Dumfries and Galloway ME and Fibromyalgia Network:

Consultation Key Findings
Final Report

April 2022

sleeping GIANTS

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Dumfries & Galloway
ME and Fibromyalgia Network
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Executive Summary

Introduction

- It is estimated that around 20,000 people in Scotland have the long term condition Myalgic Encephalomyelitis (ME), also called Chronic Fatigue Syndrome (CFS), and 1 in 20 may be affected by fibromyalgia.[1] The Dumfries & Galloway ME and Fibromyalgia Network works across the region to support people with these conditions. In recognition that many of those with long COVID experience symptoms similar to ME/CFS, the Network has broadened its reach to include people with long COVID.
- A grant from the Health and Social Care Alliance has been used to conduct a consultation exercise with local stakeholders and people with the conditions. The consultation sought to establish the need for and feasibility of three project ideas. The first two of which would aim to develop experts in the condition by:

    1. The Network working with NHS Dumfries and Galloway to identify or recruit a clinical lead and champion who would then provide specialist support to NHS staff and raise awareness.
    2. The development of an expert patient mentoring scheme for those who are newly diagnosed, with the expert patients offering peer mentoring support.

  The third idea would:

    3. Expand services for people with ME/CFS and fibromyalgia through changes that include the development of a volunteer befriending project for the most isolated individuals.

- The views of partner agencies were collected through an online survey (27 respondents), interviews and focus groups.
- 53 people with lived experience completed an online survey and additional views were captured through a focus group and Facebook discussion.

Policy Context

- Key national and local policy documents were reviewed to provide an overview of the context in which any new projects would be developed.
- National guidelines for the diagnosis and management of ME/CFS, long COVID and chronic pain (which includes fibromyalgia) have been published by the National Institute for Health and Social Care Excellence (NICE). These guidelines

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[1] www.nhsinform.scot/illnesses-and-conditions

recommend a person-centred approach that reflects an individual’s needs and the fluctuating nature of the conditions.

- A national self management strategy for long term conditions (Gaun Yersel!) was published by the Alliance and Scottish Government in 2008 and sets out a series of principles to empower people to be better informed, prepared and supported. Importantly, the strategy emphasises that self management must be a partnership between people with a condition and health and social care agencies.
- Within Dumfries and Galloway, a new Strategic Commissioning Plan for 2022-2025 is nearing completion. The plan sets out commissioning intentions for the region, which include supporting people to live independently and well in their home, and enabling and supporting people and communities to self manage and be more resilient. A new model of care and a wider Sustainability and Modernisation programme, which sees the introduction of new, multidisciplinary Home Teams, inform and underpin much of the activities planned to deliver these intentions.

Key Findings: Perceptions and Experiences of Support

- The principles of self management set out within Gaun Yersel! were used to inform questions in both the partner agency and lived experience surveys. Half (14, 51.9%) of partner agency survey respondents felt that their service effectively supported people with ME/CFS, fibromyalgia or long COVID and the majority felt that they supported the principles of self management.
- Responses to the lived experience survey were more mixed: with the exception of ‘I am the leading partner in the management of my health’ (31, 62% always experienced this), only a small minority of respondents reported always experiencing the principles of self management.
- A family member was the most commonly accessed source of support at every stage of the condition (from pre-diagnosis to flare ups and transitions) and also one of the most helpful types of support. GP surgeries and online resources were also commonly accessed, but GP surgeries had relatively lower helpfulness ratings.
- Over half of lived experience survey respondents (27, 54.0%) felt unsupported by services in the management of their condition and almost all (45, 95.7%) felt that there was a stigma surrounding people with ME/CFS, fibromyalgia and/or long COVID.
- A range of barriers to providing support were reported by partner agency survey respondents and included a lack of resources, lack of dedicated or specialist/practitioners and a lack of awareness and understanding.

- Health and social care interviewees and focus group participants expressed their frustration at not being able to better support people because of the lack of treatment options or conflicted views on management.
- Amongst people with lived experience, confidence (20, 37.7% of survey respondents), disability (16, 30.2%) and mental health (15, 28.3%) were the most commonly reported factors that had made it difficult to access services.

Key Findings: Project Ideas

- Perceptions of all three project ideas being considered by the Network were explored in the surveys, the interviews, focus groups and Facebook discussion.
- Support for all three project ideas (the creation of a clinical lead, expert patient mentors and a befriending service) was high.
- Partner agency survey respondents were asked if they thought each idea would be useful: 22 said a befriending service would be and 21 and 20 (respectively) said expert patient mentors and a clinical lead would be useful.
- The clinical lead was perceived as the most helpful by lived experience survey respondents (43, 93.5%), followed by expert patient mentors (37, 78.7%) and a befriending service (33, 70.2%).
- The clinical lead was also the service people with lived experience were most likely to use.
- Health and social care interviewees and focus group participants identified a number of challenges associated with the creation of a clinical lead role, including finding a service with the capacity to take on the role, ensuring that it is appropriately embedded and accountable and that it would be difficult to achieve in the absence of a co-ordinated approach.
- Some of these participants suggested that a GP could take on the role but acute care, the new Home Teams, third sector organisations, public health improvement teams and community pharmacists were also mentioned. One participant questioned if a team of leads would be preferable – it could enable a more multi-disciplinary approach to be adopted.
- The importance of ensuring that expert patients were appropriately trained and supported to ensure that accurate information was provided was emphasised by all participant groups.

Conclusions

- The Network’s future activity will be shaped by both the national and local policy context, including NICE guidelines and the Dumfries and Galloway Strategic Commissioning Plan for 2022-25. These policies provide a framework upon which any future projects could be developed.
- More people receive support from a family member than any other type of support at every stage of their condition, which highlights the importance of

ensuing that family members are appropriately supported to enable people to live well.

- GP surgeries were also commonly accessed for support but received lower helpfulness ratings than all but one of the other forms of support explored in the survey and the perceived helpfulness of hospital services was lower still. These findings suggest that a targeted approach to any awareness raising and education activities may improve experiences of support.
- Experiences of the principles of self management were mixed with few being consistently experienced by people with lived experience. In contrast, partner agencies perceived that they or their service regularly supported these principles.
- The lack of treatment options can be disempowering for health and social care professionals and participants expressed frustration at not being able to offer more support to people with the conditions.
- People with lived experience wanted more support from health specialists and clearer information to help them better self manage their condition.
- A large majority of people completing the lived experience survey felt that there was a stigma surrounding the conditions and half felt unsupported in the management of their condition. Together, these findings indicate that people with the conditions have poor experiences of care and further action is needed to bring about improvements.
- More people received support from the Network for day-to-day issues and flare-ups than at any other stage of their conditions. Although the relatively high helpfulness ratings at every stage suggests that its support is valued, the highest helpfulness ratings were received for flare ups and other difficult times. In addition, because they heard only negative experiences, a small number of lived experience survey respondents felt that the Network did not provide the support needed.
- Confidence made it difficult for people with the conditions to access services, which suggests that people need help to navigate the different sources of support available to them.
- Support for all three project ideas was high but participants perceived their implementation to be challenging. For example, identifying a service that could take on the clinical lead or champion role was a potential issue and expert patient mentors would need to be appropriately trained and supported.

Recommendations:

1. The Network should consider both the emerging national and local policy context in the development of their future projects.
2. Given the importance of their support, the Network might like to consider how best to engage with family and friends or signpost them to appropriate

regional sources of support. This could develop their knowledge and understanding of the conditions.

3. Change is needed in the care and support available to people with the conditions. Although such change cannot be brought about by the Network, it may wish to consider how it can continue to develop its partnerships with key regional stakeholders and organisations to raise awareness of what is needed. The potential role of a new clinical lead or champion in this process should also be considered.
4. Raising awareness and understanding of the conditions amongst professionals should be a priority of any change initiative. Again, depending on the scope of the role, a clinical lead or champion could play a valuable role in supporting professionals to follow the appropriate guidelines and recommendations.
5. The Network may like to consider developing a communications strategy to help maximise the reach and impact of any awareness raising activities. The findings from this consultation highlight the support that was perceived to be most and least helpful and could therefore be used to inform the development of any such strategy.
6. The Network should consider where there are existing resources and whether there is a need to develop their own educational materials in any such communications strategy.
7. The Network should consider how it can best engage with and support people at every stage of their condition and provide a space for positive dialogue.
8. The Network should identify how it can best work with its members and wider stakeholders to increase the confidence of people with a condition to access and navigate health and social care. Increasing knowledge of what is available within Dumfries and Galloway and how to access it could help people with the conditions to navigate services.
9. The potential role of expert patient mentors could be explored as part of this work. More broadly, appropriately trained and supported peer mentors could help people with lived experience to better understand their condition and recommended management approaches.
10. The Network should consider further consultation activity to develop each of the project ideas. The project plans developed through this process could then be used in a second stage of consultation to establish the likely reach and uptake.

Contents

1. Introduction

1.1. Background

It is estimated that around 20,000 people in Scotland have the long term condition Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), and that 1 in 20 may be affected by fibromyalgia.[2] The charity Dumfries & Galloway ME and Fibromyalgia Network (the Network) is working to support people in the region with these conditions. In recognition that many of those with long COVID experience symptoms similar to ME/CFS, the Network also offers support to them. Figures from the Office for National Statistics estimate that 99,000 people in Scotland have self-reported long COVID.[3]

Using grant funding from the Health and Social Care Alliance, the Network commissioned Sleeping Giants to conduct a consultation exercise with local stakeholders and people with one or more of the conditions. The consultation sought to establish the need for and feasibility of three project ideas. The first two of which would aim to develop experts in the condition by:

1. The Network working with NHS Dumfries and Galloway to identify or recruit a clinical lead and champion who would then provide specialist support to NHS staff and raise awareness.
2. The development of an expert patient mentoring scheme for those who are newly diagnosed, with the expert patients offering peer mentoring support.

