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Section 1: Executive Summary

1.1 The Scottish Government asked Healthcare Improvement Scotland - Community Engagement to undertake an exercise in 2019 to gather information on the lived experience of people with Myalgic Encephalomyelitis (ME). It is intended that the findings will help inform an evidence base to support the care needs of people living with the condition, with a view to understanding what good care and support looks like.

We carried out an extensive engagement exercise across Scotland to hear from individuals with the condition and the findings of this work are published in this report.

1.2 The Gathering Views exercise was undertaken during February and March 2020 in all 14 territorial NHS board areas in Scotland, using discussion groups as well as an online survey. The work gathered lived experience from individuals by asking questions about the care provided by health and social care services in the following areas:

- Establishing which services had been supportive in providing care that made a difference to quality of life.
- Considering which professional groups had (and had not) been involved in delivering care.
- Exploring how care could be more responsive to the needs of someone living with ME who also had other conditions.

To ensure that the severity of the condition could be considered in all aspects of the information gathered we used a four point severity scale (mild, moderate, severe and very severe) advised by Scottish Government colleagues, representatives from third sector organisations and those living with ME. It was clear from the submissions that many people will move between the different points on the severity scale at different times in their day or lives.

1.3 A total of 561 people across Scotland took part in this exercise over a five week period. Thirty-nine people participated in a total of seven discussion groups and a further 522 people provided feedback through an online survey or by a one-to-one interview with a member of staff from our engagement offices.

1.4 Discussion groups were arranged by our engagement offices using links with local third sector organisations. The discussions took place at existing meetings that a third sector organisation or support group had already planned and used similar questions to those posed in the online survey. This was a particular challenge as there are very

few peer support groups in Scotland. Instead much of the patient interaction and support takes place on social media where a number of Facebook groups were found.

The online survey was particularly successful with a rapid uptake in completion in the early days. However, the completion rates dropped significantly as the country was hit by the global coronavirus pandemic.

Each of the 14 NHS board areas were represented in the online survey submissions. In developing the online survey, we took account of feedback from people living with ME on a number of areas, notably the importance of individuals being able to partially complete the survey and return at a later date to finalise their submission.

We have used quotes from individuals who participated in the exercise in the body of the report where appropriate.

1.5 Equalities monitoring information was obtained from 22 of the 39 people who participated in discussion groups (56%) and 438 of the 522 online respondents provided this information (84%).

1.6 This report sets out a range of experiences of the participants who are living with ME in Scotland. Some were able to describe positive experiences of diagnosis, compassionate support and ongoing care. However many respondents outlined a less positive experience including what they described as:

- lengthy diagnosis
- unnecessary tests
- a lack of information about the condition
- an absence of person centred care planning and delivery
- low levels of knowledge about the condition among staff, and
- a lack of belief when they interact with services.

Many of the respondents felt isolated and reported that they were left to get on with managing their condition with limited input or support.

1.7 The responses received have been submitted to colleagues in Scottish Government to help shape their work in establishing an evidence base around the care and support for patients with ME.

1.8 Our recommendations following this Gathering Views exercise fall under these categories.

- Better understanding and recognition of the condition
- Better person centred care planning and holistic care
- Isolation and loneliness
- More research and clinical trials
- Provision of specialised services/clinicians
- Access to accurate and up to date information
- A more appropriate environment when a visit to a clinical location is needed
- Advice about access to practical support – coping in the home, wheelchairs, benefits, employment support and blue badges

Section 2: Background

- 2.1 The Scottish Health Council was established in 2005 to help promote Patient Focus and Public Involvement in the NHS in Scotland. On 1 April 2020, The Scottish Health Council became known as Healthcare Improvement Scotland - Community Engagement.

The purpose of Healthcare Improvement Scotland is to enable the people of Scotland to experience the best quality of health and social care, and we are committed to supporting the engagement of people and communities in the development of health and social care services.

- 2.2 Colleagues in Scottish Government approached us in early 2019 to request support in the development of an evidence base in ME with a view to understanding what good care and support looks like for people with ME. In developing our approach to this work we were grateful for the support of people living with ME who were able to provide feedback on the types of questions to be asked and the ways in which we might contact people living with ME and their families.

