Public Health Scotland

ME-CFS healthcare needs assessment: Briefing

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Introduction

In 2010, the Scottish Public Health Network (ScotPHN) undertook a healthcare needs assessment (HCNA) for adults with a diagnosis of ME-CFS[1], using as a reference point the Chief Medical Officer's short life working group (SLWG) report published in 2002[2]. The HCNA concluded that the recommendations of the SLWG had, largely, not been followed consistently by NHS Boards and consequently delivered a suite of recommendations to improve the provision, and standard, of care and service provision for this patient population.

Ten years on from that HCNA, and prior to the outbreak of COVID-19, ScotPHN was planning to revisit the topic to ascertain what, if anything, had changed with regard to service provision for ME-CFS patients. This was to have been achieved in partnership with key stakeholders (and foregrounding patient and service user experiences) by assessing ongoing health and social care needs, and whether there had been any changes in the incidence and / or prevalence of ME-CFS in Scotland in the decade from 2010 to 2020. There were also plans to consider the effects of ME-CFS on children and young adults, whose symptoms and diagnosis, care and treatment had not been included in the 2010 report.

The global COVID-19 pandemic has had a deleterious effect on plans for a full and robust service review, given the need for ScotPHN (as part of Public Health Scotland) to focus on facilitating the co-ordination of the joint response of the Directors of Public Health in Scotland and developing national and local response and recovery work.

This report outlines what has been achieved against that background; the work which has been progressed has been desk based and has focused on a review of the epidemiological literature published since the original ScotPHN report in 2010. It also includes epidemiological papers looking at the effects of ME-CFS on children and young adults, and their families and carers.

Literature review

Condition summary

The symptoms of ME-CFS are well documented[3,4,5,6,7]. The most prominent is that of disabling mental and physical fatigue, which is chronic (usually described as being for more than six months) and which is worsened by physical activity and is not relieved by rest. Other symptoms include functional and cognitive impairment; neurological, cardiovascular, gastro-intestinal and muscular symptoms; sleep disturbance; temperature disturbances; headaches; nausea; and post-exertional malaise. The severity of the symptoms experienced is also a major factor in the degree of disability experienced by individuals. Symptoms in children and adolescents are further described as being disabling (with 50% of patients in one study[8] found to be bed bound at some stage), with an extensive disease course which includes headaches, sleep disturbance, cognitive difficulties and muscle pain[9,10].

A range of case definitions have emerged over time, all of which have subtle but fundamental differences which have been shown to impact estimates of prevalence[11,12]. Differences in prevalence have also been described between studies which insist on a clinical diagnosis and those who allow patients to self-report symptoms[13]. Two of these have emerged since the previous ScotPHN report – the International Consensus Criteria and System Exertion Intolerance Disease (SEID) 2015. In general, symptoms which indicate a likely diagnosis of ME-CFS include chronic, disabling fatigue of more than six months duration and which has a definite start point (ie is not lifelong) and cannot be ascribed to any other medical condition; in conjunction with this, patients often suffer from joint and muscle pains (with no redness or swelling) and a range of other symptoms which can include endocrine, neurological and gastrointestinal systems; headaches; sore throat; and painful lymph nodes (with no pathological enlargement). The case definitions vary in the range of symptoms which must be present, and some vary in the duration of chronic fatigue; it is worth noting that the presence of chronic fatigue is generally agreed to be of shorter duration in children and adolescents (three months, compared to six months in adults).

Epidemiology

In order to scope out any epidemiological changes which might have occurred between 2010 and 2020, a search of the literature was carried out using the terms ‘myalgic encephalomyelitis’, ‘ME’, ‘chronic fatigue syndrome’, ‘CFS’, ‘epidemiology’ and ‘prevalence’ and limited to peer reviewed papers in the English language returned thirty five papers after de-duplication. Sifting for relevance reduced this number to ten papers which dealt specifically with studies exploring the prevalence of ME-CFS in the period 2010-2020. One paper was discounted due to a 2008 publication date, and one because it was a prospective study protocol; however both were of interest and thus held back for reference / comparison. The remaining eight papers were read to distinguish major themes, of which three emerged: diagnostic criteria; case definitions; and prevalence / incidence.

Theme 1: diagnostic criteria

Of the eight papers, two did not mention the diagnostic criteria for ME-CFS. Of the remaining six, the range of diagnostic criteria discussed was largely consistent with those mentioned in the various case definitions but varied from paper to paper in terms of focus. All authors mentioned the presence of chronic / disabling fatigue and the importance of a focus on the duration thereof to achieving a diagnosis. Other symptoms covered varied in specificity; some talked of general cognitive dysfunction, for example, while others specified memory impairment and disrupted concentration[14.15,16,17,18,19,20]. Where specific symptoms were discussed, these included joint pain, muscle pain, post-exertional malaise (and concomitant reduction in pre-illness activity levels), and disturbed or unrefreshing sleep. Via work done on case definitions, there has been something of a move towards categorisation of symptoms allowing for the foregrounding of assessments of severity, but in the main the recognised, headline symptoms of ME-CFS have not changed since the 2010 ScotPHN report[21].