The third idea would:

3. Expand services for people with ME/CFS and fibromyalgia through changes that include the development of a volunteer befriending project for the most isolated individuals (emotionally, physically and socially).

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[2] www.nhsinform.scot/illnesses-and-conditions

[3] Based on data from the UK Coronavirus (COVID-19) infection survey data 2 December 2021. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics (ons.gov.uk) Accessed on 20 December 2021.

1.2. Methods

Health and social care stakeholders and people with the conditions were invited to share their views in variety of ways:

Surveys:

- 27 people from partner agencies completed an online survey, 15 of whom worked in the NHS, 5 in the local authority, 3 for a charity/third sector organisation and 3 for another type of agency
- 53 people with a condition completed a separate online survey (referred to as 'lived experience online survey' hereafter), 32 of whom had ME/CFS, 28 fibromyalgia and 4 long COVID. Most (38) were female and more than half were aged 45 years

Interviews:

- 11 local stakeholders from health and social care services took part in an interview

Focus Groups:

- 4 focus groups were held with partner agencies
- 1 focus group was held with people with ME/CFS, FM or long COVID

Network Facebook Page:

- People with ME/CFS, FM or long COVID fed back their views via questions asked on a private Facebook page

1.3. About this Report

This report is structured as follows:

- Section 2 provides an overview of the local and national policy context;
- Section 3 summarises the key findings in relation to perceptions and experiences of support;
- Section 4 discusses perceptions of the 3 project ideas explored in the consultation; and
- Section 5 presents the conclusions and recommendations emerging from the findings.

2. Policy Context

2.1. Introduction

The Network's own research identified that its members experienced difficulties obtaining a timely diagnosis and clinical support; the potential projects explored in this consultation exercise aim to improve experiences of these. Should these project ideas be progressed, they will be implemented amidst the guidelines and policies set out by national and regional health and social care agencies; these guidelines and policies are summarised here. Please note, this summary is not intended to be a comprehensive review of all relevant policies and documents (which would be beyond the scope of the consultation), rather it aims to highlight key points of relevance to the project ideas.

2.2. National Guidelines

National guidance and advice to improve health and social care is provided by the UK government sponsored National Institute for Health and Care Excellence (NICE). NICE have published guidelines for the diagnosis and management of ME/CFS, long COVID and Chronic Pain (primary and secondary), which includes fibromyalgia.

ME/CFS

An updated ME/CFS guideline for diagnosis and management was published in October 2021. Evidence gathered during the preparation of the guideline showed that there was a lack of belief in ME/CFS as a real condition and therefore:

> ***"People with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals and teachers) who do not understand their illness."*** (p3)

The guideline's recommended principles of care therefore include having an awareness of the condition's complexity, fluctuating impact and that people with ME/CFS may lack trust in professionals because of their previous experiences. The guideline goes on to recommend that health and social care providers should receive training as appropriate to their role about what ME/CFS is, its diagnosis and management and experiences of it.

Other recommendations include that a diagnosis should be made where symptoms are not explained by another condition and have persisted for three months, after which adults should be referred to a specialist team for confirmation. Following an assessment by a specialist team, a personalised care and support plan should be developed and agreed with the person with ME/CFS. Recommendations for access to care and support then emphasise the need to adapt and deliver services as appropriate to each individual (for example, by adapting the time and length of appointments or offering remote appointments and where support is needed at home, carry out a social care assessment).

Evidence on interventions was inconclusive and the recommended management strategies (e.g. energy management, physical activity and exercise, diet, cognitive behavioural therapy) differ depending on individual needs and circumstances. For example, exercise was not to be recommended unless it was overseen by a specialist team and people want/ are ready to incorporate it into their management approach. More broadly, a person-centred approach to care that acknowledges the reality of living with the condition was recommended (p5).

The Scottish Government published the Scottish Good Practice Statement on Chronic Fatigue Syndrome/Myalgic Encephaloyelitis (ME-CFS) in 2010 and have made a commitment to updating it in light of the revised NICE guideline published in 2021. The current statement aims to support clinicians in the diagnosis and management of people with ME/CFS and resonates with the NICE guideline in that it states that interventions should be tailored to the needs and circumstances of individuals (p10). More broadly, the key guiding principles of the care pathway are defined as:

- Work in partnership with the patient; and
- Mutually agree all treatments (p20).

Chronic Pain

NICE published its Chronic Pain guideline in April 2021 and defined chronic pain as a pain that lasts for three months that is either primary or secondary to an underlying condition (p5). Fibromyalgia is cited as one example of chronic primary pain. As with ME/CFS, the guideline recommends the adoption of a person-centred approach to assessment and management. Following a diagnosis, a care and support plan should be discussed with the person with chronic pain to identify what is important to them. Management approaches could include exercise and physical activity, psychological therapies, acupuncture and pharmacological interventions depending on individual needs and circumstances.

Long COVID

The ‘COVID-19 rapid guideline: managing the long-term effects of COVID-19’ was first published by NICE, Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners in December 2020 and last updated in November 2021. In addressing issues of definition, it was recommended that where symptoms continue for more than 12 weeks after infection, and are not explained by another condition, a diagnosis of Post-COVID-19 syndrome could be made (long COVID). In reviewing the evidence on symptoms and prevalence, NICE concluded that although the reported symptoms varied, fatigue and shortness of breath are consistently cited. Providing information after acute COVID-19 on what to expect and when to seek medical advice were recommended to reduce anxiety on recovery from the acute infection.

> ***"People with lived experience highlighted that one of the most important issues around the long-term effects of COVID-19 is the uncertainty around what to expect when recovering from acute COVID-19. This can lead to people experiencing fear and anxiety because they do not know what to expect or who to contact for support. This fear and anxiety can be intensified by patients' experiences of having their symptoms dismissed when seeking help. Determining the main signs and symptoms of post-COVID-19 syndrome will help address these concerns."*** (p47)

As with ME/CFS and Chronic Pain, the use of a person-centred approach to assessment and care was recommended and professionals were to be aware of fluctuating symptoms. Furthermore, no one set of investigations and test were identified as suitable for everyone because of the wide range of reported symptoms. Following an assessment, it was recommended that advice on self management should be given and care referrals made where appropriate to clinical need and preferences. A personalised rehabilitation and management plan can then be made.

2.3. Self Management

A national self management strategy for long term conditions was published in 2008 by the Long Term Conditions Alliance Scotland and Scottish Government. The Long Term Conditions Alliance changed its name to the Health and Social Care Alliance Scotland in 2012 and a grant from the Alliance has funded this consultation exercise. Although published over a decade ago, the definitions and principles presented in the strategy remain relevant today. For example, the NICE guidelines recommends the adoption of a person-centred approach to ME/CFS and the strategy states that enabling people to live with and manage their conditions is central to achieving this way of working. The strategy defines self management as "***the process each person develops to manage their conditions***." (p11). However, self management can only be achieved if the person works in partnership with health and social care providers:

> ***"People need to be realistic about their condition and any limitations it may place on them, as well as how their life choices impact upon it. They also need to be aware of the positive steps they can take to manage their condition and expand their life choices. This is why partnership working with the individual is central to the self management agenda. Where people can access timely and appropriate information and support they will be more able to make well informed decisions about their life."*** (p52)

The strategy goes on to define five principles of self management that should be used to guide and support work; these are shown in Figure 1.

Figure 1: Principles of Self Management

"Be accountable to me and value my experience"

Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes.

"I am the leading partner in management of my health"

I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care.

"I am a whole person and this is for my whole life"

My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing.

"Self management is not a replacement for services. Gaun yersel doesn't mean going it alone"

Self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters.

"Clear information helps me make decisions that are right for me"

Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions.

Source: 'Gaun Yersel!' (p70)

More recently, the Alliance's website[4] set out what self management should mean for people with a long term condition:

- Better informed about their condition(s);
- Better prepared for everyday challenges; and,
- Better supported when they need it.

Because the consultation exercise is funded by the Alliance, these principles were used to inform the development of the surveys.

2.4. Local Policy

Within Dumfries and Galloway, the Integration Joint Board (IJB) have delegated responsibility for planning and delivering health and social care. The IJB are currently developing the Strategic Commissioning Plan (SCP) 2022 -2025, which sets out the region's strategic commissioning intentions and their tactical priorities for the

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[4] About Self Management - Self Management and Co-Production Hub (alliance-scotland.org.uk)

provision of care and support. Its eight strategic commissioning intentions are shown in Figure 2 and highlight the potential significance of the Plan to Network members.

Figure 2: Dumfries and Galloway Strategic Commissioning Plans Commissioning Intentions

- People are supported to live independently and well in their home
- Health and social care inequalities are significantly reduced including addressing barriers to access
- Safe, sustainable and effective care and support that improve people's chosen outcomes and lived experience
- People are supported to avoid crisis
- Health and social care and support is delivered within the financial budget available to the IJB
- National, regional and local priorities continue to be delivered alongside managing identified risks and challenges
- People and communities are enabled and supported to self manage and be more resilient
- People who deliver health and social care and support, including carers and volunteers, are valued and fully supported to maintain their wellbeing and developed to achieve their potential

Source: Dumfries and Galloway Draft Strategic Commissioning Plan 2022-2025 (P6)

Key actions proposed to achieve these priorities include a new model of community care and the development of new strategies and plans to support the development and delivery of new models of care. More broadly, the plan sets out a commitment to supporting the region’s Sustainability and Modernisation (SAM) programme. A key component of the SAM programme is the introduction of new Home Teams and 8 Teams are being set up across Dumfries and Galloway. The Home Teams aim to bring together different health and social care organisations so that people can stay as independent as possible in their own home and multi-agency discussions of patients’ needs take place through daily huddle meetings. These multi-disciplinary teams will link in with GP practices to provide person-centred care for people with the most complex needs at home and are therefore key to the new model of community care. Alongside this, a Single Access Point has been introduced which will provide a single point of contact for NHS and care services across the region. Importantly, the plan highlights eliminating a budget deficit as a key challenge for its delivery.