- 2.3 We asked participants a total of 14 questions relating to their ME using the following structure (the question schedule can be seen in Appendix 1):

- Six questions covering the lived experience of individuals reflecting on what health and social care support they had in the past, are getting now and looking at what would make a difference in future.
- Six questions asked specifically which health and social care professionals had made a difference to the support they had in the past, are getting now and looking at what would make a difference in future.
- Two questions asking about how their health and social care needs for other conditions could be more responsive to your needs around your ME.

The findings in relation to the detail obtained from these questions can be found in the feedback section of this report.

Section 3: Approach

- 3.1 Healthcare Improvement Scotland - Community Engagement has developed a methodology called Gathering Views. This aims to gather public views on specific subject areas to inform the development of policy and services.
- 3.2 Gathering Views exercises obtain feedback via discussions with small groups of people, supported by an online survey to obtain their experiences of health and care services. Our main consideration is the quality of engagement as opposed to the quantity of people involved, however, in this instance the popularity of the online survey meant that a very large response was received.
- 3.3 Gathering Views exercises are not undertaken as formal research, nor as formal public consultation. The engagement is intended to supplement work undertaken by Scottish Government.
- 3.4 There are several examples of our previous Gathering Views exercises available on our website www.hisengage.scot where this report has also been published.
- 3.5 For this Gathering Views exercise we obtained feedback around lived experience in seven discussion groups facilitated by engagement officers in six NHS board areas (Lothian, Orkney, Highland, Grampian, Dumfries & Galloway and Greater Glasgow & Clyde) across Scotland. These discussion groups were supplemented by the use of an online survey. A total of 39 individuals took part in the discussion groups and 522 individuals contributed through the online survey.

It was particularly challenging to hold face to face discussions with individuals for this Gathering Views exercise due to a lack of pre-existing discussion groups and the unpredictable nature of the condition.

- 3.6 The contributions to the discussion groups and online survey were analysed (by theming and categorising responses) and peer reviewed by members of staff in our 14 engagement offices across Scotland. This allowed for the key themes to be presented in this report. The analysis was carried out with a focus on a qualitative approach.

Section 4: Feedback

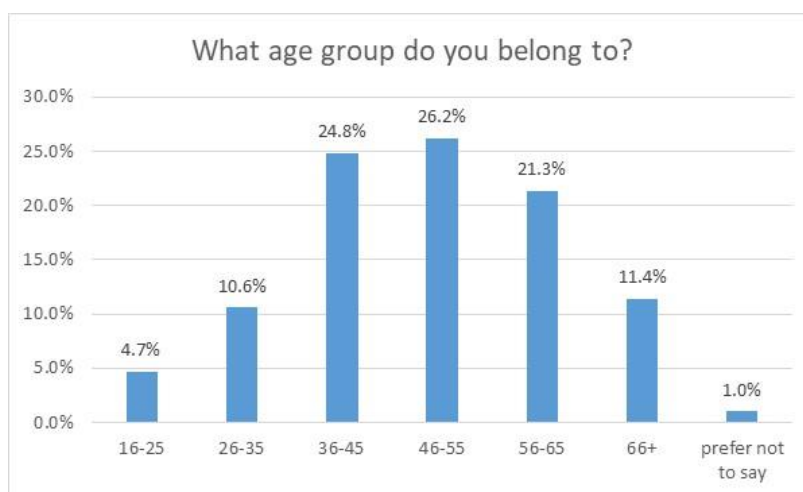
4.1 A significant amount of feedback was received through this Gathering Views exercise. The content from the online survey generated over 450 pages of content for analysis and consideration, in addition to the feedback obtained via the seven face to face discussion groups we attended. All of the comments have been carefully analysed and are covered in the thematic reporting structure in this report. The quotes that appear throughout the report are from people who took part.

Equalities Monitoring

4.2 Equalities monitoring questions were included in the online survey to enable us to capture this information about those living with ME.

4.3 The equalities monitoring information we obtained through the online survey allowed us to establish the following:

- Almost 80% of the online respondents were female.
- 71% of respondents to the online survey considered themselves to be disabled under the Equality Act (2010).
- 93.5% of respondents to the online survey identified in a white ethnicity, with only five respondents identifying with a minority ethnic group. No respondents were black, Indian or Chinese.
- 81% of respondents identified as Christian.
- 85% of respondents identified as heterosexual, with 5.7% identifying as bi-sexual, gay or lesbian.
- Less than 1% of respondents were transgender.
- There were online responses from individuals across a variety of age ranges as noted below, with the largest number of responses from the 46-55 year old age group. Over 50% of participants were in the age groups between 36 and 55.



