Healthcare Improvement Scotland

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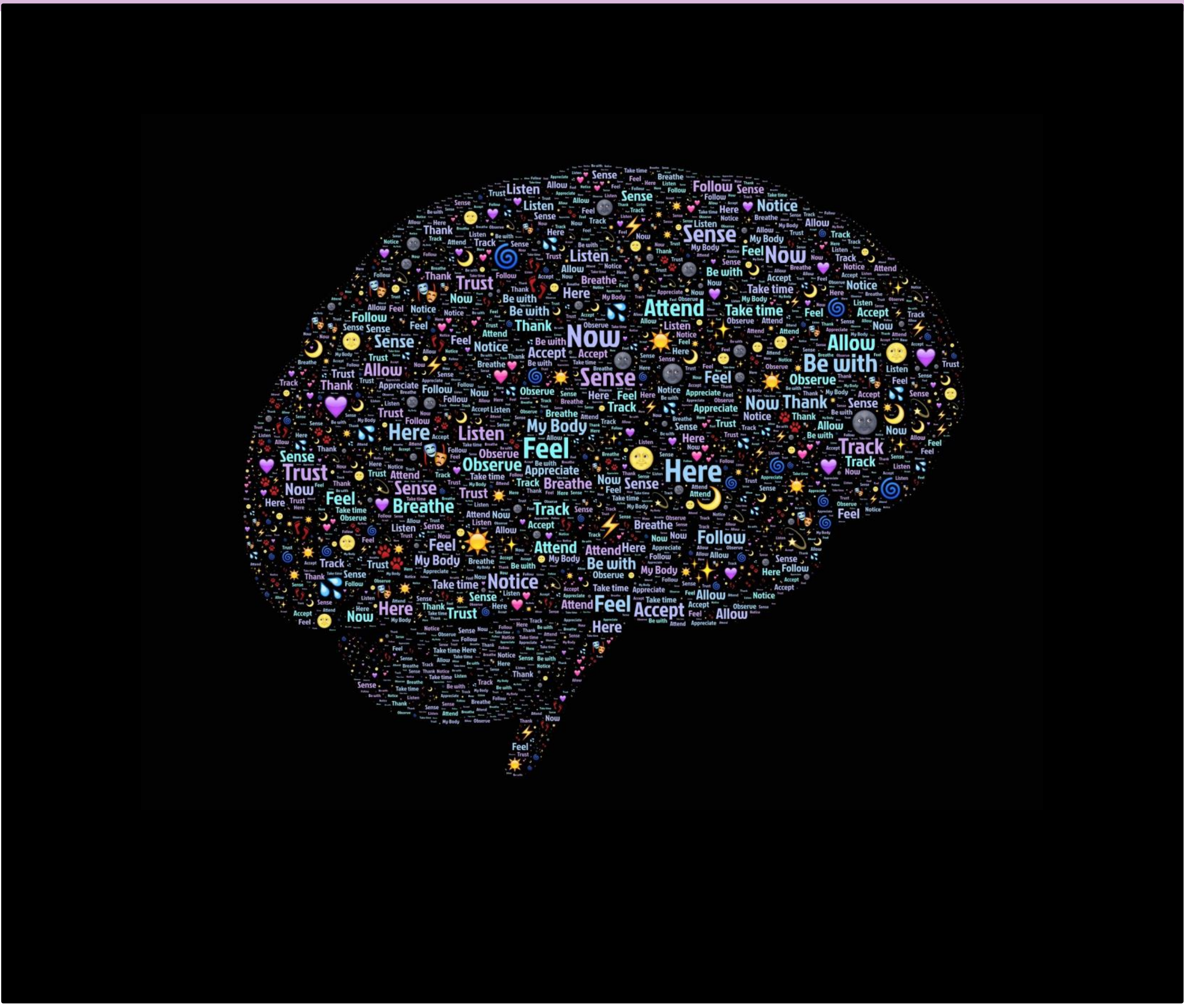
Gathering Views on General Standards for Neurological Care and Support

March 2019



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Section 1: Executive Summary

1.1 Healthcare Improvement Scotland published draft General Standards for Neurological Care and Support in September 2018. It carried out an extensive consultation exercise to obtain comments on the content of the draft standards and also asked the Scottish Health Council to gather information on the lived experience of having a neurological condition to help shape the final standards due for publication in March 2019.