3. Key Findings – Perceptions and Experiences of Support

Summary

- Half (14, 51.9%) of partner agency survey respondents felt that their service effectively supported people with ME/CFS, fibromyalgia or long COVID and the majority felt that they supported the principles of self management.
- The lived experience survey asked how often people experienced the principles of self management and the responses were more mixed. With the exception of 'I am the leading partner in the management of my health' (31, 62.0% always experienced this), only a small minority of respondents reported that they always experienced the principles of self management.
- A family member was the most commonly accessed source of support at every stage of the condition (from pre-diagnosis to flare ups and transitions) and also one of the most helpful types of support. GP surgeries and online resources were also commonly accessed, but GP surgeries had relatively lower helpfulness ratings.
- Over half of lived experience survey respondents (27, 54.0%) felt unsupported by services in the management of their condition and almost all (45, 95.7%) felt that there was a stigma surrounding people with ME/CFS, fibromyalgia and/or long COVID.
- A range of barriers to providing support were reported by partner agency survey respondents and included a lack of resources, lack of dedicated or specialist/practitioners and a lack of awareness and understanding.
- Health and social care interviewees and focus group participants expressed their frustration at not being able to better support people because of the lack of treatment options or conflicted views on management.
- Amongst people with lived experience, confidence (20, 37.7% of survey respondents), disability (16, 30.2%) and mental health (15, 28.3%) were the most commonly reported factors that had made it difficult to access services.

3.1. Introduction

The consultation included two surveys (one for people with lived experience and the other for partner agencies) and interviews and focus groups with health and social care professionals. Perceptions of the support available to people with ME/CFS, fibromyalgia and long COVID were explored through these data collection activities and the key findings emerging from them are summarised in this section.

3.2. Awareness of The Network

The majority of partner agency respondents had heard of the Network before they completed the survey (59.3%, 16 compared to 37.0% (10) who had not[5]). It is of course possible that those respondents who were already familiar with the Network were more likely to complete the survey and awareness across health and social care services could therefore be lower than reported here. Indeed, although several of the health and social care interviewees were aware of the Network, awareness amongst focus group participants was more mixed. For example, a clinician felt that levels of awareness amongst GPs were low and several emphasised that the Network was one of many groups that they could signpost people to.

3.3. Providing Support

As described in Section 2.3, the principles of self management set out within the Gaun Yerself! national strategy informed the development of the survey questions. In the partner agency survey, this meant that respondents were asked if they felt that their service effectively supported people with ME/CFS, fibromyalgia and/or long COVID to self manage their conditions and then how often they or their service supported the principles of self management (see Figure 1 for a description of the principles). Half of partner agency respondents (15, 55.6%) felt that they were effectively supporting people to self manage and a further 10 (37.0%) said they neither agreed nor disagreed with this statement or that they were unsure, and 2 (7.4%) disagreed.

Overall, responses to the question set about the principles of self management were positive with the majority indicating that each of the principles were frequently supported (they were always, sometimes or often supported). For example:

- Two thirds (18, 66.7) said that their service always supported individuals' rights to make decisions, 3 (11.1%) stated that they did so often, 2 (7.4%) sometimes and only 1 (3.7%) seldom did so; and

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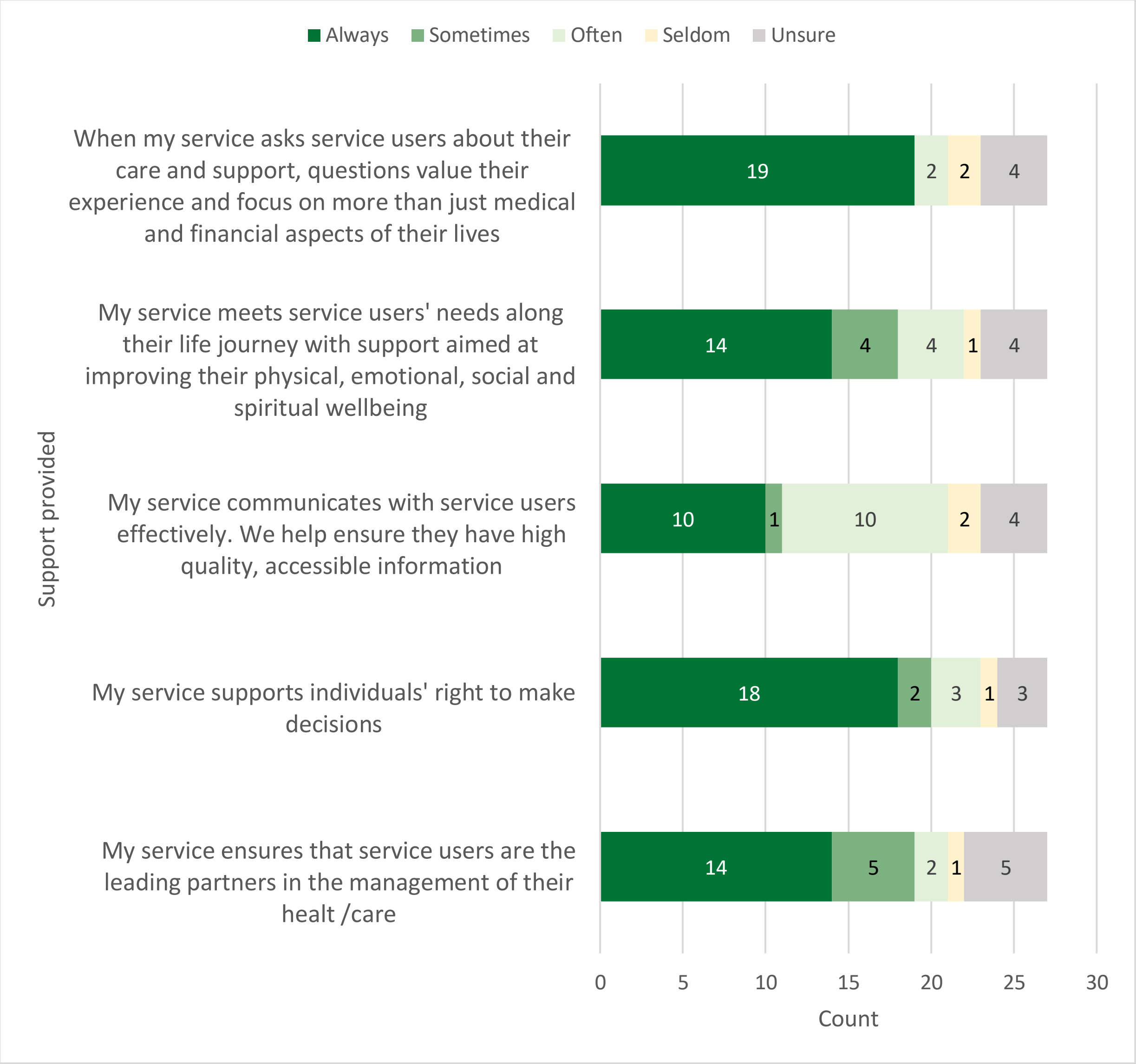
[5] One respondent was unsure if they had heard of the Network before completing the survey

- Over half (14, 51.9%) said that they always ensured service users led the management of their health/care, 2 (7.4%) did so often, 5 (18.5%) sometimes and 1 (3.7%) seldomly did this.

Chart 1: Supporting Self Management[6]



Source: Partner Agency Online Survey

16 out of the 27 partner agency respondents gave an example of how they supported self management and in doing so, provided additional insight into how they interpret self management. 2 respondents specifically mentioned adopting a person-centred approach and described how they would work with people with a condition to identify their preferences and goals (2 other respondents also described working in this way but did not explicitly refer to person-centred working). 5

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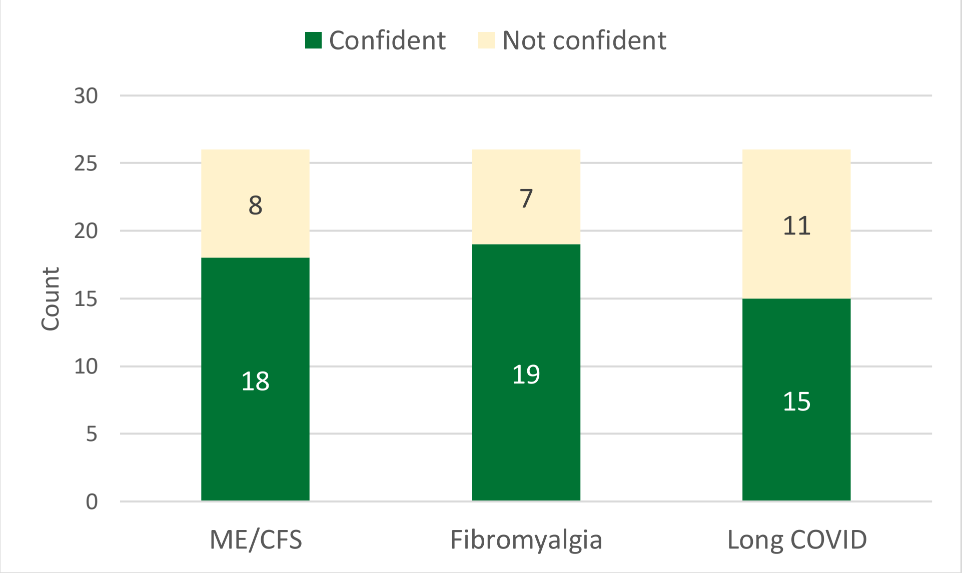
[6] The chart presents frequencies (and not percentages) because of the relatively small number of partner agency respondents

respondents described how they would signpost or refer people to websites or support groups for further information. Others described their own service or the flexibility it offered through, for example offering video/phone or flexible home visit appointments.