Severity of Condition

- 4.4 We asked individuals to tell us about the severity of their ME. To assist with this question we provided some examples to help individuals define the impact of their ME on their day to day life.

The severity scale used is noted below:

Mild – Are mobile and can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work, they will have stopped all leisure and social pursuits, often taking days off. Most will use the weekend to rest in order to cope with the week.

Moderate – Have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs of ability, dependent on the degree of symptoms. They have usually stopped work and require rest periods, often sleeping in the afternoon for one or two hours. Sleep quality at night is generally poor and disturbed.

Severe – Are normally able to carry out minimal daily tasks at best (such as face washing, cleaning teeth); cognitive difficulties are likely to be severe at times; mobility poor; mostly unable to leave the house except on rare occasions and may require support of a powered wheelchair and/or carer to do so; prone to severe and prolonged after-effects from effort.

Very severe – Are mostly unable or barely able to mobilise or carry out daily tasks; in bed for the majority of the time; sensitivity to noise, light and/or movement may be acute; cognitive difficulties can be severe with low tolerance for mental effort and adverse after effects.

Responses are noted below:

Severity	Response
Mild	19.1%
Moderate	33.1%
Severe	16.7%
Very Severe	4.4%
Other/unsure	26.6%

The 135 people who chose the other/unsure option noted that the severity of their ME fluctuated on a regular basis. Many noted coping strategies that they had used to manage their condition, such as the planning and pacing of their daily activities and the support they get from family and other informal carers as being the key to getting through each day.

Some participants noted that the use of a powered wheelchair or motorised scooter was helpful at times.

Many participants cited the negative impact that their ME has on daily activities such as washing, cleaning, cooking, brushing their teeth and gardening. Numerous people shared that were unable to work and many mentioned the importance of regular rest periods throughout the day.

Analysis – Support

4.5 Analysis of the six questions covering what support (health and social care) individuals had in the past, are getting now and looking at what would make a difference in future is detailed below using the following themes:

- diagnosis
- service provision
- information
- person centred care
- medication
- impact on quality of life
- knowledge about the condition, and
- communication.

Diagnosis

“It alone feels great when a GP, nurse etc. actually believes in what I am saying and that I have a real condition even if they cannot assist. It took me 10 years to receive my diagnosis as health professionals did not believe ME to be a real condition.”

A number of individuals mentioned the length of time that it took for them to receive a diagnosis of ME and whilst that was often frustrating and worrying the diagnosis, when it came, often brought a sense of relief. However, many people told us that a diagnosis was eventually made after other conditions were ruled out and after receiving the diagnosis, little or no support was offered.

Where we asked people what would make a difference in the future, we heard that a faster diagnosis would be helpful. There were a number of suggestions that training for GP’s and medical students would be helpful in securing a diagnosis at an early symptomatic stage. It was noted that following a diagnosis, a plan of care would be helpful in managing symptoms and seeking advice.

Service Provision

“There are NO healthcare services within the NHS which help with ME. None. I cannot emphasise this point enough”

A number of participants told us that there were little or no services that provided support for them living with ME, in particular a lack of specialist services beyond the support provided by their GP. A very large number of people told us that they received no help, care or support from services.

Individuals made specific mention of clinicians who had been very supportive in their care, particularly where a specialist nurse was available or where there were individuals both clinical and non-clinical with a specific interest in the condition. However, it was clear from the responses that this was not the experience of most of the people who shared their lived experience.

Some people mentioned that access to wheelchairs and the provision of blue badges for parking had helped them manage day to day activities. Many of those who mentioned access to wheelchairs noted that this was something they had to arrange for themselves or purchase privately.

Support provided by physiotherapists and occupational therapists in both understanding and practising how to pace activities was a prominent theme in the responses. Other clinicians who had provided support to people living with ME were dentists and pharmacists.

In a significant number of responses the support provided by voluntary groups (where these were available) and peer to peer support was found to be very helpful, with individuals often using social media groups. Most notably, people told us that the support they received from family members, friends and neighbours was key in managing on a day to day basis.