1.2 The request for support for gathering views through discussion groups included a need to hear from individuals who were:

- living in a remote/rural area
- part of a local community group, or
- part of a pain management group.

1.3 The gathering views work was undertaken in all 14 NHS Board areas in Scotland using discussion groups as well as an online survey. The work gathered lived experience using seven questions covering:

- symptom management
- initial diagnosis
- needs assessment
- care planning
- access to services, and
- care from staff.

1.4 A total of 541 people across Scotland took part over seven weeks between 26 October and 13 December 2018. 198 people participated in a total of 24 discussion groups; a further 343 people provided feedback through an online survey or one-to-one interview with a member of staff from the Scottish Health Council.

1.5 Discussion groups were arranged by local offices using links with local third sector organisations. Most took place at existing meetings that the third sector organisation had already planned to host a discussion around the seven questions.

1.6 Equalities monitoring information was obtained from 70 of the 198 people who participated in discussion groups (35%). A further 321 of the 343 online respondents provided this information (94%).

1.7 17 condition-specific discussion groups took place with individuals with a variety of conditions as noted below.

- Multiple sclerosis (3 groups)
- Parkinson’s disease (3 groups)
- Epilepsy (3 groups)
- Huntington’s disease (3 groups)
- Brain injury (2 groups)
- Myalgic encephalomyelitis (ME) or fibromyalgia (1 group)
- Myasthenia (1 group)
- Alzheimer’s disease (1 group)

In addition, there were a further seven non condition-specific discussion groups involving participants with a variety of neurological conditions.

1.8 This report sets out a range of experiences of the participants who are living with a neurological condition in Scotland. Many were able to describe positive experiences of diagnosis, compassionate support and ongoing care with specialist nurses, which they regarded as being important to them. Others described a less positive experience with what they described as delays, unnecessary tests, a lack of information and poor care planning, delivery and communication.

1.9 The responses received have been submitted to colleagues in Healthcare Improvement Scotland to help shape and inform the final standards due for publication on 28 March 2019.

Section 2: Background

2.1 The Scottish Health Council was established in 2005 to promote Patient Focus and Public Involvement in the NHS in Scotland. We work to support the engagement of people and communities in the development of health and social care services. The Scottish Health Council is part of Healthcare Improvement Scotland, which seeks to drive improvements that support the highest possible quality of care for the people of Scotland.

2.2 Healthcare Improvement Scotland developed draft standards for neurological care and support in late 2018. The standards are applicable to anyone living with a neurological condition in Scotland and health and social care providers will use them to demonstrate that they are delivering high quality services. The standards set out a level of care and support for all adults regardless of the neurological condition, geographical location or an individual's personal circumstances.

2.3 The draft standards are structured into 7 sections and comprise 36 criteria under the following priorities.

- Leadership and governance (4 criteria)
- Partnership working (3 criteria)
- Staff education, training and information (5 criteria)
- Diagnosis (6 criteria)
- Assessment of needs (5 criteria)
- Treatment and Management (6 criteria)
- Person-centred Care (7 criteria)

2.4 Healthcare Improvement Scotland carried out its own extensive engagement around the content of the standards and in addition asked the Scottish Health Council to gather views from people living with a neurological condition using 7 questions to help shape the final standards. This report summarises our findings.

2.5 The responses to the 7 questions from 541 participants have been fed back to Healthcare Improvement Scotland to inform changes to the final standards due for publication on 28 March 2019.