The survey asked partner agencies to rate their own personal level of confidence in supporting people with ME/CFS, fibromyalgia and long COVID. The majority of all respondents were confident (either extremely, moderately or somewhat confident) in supporting people with all conditions, but as Chart 2 shows, confidence was lowest for long COVID.

Chart 2: Confidence in Supporting People with ME/CFS, Fibromyalgia and long COVID



Source: Partner Agency Online Survey

3.4. Barriers to Providing Support

A range of barriers to providing effective support for self management were cited by partner agency survey respondents and can be broadly categorised as a lack of:

- Resources (time, money or staff);
- Dedicated or specialist service/ practitioner;
- Awareness and understanding within health and social care; and
- Service users presenting for help, which in turn was attributed to their previous experiences, the ability to attend appointments or lack of access to IT (for online participation).

Health and social care interviewees and focus group participants also discussed barriers to providing support. Lack of awareness emerged as a theme and a small number felt that the conditions were still perceived as a ‘lazy illness’ by some. But several highlighted their own frustrations in caring for people with the conditions; for these participants, the limited treatment or intervention options available meant people with ME/CFS, fibromyalgia or long COVID were what they’d term ‘heart sink’ patients:

> ***“There’s very little that we feel we have to offer in terms of treatment… we quite often don’t really know what to do, that’s not good for the individual with the problem and it’s somewhat disempowering for us as a service provider.”***
> Focus group participant

As an interviewee described, this meant that there was some anxiety amongst clinicians that people would feel that they were not been taken seriously. Another suggested that the conflicted views on management had led some GPs to overprescribe without improving quality of life.

More generally, the lack of a co-ordinated approach was perceived by an interviewee to have created difficulties: *“**It’s never really sat anywhere**”* and a focus group participant (who worked in secondary care) described how the absence of regular reviews meant that they saw people when their condition was particularly difficult to manage and were therefore less able to adopt a proactive approach. Other interviewees highlighted the inequitable access to services across the region or the gaps left by personnel changes.

In one of the focus groups, the principles of realistic medicine were identified as a way to de-medicalise management. Realistic medicine recognises that a one size fits all approach is not the most effective and that medicine does not just include doctors but all healthcare professionals (e.g. nurses, pharmacy, physiotherapists). [7] For these participants, this way of working would facilitate referrals to allied health, community and peer-to-peer support.

Amongst partner agency survey respondents, providing training and/or information was the most commonly identified action to help agencies improve how they support people to self manage. Several respondents suggested strengthening their links with the Network as a way to achieve this. Others suggested that a dedicated practitioner and more staffing were needed to enable support to be improved.

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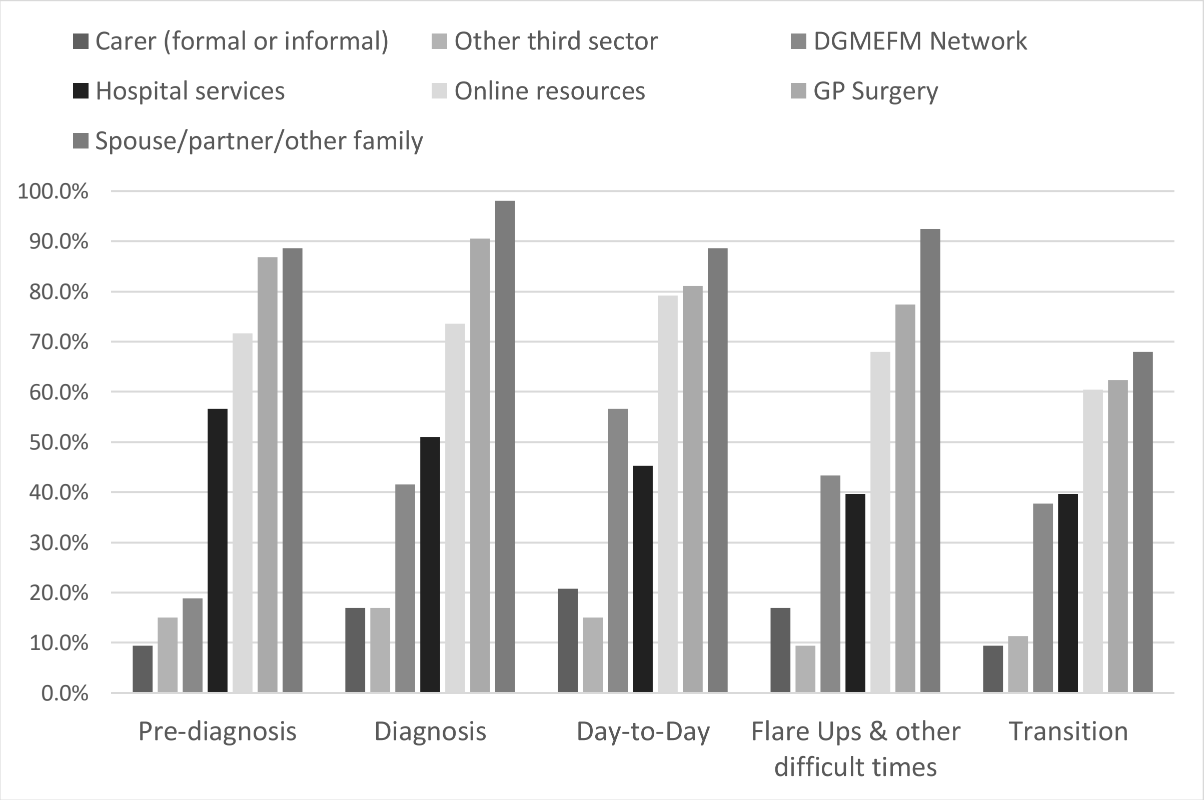
[7] Realistic Medicine Scotland | NHS inform

3.5. Experiences of Support

The lived experience survey asked about the provision of support at different stages of the conditions from pre-diagnosis to day-to-day and transition periods. Chart 3 summarises the responses to this question set and shows that support from a spouse, partner or other family member was the most commonly reported at every stage. For example, 47 (88.7%) of respondents stated they were supported by family before their diagnosis and 52 (98.1%) received this support at the time of their diagnosis. GP surgeries and online resources were also commonly reported at each stage. In contrast, carers (either formal or informal) and third sector organisations (other than the Network) were the least commonly used type of support.

Chart 3: Type of Support Received at Different Stages of Condition



Source: Lived Experience Online Survey
Base: All respondents (n=53)

Chart 3 also provides insight into how sources of support differ through a person's condition; for example, and as might be expected, more people were supported by their GP surgery before and at the time of their diagnosis than at other stage. In contrast, support from the Network was most common for day-to-day issues (30, 56.6%).

People with lived experience were also asked to rate the helpfulness of the support they had received (on a scale from very helpful to very unhelpful) and the proportion who provided a helpful rating[8] is shown in Chart 4 below. Some caution should be used when interpreting the percentage figures in this chart, particularly where only a small number had received that type of support (e.g. carer and other third sector organisations). Despite this, Chart 4 shows which types of support were most helpful across different stages of the conditions. Key points to note are:

- Hospital services received relatively lower helpfulness ratings compared to other forms of support at every stage. Hospital services were perceived to be helpful by 33.3% of respondents at all stages, with the exception of flare-ups and other difficult times where it dipped to 23.8% (5).
- The perceived helpfulness of GP surgeries was also relatively lower than other forms of support; 20 (43.5%) of respondents rated it as helpful before their diagnosis and this increased to 25 (52.1%) at the time of diagnosis.
- The perceived helpfulness of family members was relatively high compared to other forms of support and ranged from 66.0% to 95.7% of those who had received it. It was perceived as most helpful during flare ups, at other difficult times and day-to-day support;
- The Network also received a relatively high proportion of helpful ratings. For example, 16 (72.7%) of those supported by the Network at the time of diagnosis rated it as helpful and this increased to 25 (83.3%) for day-to-day living with the condition and 21 (91.3%) for flare ups and other difficult times.

The survey also asked how often people experienced the five principles of self management; as shown in Chart 5, their responses contrasted with partner agency perceptions of how these principles were being supported (see Chart 1, Section 3.3). ‘I am the leading partner in the management of my health’ was the only principle always experienced by the majority of respondents (31, 62.0%). The frequency with which the other principles were experienced was more varied but almost three quarters (36, 72.0%) seldom or never experienced ‘when I’m asked about my care and support, questions value my experience and focus on more than just medical and financial aspects of my life.’