When asked what would make a difference in the future, people advised access to specialist services for ME would be the thing that would have the biggest impact. This included all manner of clinicians but also related to specific advice around lifestyle and activities of daily living, as well as access to psychological support where this was needed.

Many people also told us that home visits by doctors and nurses would be very helpful in managing the often difficult visits to GP practices, clinics and hospitals for appointments. Some people also mentioned that access to advocacy services when needed would be beneficial.

In terms of desired support from social care, many people talked about the need for support in daily activities such as personal care, household cleaning, food preparation and cooking as well as garden maintenance. Some people also spoke about the need for household adaptations and equipment such as stair lifts, handrails and bathroom equipment. A few people told us that they lived an isolated existence and access to local befriending services would be helpful for them.

Information

“There’s such a lack of information provided so I have had to find out about the condition and find my own way of coping as best as I can through my own research”

Participants told us that there was a lack of information available about the condition for people living with ME. There were examples of good quality information being available from voluntary sector organisations rather than from health or social care services.

When asked what would make a difference in the future, people told us that high quality information such as leaflets and posters about the condition for people living with ME and their families would be helpful. This information should extend beyond the condition to cover things such as financial support, access to blue badges for parking and employment support.

Some people told us that an up to date website with information specific to ME would be a helpful resource.

Person centred care

“I have no care or support. I was diagnosed by a GP and then the system washed its hands of me.”

Several responses told us about a lack of person-centred care planning upon diagnosis and there was a definite feeling of people being left to fend for themselves with little support provided.

When asked what would make a difference in the future, people told us that a dedicated person-centred care plan developed in conjunction with the person living with ME and their family would be helpful in addressing the feelings of getting a diagnosis and then having to manage with little or no support. A dedicated care and support plan should include reference to all of the issues most relevant for each person including medication, psychological care and practical matters such as personal care, financial implications and access to support services and local groups.

Medication

“Sometimes you can feel that because you can't see ME that people don't realise how much of an impact the illness has when you are being treated for other conditions and the side effects that medicines have”

A number of people noted the effective use of some medicines in treating various aspects of their condition. In one case, an ENT specialist recognised that the trigger for the person's ME symptoms was related to sinus problems and prescribed medication with the support of the GP that has been helpful.

In other cases, there was a lack of medication for the symptoms of ME but there was provision of medication for other ME related issues, such as pain relief, insomnia and particularly the prescription of anti-depressant medication.

When asked what would make a difference in the future, we heard that access to appropriate medication when it was most needed would be helpful, but that it would be important to understand any possible side effects of any medication provided. Several people told us that more information and acceptance of alternative therapies would support them in managing their ME.

Impact on quality of life

“My quality of life is abysmal, if it wasn't for caring for my son I would have committed suicide some time ago.”

It is very clear from the responses that ME has a huge impact on the quality of life for patients. In almost every contribution, respondents told us about the impact of the condition on many aspects of day to day life as, well as the mental health implications that affect people with the condition.

Many people told us that self-care and personal research were the things that had made the difference to their quality of life rather than support from mainstream services across health and social care. This included changing diet, practising yoga, cognitive behavioural therapy and homeopathic options. Pacing activities to help with energy conservation helped some people get satisfaction in their daily routine, although for others it was not something that helped them.

When asked what would make a difference in the future, we heard about a wide range of factors that would improve quality of life. Many of these related to the information contained in other sections of this report, specifically the provision of specialist services, home visits, much improved knowledge, understanding and person-centred care. Alongside these issues, people also told us that advice and support about access to wheelchair services and coping with the tasks of daily living would be very helpful.

Knowledge about the condition

“I feel the medical profession have little understanding for what ME can do and how much devastation it can bring to your life”

A number of participants highlighted a lack of knowledge about the condition in their interaction with staff across health and social care services. In some cases, people mentioned that there was a lack of belief about the existence of their condition.

Many responses did mention the importance of having an understanding GP to support them in living with their condition. However, most commented that they thought the GP could not provide much help beyond self-care. As noted already, many people referenced prescription medication that was helping with aspects of their care.