Section 3: Engagement Approaches

3.1 The Scottish Health Council's gathering public views methodology feeds public views into the heart of the development of policy and services. There are other examples of this available on the Scottish Health Council website[1].

3.2 The approach used by the Scottish Health Council was consistent with our normal gathering views practice in that it is not undertaken as formal research nor as formal public consultation. This engagement was intended to supplement the work undertaken by Healthcare Improvement Scotland.

3.3 The Scottish Health Council regards gathering views via discussion with small groups of people as an effective way of obtaining feedback. Our main consideration is about the quality of engagement as opposed to the quantity of people involved.

3.4 For this piece of work views were gathered around lived experience in 24 discussion groups facilitated by local officers in NHS Board areas across Scotland. These discussion groups were supplemented by the use of an online survey. A total of 198 individuals took part in the discussion groups and 343 individuals contributed through the online survey.

Western Isles – Neuro Hebrides Cuppa & Catch Up

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[1] www.scottishhealthcouncil.org

Section 4: Feedback from the discussion groups

This section summarises the feedback from 198 people who engaged around the 7 questions covered in 24 discussion groups across Scotland. Quotes which appear in this section are from people who took part or are extracts from the discussions that took place. In two of the sessions, 11 individuals who did not wish to take part in the full discussion contributed their thoughts and experiences on a poster at each venue.

4.1 Can you describe your experience of when you first saw a health professional about your symptoms/neurological condition?

4.1.1 Diagnosis

The majority of participants had their first experience of engaging with a healthcare professional through their local GP practice after they made an appointment for what they described as worrying symptoms such as a tremor, persistent headache, pain or weakness.

Many people who had visited their GP found them largely supportive but often felt that there was a limited knowledge of their condition and the need for a number of tests resulted in a referral for a neurological appointment. This often involved a long wait which resulted in anxiety due to their persistent symptoms.

For some patients (particularly those with a diagnosis of epilepsy), their first experience was waking up in hospital after a sudden and unexpected seizure. They said this was particularly traumatic as they had no recollection of what had happened to them and having access to information and explanation was very important.

4.1.2 Interaction with healthcare staff

Participants made specific comment on the relationship and the communication with their GP being important to how they felt about the overall experience. A large number spoke about their experience of being treated by a compassionate, caring doctor who cared for them with a great deal of empathy.

Others spoke of a negative experience of being dismissed, not being believed, not being taken seriously or misunderstood.

4.2 Have you been diagnosed with a neurological condition?

4.2.1 Support and Information

Some participants spoke of waiting a long time for a diagnosis and then feeling isolated after finally getting one with a lack of a care plan and information. Others spoke of a sense of relief on receiving a diagnosis as it meant that they finally knew what was happening to them and they could move forward with their lives.

> “The diagnosis cost me my driving licence, my job. It changed everything.”

For some of the individuals with Huntington’s disease, participants described the importance of receiving information that could be shared with family members and children in a considerate and tactful way given the genetic component associated with that particular condition.

Overall, participants highlighted a lack of consistency in terms of communication, information and support offered upon diagnosis (even when it was for the same condition in different parts of the country).

4.2.2 Waiting times

Participants spoke about the length of time it took to receive their diagnosis, sometimes having been seen by several clinicians. In some instances a wrong diagnosis had been given. Many acknowledged the difficulties for clinicians in making a clear diagnosis with varying symptoms and the need sometimes for more than one clinician to be involved.

4.3 Have you had a needs assessment carried out or a care plan developed? If you have, can you tell us more about this and how it is working for you?

There was a mixed response to this question across the discussion groups. In some cases, all members of the discussion group were able to describe the needs assessment work and care planning that had been undertaken. In other groups, none of the participants were aware of a needs assessment being carried out or a care plan being developed. In addition, some did not think the language being used was easy to understand.

> "No, nothing at all. It would have been good to have been offered this (needs assessment or care plan)."