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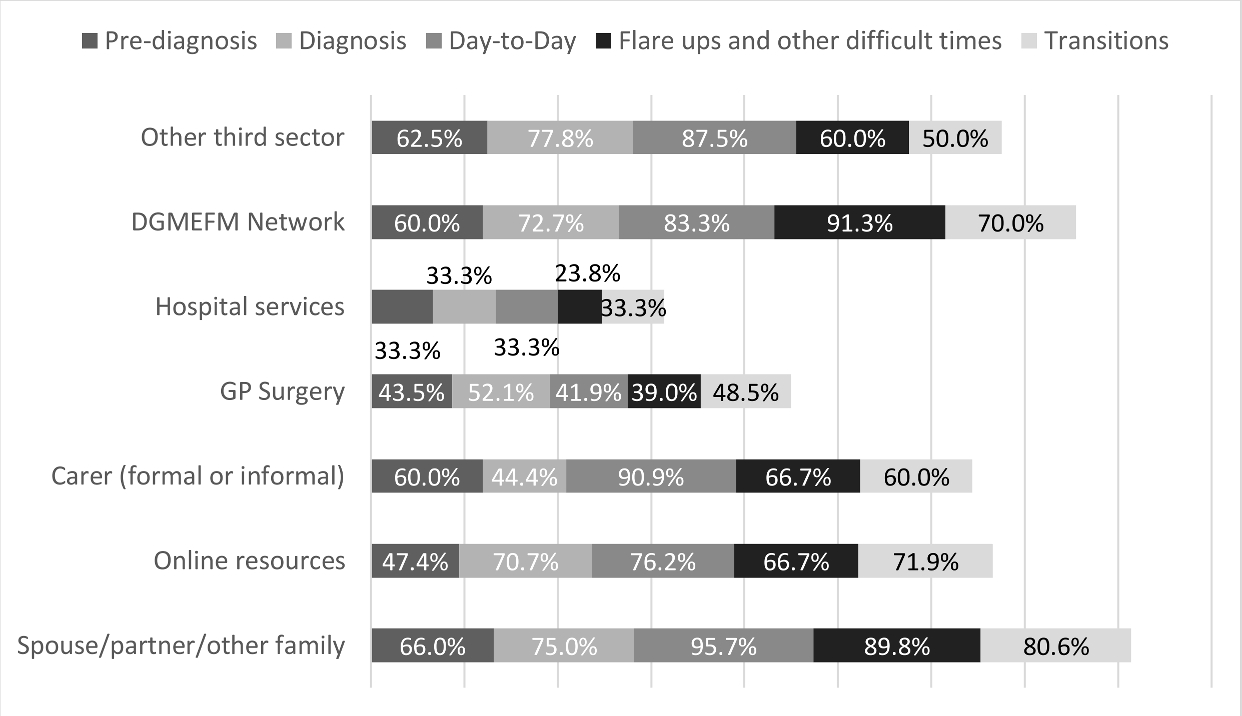
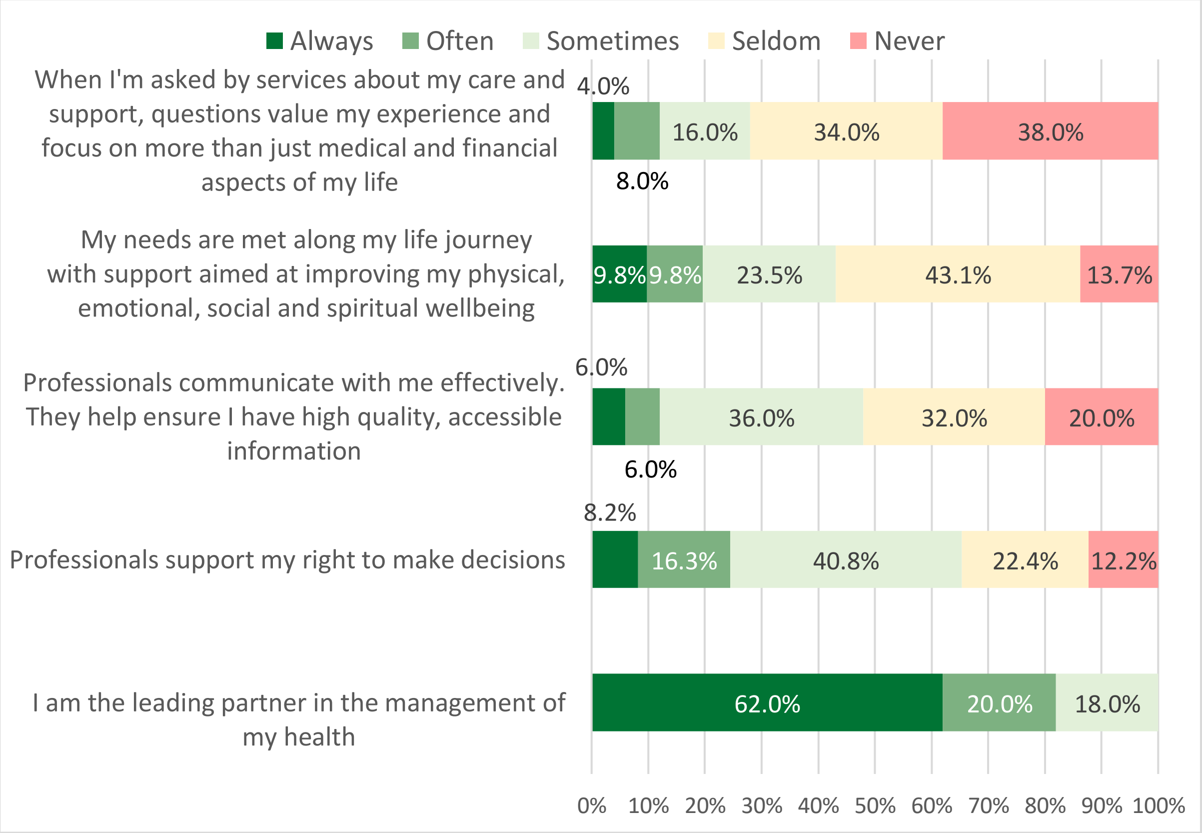
[8] This includes all respondents who provided a very helpful, somewhat helpful and a little helpful rating.

Chart 4: Proportion of People with Conditions Rating Support as 'Helpful'



Source: Lived Experience Online Survey
Base: All respondents accessing each type of care (n=various)

Chart 5: Frequency with which Principles of Self Management are Experienced



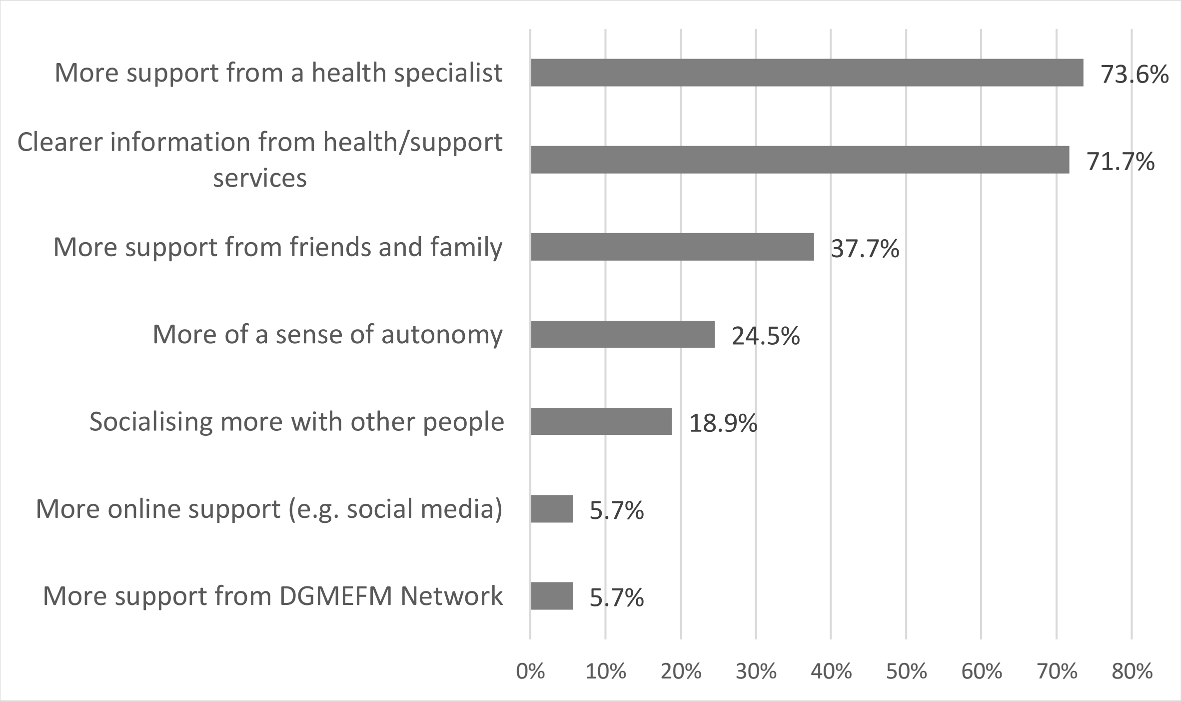
Source: Lived Experience Online Survey
Base: All respondents answering the question (n=50, 51, 50, 49, 50 respectively)

Perhaps reflecting this, over half of respondents (27, 54.0%) felt unsupported by services in the management of their condition and almost all (45, 95.7%) felt that there was a stigma surrounding people with ME/CFS, fibromyalgia and/or long COVID. Additional comments provided in the survey described a lack of understanding around hidden disabilities and the expectations that they should "***just get on and do!***" Respondents also commonly felt that they were not believed by either health professionals or friends and family:

> ***"Hard to get anyone to believe you. Some family members think you are faking and don't believe you have anything wrong."***
>
> ***"I still feel I will possibly be disbelieved when I talk about my illness. I recently spoke on the phone to a GP in my GP practice I hadn't dealt with before. I found myself thinking- 'does he think ME is nonsense?'"***

The lived experience survey asked respondents to select from a given list the actions that could help them to better self manage their condition at various stages. More support from a health specialist and clearer information from health/ support services were selected by a large majority of respondents (39, 73.6% and 38, 71.7% respectively).

Chart 6: What Could Help to Improve Self Management



Source: Lived Experience Online Survey
Base: All respondents (n=53)

When asked if there was anything else that could have helped, some respondents chose not to identify a specific action but rather describe their experiences of care. To ensure their voices are heard, extracts from their responses are presented below.

> ***"I was given a booklet from the rheumatologist to read about my condition. That was it. No follow up. No advice. No further treatment or support. I am winging it on my own. When times are bad I often feel unsupported and misunderstand. Just prescribed strong pain killers from my GP."***
>
> ***"It took me years of pain, flare ups, back and forth to GP. I finally saw a physio who's wording explained fibromyalgia to me. She explained that the pain is real but that the brain sends messages to parts of body that tells them there is pain when actually there is no reason for pain. She was encouraging, listened and for the first time I felt understood."***

Where respondents identified something that could help, the suggestions were varied and included:

- Being believed, taken seriously or greater acceptance of the condition:
  "Could have done without being pre-diagnosed, talked over, condescended and ignored by health professionals."