“My GP is fantastic. She can't always do much, but that's ok because she is honest about it and respectful. She helps where she can and I appreciate that a lot. I just wish there was more she or anyone could do.”

When asked what would make a difference in the future, we heard about a lot of different things but an improvement in the knowledge and understanding of the condition by clinicians would make the most difference in delivering empathic care for people living with ME. We heard that this could be achieved by the provision of dedicated training for clinicians, as well as the inclusion of ME in the curriculum for students at medical school.

Research

“They need to recognise ME as a genuine illness and undertake research into its wide reaching symptoms and effects both physically, mentally and emotionally”

There was a dominant theme in the responses about the need for research into ME to help with understanding about the condition. Many people asked for the development of national guidelines (based on research) specific to ME that could be used to guide care planning and help with the apparent inconsistencies in the care and support provided for ME patients and their families.

Communication

“Professionals offering the option of short breaks during an appointment or consultation, would be helpful. People with ME have a difficulty processing information and so longer appointments can be a challenge”

People spoke about having difficult conversations with professionals from health and social care in terms of having their symptoms understood and addressed, although there were a few examples where an understanding GP had made a huge difference to their quality of life.

When people were asked what would make a difference in the future, they told us that what was important and at the heart of good communication was a clinician with an empathetic approach who was willing and able to have a shared, open and honest dialogue based on belief and understanding of the condition. This in turn would lead to effective care planning and support.

Some people mentioned that it would be helpful to involve people living with ME and their families in the development of any national guidelines and highlighted at the very least the need to have consultation with people with lived experience of ME included in any developments.

Analysis – Professionals involved in care

4.6 Analysis of the six questions covering which professionals had cared for them in the past, who have made a difference to their support and looking at who would make a difference in future is detailed below.

People told us that they had seen the following groups of clinicians in their journey with ME:

- general practitioner (GP) (most common)
- advance nurse practitioner
- practice nurse (for bloods)
- allied health professionals (physiotherapist, occupational therapist, speech & language therapist and dietitian most common)
- psychologist (often for cognitive behavioural therapy)
- pain clinic
- ME specialist nurse (a number of comments stating that there was only one specialist nurse in Scotland)
- pharmacist
- psychiatrist, and
- other specialities (cardiologist, ear, nose & throat consultant, neurologist, endocrinologist and rheumatologist – mostly during the process of diagnosis to rule out other conditions).

In terms of which clinicians they were currently seeing, most were not seeing anyone for support with managing their ME and were self-managing their condition with the help of family members, friends and informal carers. A number of people had access to their GP and other practice staff but most were not using other services. Some people told us they were paying for private care services such as physiotherapy and acupuncture.

“There is no point in wasting energy explaining things to people who have no concept of how to treat this illness”

Some people living with ME told us they had access to an ME Specialist Nurse and this was an invaluable service for them.

When we asked people who should be involved in their care, many people identified that a specialist nurse or doctor leading on their care needs coupled with the ability to attend regular clinics would be very beneficial. A number of other clinicians with knowledge of ME were also mentioned including counsellors, pain management services, clinicians in mental health and allied health professionals.

However, it was clear that people felt that whoever is involved should have a good understanding of the care needs of people with ME; should provide support as part of a multi-disciplinary team; and that care should be underpinned by the existence of good training and clinical guidelines.

In terms of the questions about support from social care, only a few people had experienced any support being provided in the past and virtually nobody was receiving care from social care at the current time. It was difficult to determine if the high numbers of responses of “none” to the questions about existing support from social care meant that people did not get any support from social care, or they felt what they received was not beneficial to them.

Looking forward, people felt that support from social care services might be beneficial in the following areas:

Needs assessment

An assessment of social care need was felt to be beneficial in trying to determine what support might be provided, although some people recognised that support for care in the home and shopping and other day to day activities might be challenging financially for social care services. People also told us that having a regular review of their needs would also be helpful.

Benefits advice and employment support

Many people told us that access to agencies who could provide advice and support about claiming benefits would be helpful for them, as well as being able to have Occupational Therapists involved in providing support for them and their employer in providing a safe workplace. Others spoke about the need to be able to access an accessible parking permit (blue badge) to help make things easier for them given their mobility issues.