Where a needs assessment had been carried out and/or a care plan developed, participants said that this was helpful in delivering a flexible, person-centred approach to managing their health and care needs. Some of the participants highlighted that organisations and individuals in the third sector had been supportive in helping them to get access to information and care planning.

Many participants also identified the important role in both involving and supporting carers (who are often family members) in care planning. This was noted by participants as particularly relevant since the implementation of The Carers (Scotland) Act 2016[2].

4.4 What has been your experience with staff and services who may have been providing/provided neurological care and support to you?

4.4.1 Staff

The provision of specialist nurses for some conditions was noted as being hugely important with these nurses being viewed as the key individuals in co-ordinating care. Similarly, where there are no specialist nurses for certain conditions or in specific geographical areas this was seen to be a major shortfall in the care and support provided. Some participants commented that specialist nurses provided more holistic care by focusing on the person rather than just the condition or the symptoms. However, some participants highlighted what they perceived as a lack of awareness among non-specialist healthcare professionals around certain conditions, which was seen as problematic and could cause delays for treatment.

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[2] http://www.legislation.gov.uk/asp/2016/9/contents

4.4.2 Services

Participants commented that services often did not seem sufficiently person-centred or flexible for supporting people with neurological conditions as symptoms can vary from day to day.

The importance of information and peer support provided by third sector organisations and services was highlighted by many participants who were very appreciative of the role they fulfill.

4.5 What has your experience been of being able to access services for your treatment and/or management of your neurological condition?

There were both positive and negative experiences in the feedback around accessing services – the themes are noted below.

Participants highlighted support from third sector partners including support for managing anxiety and stress and completion of forms relating to claiming benefits as being particularly beneficial.

They also spoke of the difficulties in accessing some services where obtaining a clear diagnosis had been time consuming followed by a lack of consistency of a care pathway once a diagnosis had been made.

It was clear from the participants living in remote and rural areas that travelling distance and time (including flights from the islands) could be problematic and time consuming. Participants also highlighted the lack of specialist staff available in remote and rural areas.

> “A fight to get what is needed rather than things being automatic on diagnosis.”

4.5.3 Waiting times

Participants highlighted that waiting times for appointments could often be lengthy and this could be particularly challenging for people with progressive long term conditions. Participants from remote and rural settings noted that they also tended to have access to fewer services and this could be difficult.

4.6 On reflection of your experience of living with a neurological condition, is there anything you think could have gone better?

4.6.1 Greater awareness of neurological conditions

Most groups felt that increased awareness about less well known conditions was needed for all clinical teams to help with information, communication and diagnosis. Interestingly, two groups also commented on the need to raise the profile of some conditions with the general public so that people would know what to do if they encountered someone having a seizure.

4.6.2 Improved information and support

Many groups commented on the lack of information materials for their particular condition and inconsistencies in how they were provided. A number of participants said they relied on the internet to find out more information and places that could help provide support. Being part of a local condition-specific support group was felt to be very helpful.

A number of groups spoke about finances, particularly the difficulties in accessing financial support along with a lack of consistent information about financial support and benefits to help a person living with a neurological condition.

4.6.3 Faster referral and diagnosis

This was a common theme for most groups. It was generally felt that diagnosis was a long and drawn-out process that was difficult to navigate.

Some of the groups noted a lack of awareness of third sector support from clinicians when they received a diagnosis and suggested improved sign-posting would be helpful.

4.6.4 Better assessment and care planning

There were a number of comments about the importance of appropriate care planning relating to medication (particularly from patients with epilepsy, Huntington’s disease and Parkinson’s disease) when complexities with the condition (or an unscheduled hospital admission) could sometimes cause problems with prescribed medication being stopped.

4.7 Have you had any positive experiences whether that be of people, services or other experiences that you would like to tell us about?

4.7.1 Staff

Participants highlighted that a range of support from a wide variety of clinicians and support workers was valuable in helping them live with their condition. Participants specifically mentioned nurses, consultants, GPs, pharmacists and Allied Health Professionals.