- A quicker diagnosis:
  "A quicker diagnosis of fibro, I had been struggling for about 13 years. During which time I have been backwards and forwards to the GP, had scans etc. Nothing was diagnosed until I heard of fibro and asked my GP if this could be what was wrong with me."

- Peer support:
  "Being directed or referred to peer support or fellow sufferers. Knowing that you are not alone made a big difference to me."

- More information:
  "More information about the pros and cons of taking certain medications."

- NICE guidelines:
  "Since the updated NICE guidelines my GP is refusing to consider medication and recommends alternative therapies. However, unlike other NHS boards Tai Chi and gym memberships are not available in D&G."

3.6. Barriers to Support

The lived experience survey also asked about barriers and some of their comments resonate with those made by health and social care professionals (see Section 3.4). For example, some described the difficulties faced in making it to an appointment, especially given fluctuations in their condition, and others highlighted a lack of information or knowing who to contact.

When asked what had made it difficult to access services, just under a third felt that their disability and mental health had made it difficult and a small number that their gender (4) and age (3) had done so (see Table 1). However, confidence emerged as the most commonly reported barrier to services. Other practical factors – geographical location, finances, caring responsibilities - also emerged as barriers.

Table 1: Factors Making Access to Services Difficult

	Count	Percent
Confidence	20	37.7%
Disability	16	30.2%
Mental health	15	28.3%
Geographical location	11	20.8%
Personal finances	7	13.2%
Lack of transport	7	13.2%
Caring responsibility	6	11.3%
Gender	4	7.5%
Age	3	5.7%
Ethnic background	0	0.0%
Religion or belief	0	0.0%
Sexual orientation	0	0.0%
Transgender status	0	0.0%

Source: Lived Experience Online Survey
Base: All respondents (n=53)

3.7. Living with ME/CFS, Fibromyalgia and Long COVID

People with the conditions were also asked in the survey, 'What is the one thing that you would most like to be able to do but currently can't because of the impact of your illness?" The responses were varied but most often related to doing some form of activity or exercise and being able to work again, work more or work more flexibly. For others, there was a more general want of having an improved quality of life or not feeling exhausted.

The responses to the question, “what would help you do that?” was indicative of a sense of helplessness; for example, several respondents answered:

> ***“Magic pill. New body. A miracle.”***
>
> ***“Not having ME”***
>
> ***“Only getting better/ recovering.”***
>
> ***“Nothing. My illness to relent.”***

Where more practical actions were cited, they often reiterated answers to previous questions such as timely diagnosis and treatment, more or better information, and more understanding from employers. Other responses included increased financial support and better pain relief.

3.8. The Impact of COVID-19

The effects of the COVID-19 pandemic have been wide ranging for all but especially for people with long-term conditions. The Network, in its project plan, described the differential impacts on its members from increased loneliness and isolation, difficulty implementing self management strategies, declining mental health and lack of access to care and support.

The survey also provided some insight into how COVID-19 has affected people’s health physically and mentally; over half felt that both their physical (23, 52.3%) and mental (23, 52.3%) health had worsened because of the pandemic. Some of these respondents described how the stress and anxiety brought about by COVID-19 had exhausted them and others attributed the change to a lack of services (e.g. face-to-face GP appointments, physiotherapy, leisure centre access).

Conversely, over a third (16, 36.4%) felt that their physical and mental health were unchanged by the pandemic and a few (5, 11.4%) reported an improvement. For these respondents, the stay at home restrictions meant that they were less likely to exhaust themselves or that the expectations they perceived to be on them removed. One person with ME also reported that walking more during the lockdowns had brought about improvements.

4. Key Findings – Project Ideas

Summary

- Support for all three project ideas (the creation of a clinical lead, expert patient mentors and a befriending service) was high.
- Partner agency survey respondents were asked if they thought each idea would be useful: 22 said a befriending service would be and 21 and 20 (respectively) said expert patient mentors and a clinical lead would be useful.
- The clinical lead was perceived as the most helpful by respondents to the lived experience survey (43, 93.5%), followed by expert patient mentors (37, 78.7%) and a befriending service (33, 70.2%).
- The clinical lead was also the service people with lived experience were most likely to use.
- Health and social care interviewees and focus group participants identified a number of challenges associated with the creation of a clinical lead role, including finding a service with the capacity to take on the role, ensuring that it is appropriately embedded and accountable and that it would be difficult to achieve in the absence of a co-ordinated approach.
- Some of these participants suggested that a GP could take on the role but acute care, the new Home Teams, third sector organisations, public health improvement teams and community pharmacists were also mentioned. One participant questioned if a team of leads would be preferable – it could enable a more multi-disciplinary approach to be adopted.
- The importance of ensuring that expert patients were appropriately trained and supported to ensure that accurate information was provided was emphasised by all participant groups.

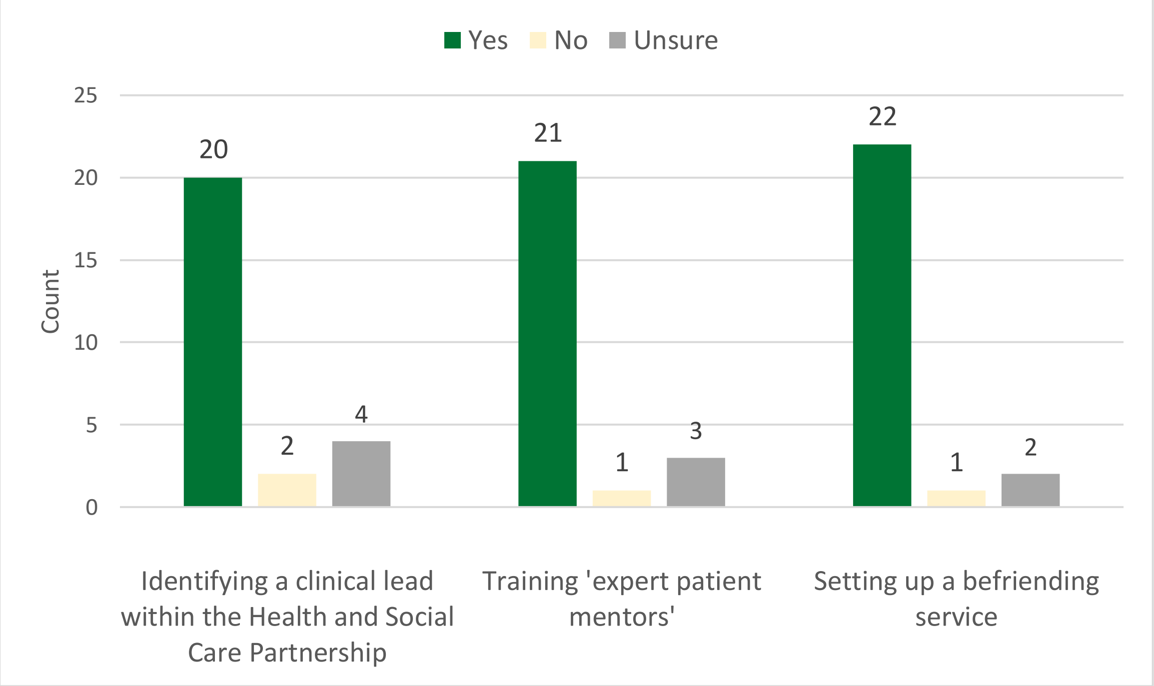
4.1. Introduction

All survey respondents, interview and focus group participants were asked to share their views on the three project ideas: a clinical lead, expert patient mentor and befriending scheme. The emerging findings are presented separately for health and social care professionals and people with lived experience in this section.

4.2. Health and Social Care Professionals - Perceptions of Project Ideas

As shown in Chart 7, support was high amongst partner agency survey respondents with the majority stating that all three of the ideas would be useful to people with the conditions.

Chart 7: Number of Partner Agency Respondents Perceiving Project Ideas to be Useful



Source: Partner Agency Survey

Health and social care interviewees were also broadly supportive of the clinical lead and expert patient mentor ideas (befriending was not explored in depth in the interviews). For example, a clinical lead was perceived to be a potentially useful mechanism to raise awareness and understanding of the conditions, or provide a resource that others could '***tap into'***. Another suggested that it would demonstrate to people with the conditions that they were recognised and valued.

However, interviewees often highlighted the challenges associated with the creation of such a role. These included:

- Identifying a service with the capacity to take on the role, especially given the unprecedented pressures created by COVID-19;
- Creating a role that is not embedded within a wider organisation or accountable to any organisation;
- Creating a role in the absence of a co-ordinated or structured approach to chronic conditions; and

- A concern that the champion is used in a tokenistic way to engage with the community.

Where a clinical lead could sit was also discussed; two interviewees felt that a GP lead would be beneficial as the majority of patients access primary care and a GP's input could be secured by paying for a session a week. But a focus group participant felt that it would be difficult to find someone with sufficient time and suggested that it didn't necessarily have to be a GP in the role (an advanced nurse practitioner could be an alternative). Another felt that a multi-disciplinary approach would be preferable, whereby each service (e.g. primary care, physiotherapy, acute services) identified a lead and then all leads come together as a group. Acute care, the new Home Teams, third sector organisations, public health improvement teams, community pharmacists were also mentioned by interviewees and focus group participants. A participant also questioned whether it had to be a clinical role and emphasised the importance of having someone with the understanding and qualities needed to engage with people.

The perceived value of expert patient mentors was, for several interviewees and focus group participants, also contingent on a number of factors. The need to ensure that those in the role were appropriately supported and trained to deliver accurate information and advice was particularly important. In addition, establishing a system with the appropriate back ups in place was identified as necessary to accommodate the fluctuating capacity of individuals to fulfil the role.