Housing support and adaptations

Some people spoke about the need for more support in accessing advice about suitable housing, particularly for those who described their condition as severe or very severe. Others told us about the importance of having adaptations to their house which would make a difference to their lives such as grab rails, shower rails and shower seats, when they were needed.

Isolation and loneliness

A large number of people highlighted that isolation and loneliness was often a major factor in living with ME and some made suggestions that a befriending service might be something that could help with their situation. However, given the lack of support people reported across health and social care, making the connections necessary to access services such as befriending is beyond many people living with ME. Although many people spoke about the excellent support they get from friends and family, several told us that just having someone outside of their friends and family circle to talk to would be helpful.

“It would be nice knowing you have someone in your corner but we are the forgotten people. We don't have the energy to have a voice.”

Care and support in the home

Many people told us that having access to a service or a person who could help with day to day activities such as washing clothes, cleaning, shopping, cooking etc. would be very helpful in improving their quality of life. Others highlighted that having access to support of this nature would provide respite for family members who often provide the majority of care and support. The family care and support is unpaid and many of these people would not see themselves as carers.

Some people referred to this as ‘home help’ which they said would be particularly supportive for people with severe or very severe symptoms of ME and who described themselves as being ‘housebound’ or ‘bedridden’.

Analysis – care for other conditions

- 4.7 Analysis of the two questions covering how the health and social care you are getting for other conditions could be more responsive to your needs around your ME is noted below.

A large number of people told us that it was very important that those providing health and social care support have a much better understanding about the nature of ME and the unpredictability of the condition to be able to provide appropriate levels of care and support where the person living with ME also has another condition. To help facilitate this, people told us that research was required to help inform training and guidelines to support good holistic care.

As well as an understanding of the condition, people often mentioned that they sometimes felt their ME was dismissed and they needed to be believed when they accessed support, with many citing examples of when they were told “it’s all in your head.”

“The main thing is, as many people with ME will tell you, is for medical professionals not to do what we call the “ME eye roll”, where as soon as you tell them you have ME, their entire attitude changes.”

Many people spoke about the need to listen to the person living with ME empathetically and then treat the whole person rather than treat a set of individual symptoms. It was clear from the responses that people felt that a person centred approach would go some way to helping with this.

“Listen and be aware of M.E. and the effects it may or may not have. Work with each person as an individual”

Several people spoke about the importance of having regular medication reviews and ensuring that healthcare professionals understand the impact that recovery from other treatments can have on ME. Some people mentioned the side effects that medication for conditions such as depression, anxiety, irritable bowel syndrome and arthritis can have and wanted more research to be carried out in this area.

“Better knowledge on the subject and how it can affect illness / treatment / recovery e.g. oncology and radiotherapy very demanding on the body and having ME adds a whole new dimension to that”

A small number of people provided examples of where they were getting good, holistic support when they had treatment for other conditions.

“Plenty crossover of symptoms, but happy with the way my GP handled it”

Accessibility to flexible services was a prominent theme in the responses we received where people talked about the need for home visits, prescription delivery, better use of technology, the location of services (and the proximity of parking) and consideration of the time of day for appointments (not early morning appointments).

People also told us about environmental challenges such as noise and bright light when they had to attend a busy hospital for treatment for conditions other than their ME. Some told us that they had a suitable environment provided when they asked for it.

“When I was hospitalised for my gall bladder I requested a single darkened room and this was accommodated.”

A number of people made specific mention of good empathetic care and communication when they visited their dentist for treatment, whereas others talked about the difficulty of being asked to do exercises or undertake physiotherapy for other conditions because of the effects of their ME.

People also told us that other conditions had gone undiagnosed for longer than necessary because symptoms they had were attributed to their ME rather than being explored as though they didn't have ME.

Section 5: Conclusions and recommendations

This section of the report brings together the main conclusions drawn as a result of the exercise with recommendations included where appropriate. These findings are not ranked in order, they are numbered for ease of reference.

5.1 Better understanding and recognition of the condition

It is clear from the findings that people who have ME believe there is a very limited understanding of the condition in all areas of health and social care across Scotland.

In particular, people told us they felt that GPs had difficulties in making a diagnosis of ME and recognising the symptoms they experienced and further training would be helpful to aid with early diagnosis and care.