4.7.2 Specialist nurses

Specialist nurses, where they existed for specific conditions, were felt to be making a positive contribution to the quality of life for participants. Many spoke of the dedication, commitment and person-centred approach of their specialist nurse.

> “(Specialist nurses) provide a very valuable service.”

> “(The specialist nurse) speaks at an understandable level, not jargon”

4.7.3 Third sector support

The majority of participants were complimentary about the important role that third sector organisations play in helping them live with their condition. They also highlighted the benefit of peer support in attending the variety of meetings and sessions that third sector organisations host.

Some participants also highlighted particular therapies that were on offer at third sector meetings as being beneficial. One group explained that their young people’s group deliver a ‘train the trainer’ session to provide information as part of a campaign to raise awareness of a particular condition among employers, schools and the general public.

One particular patient took the time to bring a handwritten note detailing their lived experience to one of the discussion groups and this experience (shared with their consent) is below.

> *“When I was originally diagnosed with tonic clonic epilepsy at the age of 21 unfortunately the epilepsy services were worrying.*
>
> *I experienced extremely long waiting times even though I had a life threatening and devastating seizure causing extreme injuries and I am very lucky to be here.*
>
> *I was never offered a review by my consultant or GPs to discuss my epilepsy and the impact the medication is having on my body and mental health.*
>
> *I was never provided a care plan, my epilepsy was never ever controlled during my time with the consultant. Why? I felt let down as I said my epilepsy was never controlled.*
>
> *I wanted to be in a position where I knew more about my condition and the impact my medications were having on me, my consultant didn’t even know.*
>
> *There was a lack of knowledge and awareness as I could have been receiving beneficial and amazing support and attending epilepsy support groups from a local epilepsy specialist nurse. Why does a consultant not know these things?*
>
> *I felt fortunate that I had a consultant every 6 months, I didn’t feel supported though. He was ignorant, my medication would change on each and every visit. I’ve probably been on every anti epileptic medication there is.*
>
> *I have a different consultant now and a much more positive and encouraging experience. I see my consultant every 6 months and he referred me to an epilepsy specialist nurse.*
>
> *I can call or email my specialist nurse if I have any concerns or worries. He referred me on to an Epilepsy Connections field worker who runs support groups in my local area. My consultant and specialist nurse keep in regular contact with my GP regarding seizure activity or changes in medication.”*

Section 5: Feedback from the online survey

This section summarises the feedback from 343 responses to the 7 questions covered in the online survey. The quotes that appear in this section are from people who took part.

5.1 Can you describe your experience of when you first saw a health professional about your symptoms/neurological condition?

339 people responded to this question.

5.1.1 Diagnosis

The majority of people who responded shared their experiences of trying to obtain a diagnosis after accessing healthcare for particular symptoms or in response to an emergency admission to hospital. A number of the participants had a positive experience of diagnosis however the majority shared difficulties in their experiences of first seeing a healthcare professional. Particular difficulties noted were:

- inappropriate tests or referral
- inconclusive results not being explored further
- misdiagnosis
- a lack of specialist healthcare professionals
- a lack of knowledge about specific conditions
- a lack of person-centred holistic care, and
- poor communication.

5.1.2 Interaction with healthcare staff

Several people mentioned kind and understanding GPs, neurologists and specialist nurses who listened to them. However a large number of the participants commented on issues around a lack of information, rushed appointments and a lack of empathy and compassion.

5.1.3 Waiting times

Time was a prominent theme in the responses to this question with some people saying they had waited many months for a diagnosis of their particular condition. For some this resulted in them using private healthcare facilities instead of waiting to be seen by the NHS.

5.1.4 Emotional experiences

Some of the people who responded to this question shared how they felt when they had when they first saw a healthcare professional. Some of the words they used were “frustration”, “nervous”, “isolation”, “frightened” and “confusion”.