More broadly, there was some discussion of whether the clinical lead and expert patient roles should encompass a number of conditions (e.g. chronic pain and long COVID) rather than focusing on just one.

Partner agencies were asked to choose from a given list how they, their department or service could support these ideas; taking part in further training (66.7%, 18) and attending a one-off meeting (40.7%, 11) were the most commonly selected. 4 respondents said that they could offer a clinical lead or champion and provide training, 3 of whom worked in the NHS and 1 in the local authority. Of the 3 that said they could provide financial support, 1 was from a charity/third sector organisation, another the NHS and the third the local authority.

Table 2: How Partner Agencies Could Provide Support

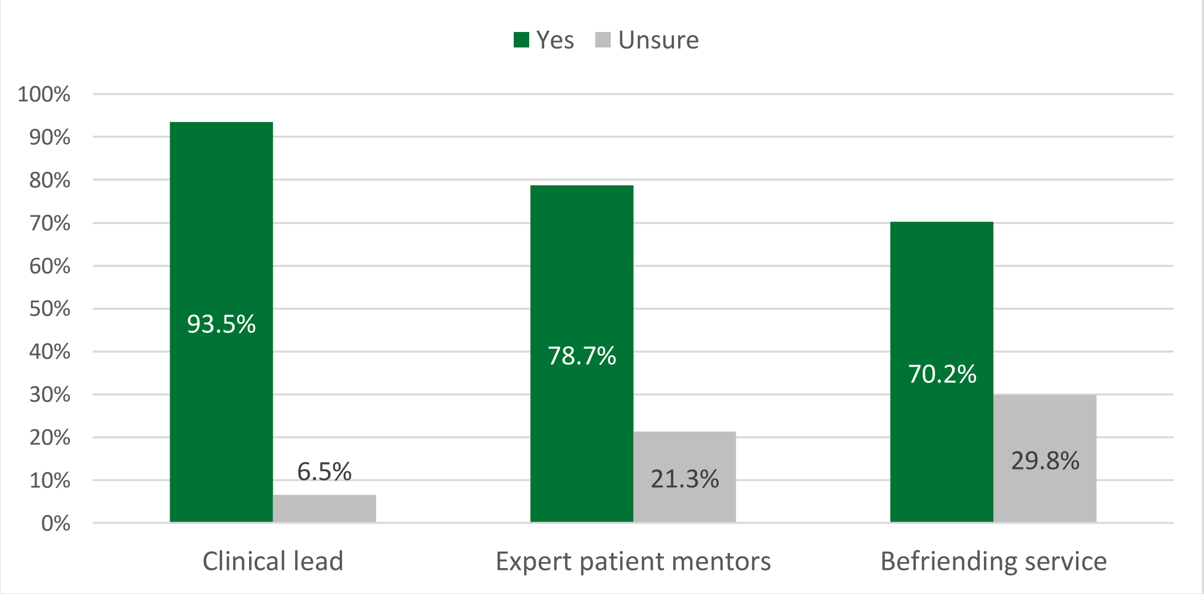
	Count	Percent
Undertaking further training in ME, CFS, fibromyalgia and/or long COVID	18	66.7%
Attending a one-off meeting	11	40.7%
Introductions to colleagues	9	33.3%
Joining a steering group	8	29.6%
Providing information e.g. reports, training materials	5	18.5%
Providing training	4	14.8%
Offering a clinical lead / champion	4	14.8%
Providing financial support for one of more of these initiatives	3	11.1%

Source: Partner Agency Survey
Base: All respondents (n=27)

4.3. People with Lived Experience - Perceptions of Project Ideas

People with lived experience were also asked what they thought of the ideas and all 3 ideas were perceived to be helpful by the majority of survey respondents. As shown in Chart 8, 93.5% (43) thought that the clinical lead would be helpful and a smaller majority thought that both the expert patient mentors (37, 78.7%) and befriending service (33, 70.2%) would be helpful.

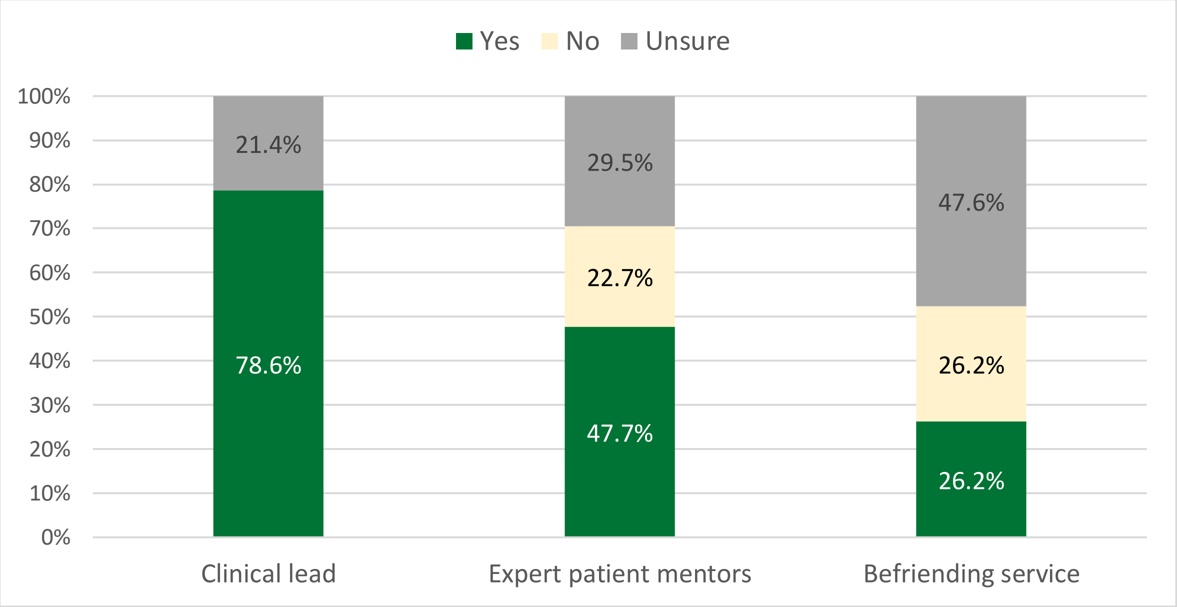
Chart 8: Would the Ideas Help People with the Conditions?



Source: Lived Experience Online Survey
Base: All respondents answering the question (Clinical lead n= 46, Expert patient mentors and befriending service n=47)

As shown in Chart 9, the clinical lead also emerged as the service respondents were most likely to use (33, 78.6%, a further 9, 21.4% were unsure). Around half would use the expert patient mentor scheme (21, 47.7%) and a quarter the befriending service (11, 26.2%).

Chart 9: Proportion That Would Use the Service Now



Source: Lived Experience Online Survey
Base: All respondents answering the question (clinical lead and befriending scheme, n=42; expert patient mentors, n=44)

Some of the survey respondents chose to provide additional comments to explain their answer and the comments made suggest that the perceived benefits of each idea are shaped by the stage of the condition. For example, a respondent who was diagnosed over 30 years ago felt that they had tried all available treatments, developed strong contacts and become an expert in the condition and were therefore unsure if they would use any of the proposed ideas. However, the respondents stating that they would use the clinical lead felt that there was a need for greater awareness and access to a specialist with knowledge of the latest research/ treatments.

Although the opportunity to speak with someone who understood the condition was welcomed by some, others described a more negative experience of patient groups:

> ***"Personally, I found the few times I used DGMEFM Network it felt uncomfortable and a bit negative. I really do understand people are very poorly but I felt listening to all the negative experiences brought my spirits down. On one occasion, a guest speaker was there and I felt people were rude and didn't want to hear what they could offer. I did only start to use the service during the pandemic so it was on Zoom and I appreciate that wouldn't suit everyone either. I know for some the group will be a life line but it wasn't for me. That's why I took a different approach."***

> ***"I have very little confidence in people with fancy job titles. The couple of people I have come across with CFS were very pessimistic about their condition and made me feel worse."***

These respondents either would not or were unsure if they would use any of the three projects.

In contrast, a few survey respondents felt that a befriending scheme would help to reduce isolation or provide a space for people to talk without fear of being judged. Further understanding of the potential role of a befriending scheme was provided by feedback received via a Facebook discussion. A series of questions were asked on a private Facebook page and the responses emphasise the importance of peer-to-peer support for some. For example, when asked why they were part of the Facebook group, responses included:

> ***"For support and to give and receive advice on different subjects. I found it so helpful to see I'm not alone."***
>
> ***"To see what people say or speak to people who have similar conditions and understand how you're feeling."***
>
> ***"A connection to other [people] in the same position, also peace of mind I'm not imagining symptoms. This group has been a life line for me, not sure if or how I would have coped."***

When asked specifically about a befriending service, all those responding felt that it was a good idea and would be beneficial to them. The idea of an expert patient mentor scheme was also welcomed, especially at the time of diagnosis. The type of support and information that would have been most helpful at diagnosis was also explored; several simply answered "***support***" but the other responses included:

- Guidance on the next steps – where to go and what to do to help;
- Advice on what helps to manage the condition;
- Talking to someone with the condition;
- More understanding amongst health and social care providers;
- Being signposted to the Network; and
- An understanding employer/ employer support plan.

The survey also asked respondents what else they thought might be useful and the suggested actions resonate with earlier responses on how best to improve support.

For example, raising awareness of the conditions and dedicated or specialist staff were both mentioned.

> ***"A campaign to create more awareness, especially in the workplace."***
>
> ***"Access to information on support available in people's own area that they can use to self manage. Awareness of carer support."***
>
> ***"An identified specialist nurse to follow the journey with people, able to provide advice when needed."***
>
> ***"More awareness raising in agencies as I hear from clients the frustration that their condition (in particular when mixed with long COVID) is not recognised. I think any education to people living with these conditions as well as services supporting them would be helpful."***
>
> ***"Training services who will come across people with these conditions who are less likely to be involved, but may be supporting or providing services for dependents or other family members."***

Like health and social care professionals, a few of the lived experience survey respondents flagged the importance of ensuring that patient mentors were appropriately trained or the potential difficulty of providing support during a flare up.