Recommendation

Scottish Government to develop clinical guidance for staff to support the diagnosis and treatment of ME. This could be developed with the support from charities and third sector organisations who provide advice and support for people living with ME as well as specialist nurses and clinicians. People living with ME and their families must also be involved.

5.2 Provision of specialised services/clinicians

Many people told us about the lack of specialist care for their condition citing the existence of one NHS board who provided a specialist nurse to provide support.

People who participated highlighted the need to have specialist services with people who clearly understood the condition and the impact it has on their quality of life.

Recommendation

Scottish Government to look at how to increase access to specialist services for people living with ME across Scotland. Digital and other technologies could be explored to enable this to be achieved.

5.3 Advice about access to practical support – coping in the home, wheelchairs, benefits, employment support and blue badges

Many people spoke about the real need to be able to access advice and support for day to day living and activity such as household tasks. Practical support for being able to access benefits as well as information to help employers understand the condition and associated needs was highlighted.

Recommendation

Health and social care services to ensure that people living with ME can access relevant professionals and services to enable them to have their needs met.

5.4 More research and clinical trials

Many people said they believed there was a need for more research into the condition, both in terms of the diagnosis and treatment options.

Recommendation

Scottish Government to encourage and support further research into ME and how people live with the condition, including working with third sector organisations and charities. People with lived experience should be involved in any research.

5.5 Better person centred care planning and holistic care

Many people reported that the care they received was patchy and ad hoc rather than being a joined up care package that could be reviewed and adapted as symptoms worsened or situations changed.

People also told us they felt they were often not believed when they sought care and support for their ME. They felt this often led to care which could have been more empathetic to their needs.

It is also clear from the lived experience people shared with us they feel they are often left to self-care with little or no support from services.

Recommendation

Scottish Government and health and social care services, working with people living with ME, to develop a person-centred holistic approach to the provision of care for people living with ME. This would include input from informal carers.

5.6 Access to accurate and up to date information

A number of people told us there was a lack of information available for both themselves and family members as well as clinicians and social care staff. It should be noted the NHS Inform website contains some information. A link to national good practice guide for practitioners and patients was developed in 2010 and can be found there.

People also highlighted helpful sources of information available on third sector organisations' websites.

Recommendation

Scottish Government should update relevant national publications where appropriate and consider how to improve access to relevant information for both clinicians and those living with ME.

5.7 A more appropriate environment when a visit to a clinical location is needed

People told us it was often challenging for them when they visited clinical settings. This was primarily in terms of the time of appointments, the availability of parking next to buildings and the lighting and noise in those places.

Recommendation

Health and social care services should work with those living with ME to ensure appropriate appointments are given. This should include the exploration of digital and other technologies to provide an appointment for people within their own home.

5.8 Isolation and loneliness

There was a prominent theme in the findings showing that people with ME often experience feelings of isolation and loneliness despite the much valued support they currently receive from family members, friends and informal carers.

Recommendation

Health and social care providers should consider how they ensure appropriate links with services such as mental health and befriending can be provided to those living with ME and their families.

Section 6: Next steps and acknowledgments

- 6.1 Healthcare Improvement Scotland - Community Engagement thanks everyone who took part and shared their lived experience, thoughts, comments and suggestions for the improvement of ME services.
- 6.2 This report has been shared with the Scottish Government and the information gathered through this exercise will be used to help inform an evidence base to support the care and needs of people living with the condition with a view to the development of a national action plan.
- 6.3 Healthcare Improvement Scotland - Community Engagement will liaise with the Scottish Government in order to provide feedback to participants about how the views expressed in this report have been used.
- 6.4 This report will be published on the Healthcare Improvement Scotland - Community Engagement website www.hisengage.scot and we will use the learning and experience of this exercise (including the equalities monitoring information) within our work to inform future methods of Gathering Views.

Appendix

Appendix 1 – The questions used in the Gathering Views exercise.

1. How did you find out about this survey? (Optional)

- Social media (Twitter, Facebook)
- Poster/flyer
- Friend or relative
- Local group
- GP
- Hospital clinic
- Scottish Health Council local office
- Other organisation
- Carers Centre
- Other (please specify)

2. Which NHS Scotland board area do you live in? *

- Ayrshire & Arran
- Borders
- Dumfries & Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow and Clyde
- Highland
- Lanarkshire
- Lothian
- Orkney
- Shetland
- Tayside
- Western Isles
- Unsure
- Prefer not to say

For information

This survey asks for your experiences (e.g. what has worked well, is working well, what would make things better; what professionals have been, are currently or should be involved in your care and support) of both health and social care services separately.