5.2 Have you been diagnosed with a neurological condition?

338 people responded to this question. 310 had been diagnosed with a neurological condition, 28 had not been given a diagnosis.

5.2.1 Support and information

People who responded to this question generally felt that there was a lack of support and information available after a diagnosis was made. They spoke of feeling isolated or dismissed and “left to get on with it”. There were a number of references about difficulties individuals had experienced with having Myalgic Encephalomyelitis (ME) recognised as a neurological condition by healthcare staff.

Some people said that third sector condition-specific charities and organisations were a particular source of assistance in terms of finding information about managing symptoms but also in terms of offering peer support.

5.2.2 Waiting times

Many participants gave similar responses to those noted above for question 1 in section 5.1.3. Others commented on the impact their symptoms had on their day-to-day activities of daily living whilst awaiting a diagnosis and treatment plan.

5.2.3 Emotional responses

A large number of people shared their feelings on being given a diagnosis of a neurological condition. Although some shared positive feelings such as feeling happy (because they now had a diagnosis), reassured and acceptance, there were others who shared negative feelings such as loneliness, shock, devastation, distress, anger and confusion.

5.3 Have you had a needs assessment carried out or a care plan developed? If you have, can you tell us more about this and how it is working for you?

334 people responded to this question.

Around 1 in 6 of the people who responded to this question provided enough information to ascertain that they had a needs assessment carried out or had a care plan developed. In the majority of cases where this had been done, it was felt to be of benefit to the person living with a neurological condition. A variety of different healthcare professionals were mentioned including specialist nurses and Allied Health Professionals as having an important role in needs assessment and care planning.

> "(My care) is outcomes focused and tailored to my wants and needs."

Where it was clear that a needs assessment had not been carried out or a care plan developed, most participants did not have an awareness or understanding of how a care plan would help to manage their condition or symptoms.

> "Until last week I had never even heard of those terms (needs assessment and care plan). I've no idea what they are."

5.4 What has been your experience with staff and services who may have been providing/provided neurological care and support to you?

336 people responded to this question.

5.4.1 Staff

The majority of comments related to staff providing care and support – they were mostly positive but not specific about which groups of staff they related to (although GPs, specialist nurses and neurologists were frequently mentioned.) Some examples of the comments received are noted below.

> "I have the highest regard for the staff."

> "MS nurses are worth their weight in gold."

5.4.2 Services

Comments relating to the services provided were mostly negative. Many participants felt that they were not always listened to and consequently not always provided with adequate services which were appropriate to their needs. Some examples are noted below.

> “Don’t get care, feel completely abandoned.”

> “A lack of knowledge and understanding.”

5.5 What has your experience been of being able to access services for your treatment and/or management of your neurological condition?

327 people responded to this question.

Although the majority of comments highlighted challenges for many participants, there were some individuals who have had a positive experience when accessing services.

Some described the care as “very good” or “excellent” and others shared that it was understanding staff or being offered support that made things better for them. People mentioned the importance of being able to make appointments or contact healthcare professionals when needed.

Many participants described their experience of being able to access services as “awful”, “poor” or “absent”. Some people felt that services were “non-existent” in some cases.

> “Treatment and management lacking.”

> “An exhausting time carrying out my own research.”

5.5.3 Waiting times

Waiting times was a prominent theme for participants with some describing having to wait several months for an appointment or even years before diagnosis. This was particularly challenging when dealing with conditions where symptoms fluctuated frequently.

Some people felt that if they were able to access services more quickly they would feel better cared for.

> "Everything seems to take a long time to arrange but when things happen they seem to be reasonably good."

5.6 On reflection of your experience of living with a neurological condition, is there anything you think could have gone better?

328 people responded to this question.

5.6.1 Awareness of Neurological conditions

Many participants said that they felt healthcare professionals, in particular GPs, did not have enough awareness of neurological conditions. People said that if GPs had better knowledge and understanding of conditions it would have made their patient journey easier. It was felt that appropriate tests and treatments could be better utilised to enable quicker diagnosis and help prevent misdiagnosis.

