to communication and consultation, each made by only one or two respondents included;

- A need to communicate the plan at a workforce level.
- Holding roadshows or workshops at a local level to look at the different pathways.
- A need for an awareness-raising exercise or media strategy.

160. Another key theme emerging at this question related to the health and social care workforce. Some respondents referred to the need for sufficient staff or specialised staff in order to meet the aims and commitments. Linked to this, some others referred to the need for training to ensure that staff have the required expertise.

161. A small number of respondents noted the importance of having a National Implementation Lead and Local Implementation Leads.

162. Another key theme related to service provision, with a number of respondents commenting on the need for consistency in services across all areas of Scotland, including the more rural and remote areas; as well as providing appropriate services for all neurological conditions.

163. There was also reference to a need for integrated services and co-operation between different organisations and Health Boards, so that there is a truly multi-

disciplinary approach offering full integration in the development of an appropriate workforce.

164. Linked to this, there was also reference to the need for funding and resources, with some respondents referring specifically to the need for specialist centres, or the need for resources for specific neurological conditions such as ME, while other respondents simply noted the need for adequate funding so that all necessary services can be provided in a timely and accessible manner. One Health and Social Care Partnership referred specifically to the need for resources to help support Partnerships to develop local action plans that link with existing strategic plans.

165. The need for timescales for implementation was cited by a few respondents.

166. A small number of respondents also made specific reference to the need for improved IT systems and development of a national digital platform.

167. Another key theme referred to reporting and accountability. Some of these respondents referred to the need for detailed targets and identified milestones, and others noted the need for tools for outcome measurement and assessment so as to ensure the plan when implemented is effective. Overall, there was a perception of a need to ensure that detailed monitoring is undertaken, with regular reporting of success and the need to hold NHS Boards to account.

168. Small numbers of respondents referred to the need for strong leadership to ensure the aspirations of the plan are met, with a couple of respondents referring to the need for ministerial leadership and ownership of the National Action Plan. Allied to this, there were a small number of comments that there will also need to be ownership of the plan across the neurological community including third sector organisations and NHS staff. One third sector organisation noted that there are differences in accountability between national government, NHS Boards and Integrated Authorities and that these will need to be addressed for the plan to be effectively implemented.

169. A few respondents noted the need for the development and sharing of good practice. Two organisations in the NHS / Health sector suggested utilising good practice that already exists and ensuring that existing teams and their expertise are well utilised.

170. Finally, at this question, a number of respondents – mostly individuals – commented on the need for research, with most of them referring specifically to ME.

171. Question 34 of the draft National Action Plan went on to ask 'What is the most important thing we need to change to improve the NAP?' A total of 86 respondents answered this question.

172. To a large extent, many of the comments made in response to this question echoed those seen at earlier questions. The key themes emerging included the need:

- For the plan to be realistic and succeed, and have a clear approach to leadership and governance; and professional leadership within and across statutory organisations working closely with third sector partners. There also needs to be clarity over where responsibility sits for delivering each commitment and how progress will be monitored. One third sector organisation noted a need for external scrutiny of standards by Health Improvement Scotland and the Care Inspectorate alongside clear processes for clinical and care governance at a local level to ensure delivery of all the Aims and Commitments.
- For clear definitions of some of the terms used in the document.
- For the plan to link into other strategies and policy areas, and have clearer reference to existing clinical guidance and standards. Also to have more clarity on the relationship between Health and Social Care Standards, the new Health Improvement Scotland neurological standards and the Neurological Action Plan.
- To ensure sufficient and additional funding is set aside.
- To develop effective targets and milestones, measurement tools for the plan and its outcomes to be robustly monitored and evaluated regularly and consistently.
- For data collection and research, for example, to understand the prevalence of different neurological conditions or to provide evidence of the services needed across Scotland.
- For an enhanced workforce to meet demand, with sufficient staff who can provide knowledge, skills and experience across the full range of neurological conditions and across Scotland.
- For support for individuals with neurological conditions; easy and equitable access to co-ordinated support and care provided by a multi-disciplinary team, and also timely access to the necessary support and reduced waiting times. This support should be offered to individuals with a wide range of neurological conditions, including prisoners and those with Functional Neurological Disorder (FND), ME and MS.
- For increased awareness and training on neurological conditions, so that those within the workforce are aware of the impact of these conditions. There was also some reference to the need for GPs to have training on these conditions as they are often the first port of call for initial diagnosis.
- For improved and integrated IT infrastructure and systems so that all necessary professionals can access and share relevant data. One third sector organisation noted the need for more integration and dissemination across specialisms and between tiers of service.

- For recognition of all neurological conditions as well as recognition of the different contexts and needs of progressive neurological conditions; there was some specific reference to ME and MS.
- The needs of individuals with ME will not be addressed by this Plan as they were excluded from the two key pieces of work commissioned to underpin the report (the report on the prevalence of neurological conditions and the mapping of neurological services).
- Clarity over what constitutes good practice.

173. Other comments made by respondents included suggestions for the ParkinsonNet to be referred to in the final Action Plan, and a request for clarity over whether the National Care Framework for Huntington's Disease will be used as a template for people with other neurological conditions.

174. The final question of the consultation gave respondents an opportunity to provide any other comments or suggestions, and most comments echoed those seen at previous questions. Some individuals within organisations took the opportunity to provide some background to their organisation to help set their responses in context and some individuals provided information on their lived experience with a neurological condition.

175. Some respondents welcomed the opportunity to respond to this consultation.

In summary:

A number of key themes emerged at this question. These included some comments that while there is support for the Plan, there were concerns that it is too ambitious as it stands and that there needs to be further detail; for example, what funding and support will be available, clarity in timescales and what services would look like.

This consultation report has been produced by WHY Research on behalf of the Scottish Government.

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APPENDIX 1: Respondent Organisations

Consultation respondents are only included if they have provided consent for their names/name of the organisation they are responding on behalf of to be made public.

Action for M.E.
Age Scotland
Association of British Neurologists, Epilepsy Advisory Group
Association of British Neurologists
Bobath Scotland
Capability Scotland
Compass Brain Injury Specialists Ltd
Epilepsy Scotland
Fife Rehabilitation Service, Cameron Hospital, Fife
FND Hope UK
Greater Glasgow & Clyde Health Board, Rehab Dietitians
Heads of Clinical Neuropsychology services in NHS Scotland
Healthcare Improvement Scotland
Leuchie House
Marie Curie
MND Scotland
MS Society Scotland
Myaware
National Prisoner Healthcare Network
NHS Ayrshire and Arran
NHS GG&C, Older People's Psychology Service
NHS Grampian
NHS Lothian
Neurological Alliance of Scotland

Parkinson's Edinburgh Branch
Parkinson's UK in Scotland
Roche Products Limited
Royal Blind
Royal College of Occupational Therapists
Scottish Acquired Brain Injury Network
Scottish Care
Scottish Headache Interest Group
Scottish Partnership for Palliative Care
Scottish Post Polio Network
South Lanarkshire Health and Social Care Partnership
SUDEP Action/SUDEP Action Scotland
Sue Ryder
The Brain Tumour Charity
The British Psychological Society
The Digital Health & Care Institute
The Dystonia Society
The Myalgic Encephalopathy Association
The Royal College of Speech and Language Therapists
#ME Action Scotland
+ 96 individuals



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