Questions will be asked about your thoughts solely on **healthcare services**, and separately on **social care services**. The final question will also ask about the severity of your condition.

The next 3 questions are asking you about the care and support from the NHS in Scotland. This includes Doctors, Nurses, Dentists, and Opticians, Pharmacies as well as anyone in hospital. It also includes physiotherapists and speech and language therapists.

These people will help with managing more clinical or medical aspects of your care including medicines to help with headaches, sore throats or sickness and dizziness.

3. What health care and support (for ME) has made a difference to the quality of your life?

4. What health care and support (for ME) is making a difference to the quality of your life?

5. What health care and support (for ME) would make a difference to the quality of your life?

The next 3 questions are asking you about care and support from Social Services in Scotland. This includes support from a social worker, a care worker or a personal assistant who may come into your home to help around bed times, meal times or to assist with mobility. There may also be people from social care who help with advice about benefits, employment or housing.

6. What social care and support (for ME) has made a difference to your quality of life?

7. What social care and support (for ME) is making a difference to your quality of life?

8. What social care and support (for ME) would make a difference to your quality of life?

The next 3 questions are asking you about the care and support from the NHS in Scotland. This includes Doctors, Nurses, Dentists, and Opticians, Pharmacies as well as anyone in hospital. It also includes physiotherapists and speech and language therapists. These people will help with managing more clinical or medical aspects of your care including medicines to help with headaches, sore throats or sickness and dizziness.

9. What healthcare professionals have been involved previously in your care and support for ME?

10. What healthcare professionals are currently involved in your care and support for ME?

11. What healthcare professionals should be involved in your care and support for ME?

The next 3 questions are asking you about care and support from Social Services in Scotland. This includes support from a social worker, a care worker or a personal assistant who may come into your home to help around bed times, meal times or to assist with mobility. There may also be people from social care who help with advice about benefits, employment or housing.

12. What social care professionals have been involved previously in your care and support for ME?

13. What social care professionals are currently involved in your care and support for ME?

14. What social care professionals should be involved in your care and support for ME?

The next 2 questions are asking how health staff from the NHS (question 15) and staff from social care (question 16) who may be supporting you for reasons other than to help with your ME could do more (or do better) by taking account of your ME.

For example, they may be giving you medicine or treatment for something such as back pain or stomach pain that might make your ME worse. If this is familiar to you, what could they do differently to care for you?

15. How can healthcare and support provided to you for other reasons (another condition or ailment unrelated to ME) be more responsive to your needs and wishes around ME

16. How can social care and support provided to you for other reasons (another condition or ailment unrelated to ME) be more responsive to your needs and wishes around ME?

17. Your level of severity of ME

People with ME have different levels of severity of the condition. The question below is asking how severe your ME is. We appreciate that people's ME condition can fluctuate and people may be at a different stage day to day. However, we are asking you to answer this question where you see yourself to be for the majority of the time. Please check the box which best describes your condition most often:

- Mild** – Are mobile and can care for themselves and can do light domestic tasks with difficulty. The majority will still be working. However, in order to remain in work, they will have stopped all leisure and social pursuits, often taking days off. Most will use the weekend to rest in order to cope with the week.
- Moderate** – Have reduced mobility and are restricted in all activities of daily living, often having peaks and troughs of ability, dependent on the degree of symptoms. They have usually stopped work and require rest periods, often sleeping in the afternoon for one or two hours. Sleep quality at night is generally poor and disturbed.
- Severe** – normally able to carry out minimal daily tasks at best (such as face washing, cleaning teeth); cognitive difficulties are likely to be severe at times; mobility poor; mostly unable to leave the house except on rare occasions and may require support of a powered wheelchair and/or carer to do so; prone to severe and prolonged after-effects from effort.
- Very severe** – mostly unable or barely able to mobilise or carry out daily tasks; in bed for the majority of the time; sensitivity to noise, light and/or movement may be acute; cognitive difficulties can be severe with low tolerance for mental effort and adverse after effects.
- Unsure**

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