5.6.2 Information and Support

Participants told us that better information and improved support would have made for a more positive experience for many. One person described feeling "abandoned by the NHS" and others would have appreciated ongoing support but felt that there was none.

People would have liked more information about their specific conditions and advice on what support was available to them (such as local support groups). Others said they felt like they would have felt better supported if the healthcare professional had explained their diagnosis with empathy and sympathy.

5.6.3 Referral and Diagnosis

A common theme was about the time taken for referrals to a specialist or time taken to be diagnosed. Participants talked about long waiting times and said that earlier diagnosis would have made a big difference as it would have allowed treatments to start sooner.

5.6.4 Assessment and Care Planning

A number of participants said that they would have benefited from further needs assessment, rehabilitation and care planning. Generally, people living with a neurological condition would like to see better co-ordination between agencies to improve ongoing care and support.

In addition to these four themes, many participants also mentioned the need for:

- communication to improve,
- improvements to travel and parking when visiting a hospital, and
- better support around benefits and finance.

5.7 Have you had any positive experiences whether that be of people, services or other experiences that you would like to tell us about?

314 people responded to this question.

5.7.1 Staff

A number of people shared how staff had provided a positive experience for them. Many did not specify individuals, but instead acknowledged the range of healthcare professionals or teams involved in their care including GPs, consultants, occupational therapists, physiotherapists and/or speech and language therapists.

A few individuals noted how psychiatrists and psychologists had been helpful in either supporting diagnosis of a neurological condition by confirming the condition was not psychological or providing support to cope once a diagnosis had been made.

Participants highlighted that when staff made them feel cared for and treated them in a person-centred and understanding way, this made a huge difference to their experience. It was acknowledged by some that, while staff were generally good, overall they felt let down by the system as a whole.

5.7.2 Specialist Nurses

Many people said that it was specialist nurses who had provided a positive experience for them. Nurses were described as “excellent, experienced, knowledgeable and easy going” as well being “supportive, dedicated, helpful, brilliant, proactive and amazing”.

Some people said that the only positive source of support and information had been the specialist nurse.

> “Specialist nurses handle it (my care) with professionalism, compassion and empathy.”

5.7.3 Third sector support

Many people said the positive for them was the support received from third sector organisations and peers they meet at local groups. For some, it was the social aspects which were of most benefit as they had made friends, met socially on a regular basis and were able to provide moral support to each other.

For others, third sector organisations have been an invaluable source of information they felt was lacking from the NHS as well as providing therapies to help manage symptoms.

> “Third sector organisations help with tips on how to manage a debilitating condition.”

Section 6: Next steps and Acknowledgements

6.1 The Scottish Health Council would like to thank all the participants who shared their personal experiences and views on the draft standards The feedback received has been invaluable in shaping the final General Standards for Neurological Care and Support.

6.2 The feedback obtained from each of the discussion sessions and the online survey has been shared with the colleagues from Healthcare Improvement Scotland in finalising the standards. Examples of where the feedback we received has shaped the final standards are noted below.

- The importance of family and carer support was a strong theme from the views gathered. This has been incorporated more explicitly throughout each of the seven standards.

- Mental health support was a consistent theme. Additional criteria have been included within the standards detailing appropriate access to emotional, cognitive, mental health and wellbeing support as well as specialist interventions including neuropsychology and neuropsychiatry.

- Information about how to re-access services was highlighted as being important for people. A new criterion has been developed which sets out that people will be fully informed of who to contact for further advice and access to support and services throughout the course of their neurological care.

6.3 We also like to thank staff from all of the partner organisations who accommodated discussion groups across Scotland for their valuable support in gathering views. The Scottish Health Council is also grateful for the practical support we received to run the sessions and for assistance in making the engagement accessible and meaningful for all participants.