5. Conclusions and Recommendations

5.1. Introduction

The consultation has provided valuable insight into perceptions and experiences of services and in doing so, developed the evidence base upon which DGMEFM Network can progress their project plans. The conclusions and suggested actions emerging from the consultation are summarised in this final section.

5.2. Conclusions and Recommendations

- **The Network's future activity will be shaped by both the national and local policy context:**
  The NICE guidelines for ME/CFS, fibromyalgia (as part of the Chronic Pain guideline) and long COVID set out the recommended approach to the diagnosis, care and management of the conditions. In doing so, they provide a framework upon which the Network could develop any future projects. However, it should be highlighted that the updated version of the ME/CFS NICE guidelines were published in October 2021 and the approach to their implementation in Scotland is not yet clear. For example, the guidelines recommend a referral to a specialist team for confirmation of a ME/CFS diagnosis and assessment yet few specialist teams currently exist. The Network should therefore be mindful that future guidance may be published to aid the Scottish implementation of the guidelines.

  More locally, the preparation of the Dumfries and Galloway Strategic Commissioning Plan for 2022-2025 is nearing completion and will set out a series of commissioning intentions for the region and in doing so, the framework in which any future investments will be made. This is likely to be particularly pertinent for the development of any clinical lead or champion role. Furthermore, Home Teams are an important component the new models of care set out in the Plan but are yet to be fully operationalised in all localities across the region. The extent to which they provide an opportunity for the Network to engage with health and social care partners, or even act as a potential site for a new lead/champion role, should be reviewed as the Home Teams continue to develop.

Recommendation 1:
The Network should consider both the emerging national and local policy context in the development of their future projects.

- **More people receive support from a family member than any other type of support at every stage of their condition:**
  The lived experience survey showed that support is most often provided by a spouse, partner or other family member from before the time of diagnosis through to day-to-day management, flare-ups and transitions. This finding highlights the importance of ensuring that family members are appropriately supported to enable people to live well. Carers had attended face-to-face meetings prior to the pandemic and consideration could be given to how to re-engage with them and wider family and friends now. With the potential to raise awareness of the conditions, offering family and friends events could also be beneficial for those people who feel they are not believed by friends and family. In addition, the Network could also signpost family and friends to the region's Carers Centre to enable more comprehensive support to be offered.

Recommendation 2:
Given the importance of their support, the Network might like to consider how best to engage with family and friends or signpost them to appropriate sources of support. This could develop their knowledge and understanding of the conditions.

- **GP surgeries were also commonly accessed for support but received lower helpfulness ratings than all but one of the other forms of the support explored in the survey:**
  GP surgeries helpfulness ratings were lowest for flare ups and other difficult times and highest at diagnosis. However, the perceived helpfulness of hospital services was lower still at every stage of the condition. These findings suggest that any awareness raising and education activities should target GP surgeries and hospital services to improve experiences of support. Should a new clinical role be developed, consideration should be given as to how best they could help to facilitate engagement with these professionals.

- **Experiences of the principles of self management were mixed:**
  The Alliance's strategy for the self management of long term conditions, Gaun Yersel!, sets out five principles for self management and the lived experience survey indicates that few of these are consistently experienced. In contrast, partner agencies perceived that they or their service regularly supported these principles. Although it is not known how representative these views are of all services and lived experiences across Dumfries and Galloway (it is possible that both lived experience and partner agency respondents were motivated to participate either because of a particularly positive or negative experience or

perception), the findings nevertheless highlight an important contrast in how services are experienced by those accessing and delivering them.

- **The lack of treatment options can be disempowering for health and social care professionals:**
  Health and social care participants expressed frustration at not being able to offer more support to people with the conditions. It was also recognised that the lack of treatment, and the contentious nature of some treatments, meant that GPs sometimes overprescribed without bringing about improvements in quality of life. Although there is no cure, professionals should be aware of the recommended approaches to symptom management (as set out within the respective guidelines) to enable them to support or refer people as appropriate.

- **People with lived experience want more support from a health specialist and clearer information to help them better self manage their condition:**
  These activities were selected from a given list in the lived experience survey more often than family, online or DGMEFM Network support. Although the reasons why they were selected were not explored, the wider findings (e.g. perceived helpfulness of different support types) suggest that respondents selected those areas where they felt change was needed.

- **A large majority of people completing the lived experience survey felt that there was a stigma surrounding the conditions and half felt unsupported in the management of their condition**:
  Together, these findings indicate that people with the conditions have poor experiences of care and further action is needed to bring about improvements. The Network cannot of course achieve this in isolation, instead they should continue to develop their partnerships with key regional stakeholders and organisations to raise awareness of and advocate for the need for change. Again, consideration should be given to the role of any new clinical lead here: for example, how could they help to disseminate information across health and social care and facilitate change?

Recommendation 3:
Change is needed in the care and support available to people with the conditions. Although such change cannot be brought about by the Network, it may wish to consider how it can continue to develop its partnerships with key regional stakeholders and organisations to raise awareness of what is needed. The potential role of a new clinical lead or champion in this process should also be considered.

Recommendation 4:
Raising awareness and understanding of the conditions amongst professionals should be a priority of any change initiative. Again, depending on the scope of the role, a clinical lead or champion could play a valuable role in supporting professionals to follow the appropriate guidelines and recommendations.

Recommendation 5:
The Network may like to consider developing a communications strategy to help maximise the reach and impact of any awareness raising activities. The findings from this consultation highlight the support that was perceived to be most and least helpful and could therefore be used to inform the development of any such strategy.

Recommendation 6:
The Network should consider where there are existing resources and whether there is a need to develop their own educational materials. For example, a free online ME/CFS training course for health professionals has been developed by Dr Nina Muirhead and the Medical Education Working Group. Action for ME have already prepared a template for people who would like to make their GP surgery aware of the course. A link to these resources could therefore be easily shared by the Network.

- **More people received support from the Network for day-to-day and flare-ups than at any other stage of their condition:**
  The reasons for accessing different types of support at different stages of the conditions were not explored in the survey, but this finding may reflect that the Network is more likely to be identified as a source of support after a diagnosis is made. Although the relatively high helpfulness ratings at every stage suggests that its support is valued, the highest helpfulness ratings were received for flare ups and other difficult times. In considering this finding, the Network has observed that their Facebook groups are most often accessed when the need for support is greatest (during a flare up for example). The Network may therefore like to consider how experiences of day-to-day and transition support could be as positive. When considering the support offered, the Network should be mindful that a small number of lived experience survey respondents reported a negative experience of it. For them, hearing only negative experiences did not provide the support needed. Establishing a space for more positive dialogue, through the online craft sessions for example, could therefore potentially increase the

Network's engagement with the wider ME/CFS, fibromyalgia and long Covid communities.

Recommendation 7:
The Network should consider how it can best engage with and support people at every stage of their condition and provide a space for positive dialogue.

- **Confidence made it difficult for people with the conditions to access services:** Respondents to the lived experience survey were asked to select from a given list all the factors that made accessing services difficult and confidence was selected more often than disability, mental health, geographical location, transport and personal finances. This is an important finding and highlights a need to support people with a condition to access and navigate services. Responses to a Facebook discussion on what would be most helpful at the time of diagnosis provide some insight into how this might be addressed: respondents called for more guidance on where to go and what to do after diagnosis and advice on how to manage the condition. Being better informed is an important part of being able to self manage and therefore the Network should give consideration as to how the different project ideas could help to achieve this.

  By supporting both professionals and people with lived experience to increase awareness and understanding of the conditions and the recommended management approaches, the Network could contribute to the development of a more effective partnership between the two communities and, in turn, improved experiences for both.

Recommendation 8:
The Network should identify how it can best work with its members and wider stakeholders to increase the confidence of people with a condition to access and navigate health and social care. Increasing knowledge of what is available within Dumfries and Galloway and how to access it could help people with the conditions to navigate services.

Recommendation 9:
The potential role of expert patient mentors could be explored as part of this work. More broadly, appropriately trained and supported peer mentors could help people with lived experience to better understand their condition and recommended management approaches.

- **Support for all three project ideas was high:**
  Amongst partner agency survey respondents, the befriending service was perceived as the most helpful, closely followed by expert patients mentors and a clinical lead or champion. Conversely, the clinical lead was perceived as the being the most helpful by lived experience survey respondents and was also the project that they were most likely to use.

- **Implementation of the projects faced key challenges:**
  Identifying a service that could take on the clinical lead role and ensuring it would be appropriately embedded within organisational structures were highlighted as potential issues by health and social care participants. The lack of specialist services nationally is a key issue here and the Network should again be mindful of how the updated ME/CFS NICE guidelines are implemented in Scotland.

  With expert patient mentors, the importance of ensuring that those in the role were appropriately trained and supported was emphasised so that accurate and up-to-date information could be provided. Drawing upon the experiences of their own pilot programme, Action for ME have produced a potentially useful step-by-step guide to setting up a peer mentoring scheme. Should the Network pursue an expert patient mentor scheme, reference to this document could be a valuable first step.

  Furthermore, it's important to acknowledge that the consultation explored the perceived helpfulness of the basic premise of each of the three project ideas; now that broad support for them has been established, further consultation should take place to develop more detailed project plans. It is understood that the Network are currently exploring funding opportunities to appoint project officers to take forward the expert patient and befriending schemes. A co-produced remit for these projects will help to establish their potential reach and uptake.

Recommendation 10:
The Network should consider further consultation activity to develop each of the project ideas. The project plans developed through this process could then be used in a second stage of consultation to establish the likely reach and uptake.

6. References

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