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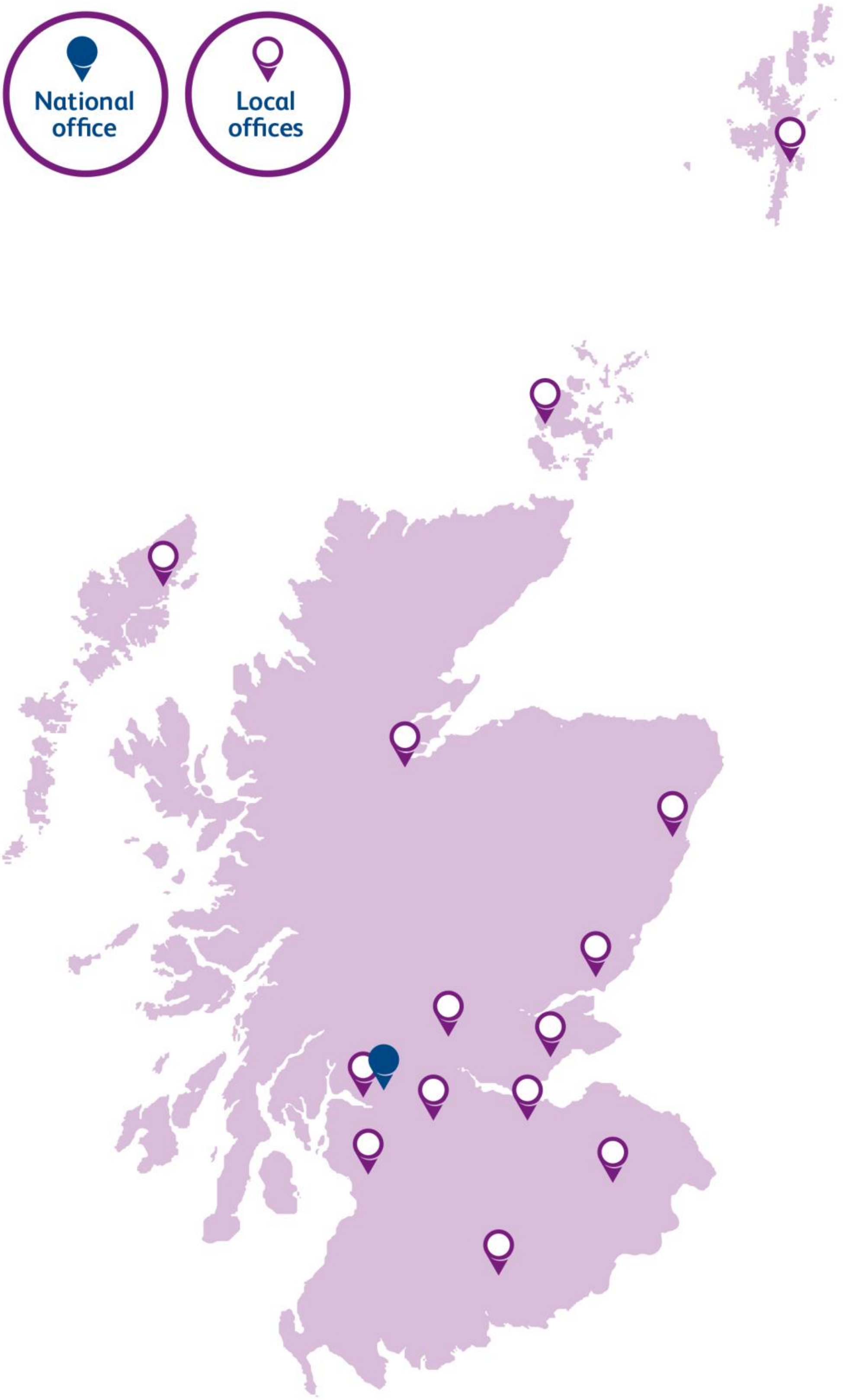

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