Symptoms reported in children remain broadly the same as those reported for adults, with the significant difference being that long standing fatigue needs to have been present, in general, for three months rather than six before a diagnosis of ME-CFS can be considered[22,23,24] (although this is not stated explicitly in any of the extant

case definitions). There remains no identified biological marker, or simple diagnostic test, to facilitate the diagnosis of ME-CFS in either children or adults[25,26,27].

Theme 2: case definitions

Review or assessment of case definitions formed the substantive focus of five of the eight papers[28,29,30,31] particularly in terms of their impact on prevalence estimates. Ten distinct case definitions were discussed, albeit some were updates of earlier versions. Two new definitions have emerged: the 2011 International Consensus Criteria (ICC)[32] and the 2015 Systemic Exertion Intolerance Disease (SEID)[33] guidance. The former is an update of the 2003 Canadian Consensus Criteria, and is simpler for clinicians to follow, aiming for a more streamlined approach to diagnosis which would allow patients to access support and care or treatment services at an earlier stage. The latter was developed by and for the CDC and is also designed as an updated definition, aiming to allow for a speedier diagnosis than the earlier Fukuda definition used by the CDC.

For children and young adults, the case definition described by the Royal College of Paediatrics and Child Health (RCPCH) has been taken down from their website; the College is currently working to the case definition set out in the 2007 NICE guideline[34]. Work to update the NICE guideline commenced in 2018, with an expected publication date in 2020; this has been significantly delayed and is now expected to be published in April 2021[35]. In the interim and in response to concerns raised about connections between the long term effects of COVID-19 and ME-CFS, a short guidance note[36] has been published stressing that therapeutic recommendations for ME-CFS should not be used as part of a treatment programme for COVID-19 patients. The guidance note acknowledges that this may change in the light of evidence emerging as a result of further study of the long term effects of the virus.

The RCPCH is, however, running the British Paediatric Surveillance Unit (BPSU) study on severe chronic fatigue syndrome / myalgic encephalomyelitis which aims to ‘collect information on all young people aged between five and 16 years who receive a diagnosis of severe Chronic Fatigue Syndrome or Myalgic Encephalitis (CFS/ME).

The study aims to explore how many young people across the UK and Ireland have severe CFS/ME, the length of time from symptom onset to diagnosis and how the condition is managed in clinical services'. The study included 13 months of surveillance (February 2019 – February 2020) with a further 12 months of follow up due to conclude in February 2021. The results will be of particular interest both epidemiologically and in terms of future service planning given the follow up period encompasses the global COVID-19 pandemic.

It has been suggested that the specificity of research case definitions could be improved by incorporating clinical diagnostic criteria[37], and that the research community should perhaps move on from using the 1994 CDC (Fukuda) definition as the principal internationally recognised case definition for CFS[38]. This reflects the findings of the 2010 ScotPHN report, which proposed that (in the absence of epidemiological data specific to the Scottish population) Scotland should adopt the 2003 Canadian Consensus Criteria for the diagnosis of ME and the 2007 NICE guideline for the diagnosis of CFS. In the continued absence of Scotland-specific epidemiological data, these recommendations stand with the caveat that investigating the utility of ICC 2011 and SEID 2015 might have some benefits for Scottish ME/CFS patients going through the diagnostic process, potentially enabling them to access treatment, care or support more quickly.

Theme 3: incidence / prevalence

The 2010 ScotPHN report found that:

'The absence of a diagnostic test for ME-CFS, linked to the differences in the clinical guidelines, has made describing the epidemiology of ME and of CFS problematic. This is an international problem which is yet to find an adequate resolution' (p42)[39].

The variation in prevalence estimates described in the literature since 2010 indicates that this is still the case, with Brurberg et al[40] and Johnston et al[41] demonstrating that wide variation in prevalence can be found in the same population depending on the case definition criteria used.

In terms of ME/CFS prevalence in children and young people, the picture is just as varied. Parslow et al[42] noted, in their study looking at what children and young people considered to be most important to their recovery, that prevalence estimates in children and young people varied widely between 0.6-2.4%, and this was supported by Jason et al[43] in their investigation into a community based sample which found (as in adult studies) wide variation in prevalence estimates depending on the choice of case definition, study design, study population, diagnostic criteria and study inclusion criteria. They estimated prevalence at 0.75%, slightly higher than the 0.55% prevalence in children and young people found in the meta-analysis conducted by Lim et al[44]. Across both adult and paediatric ME/CFS research, then, there is continued consensus that prevalence is difficult to estimate and highly dependent on the potential biases introduced by variation in study design, case definition, study population and whether diagnosis is reached with physician input or whether study participants are encouraged to self-report; this remains unchanged since the ScotPHN 2010 report.

The plans described in the 2010 report which anticipated using ME Observatory data to calculate future prevalence estimates for the Scottish population in the continued absence of a Scotland-specific study have been disrupted by the closure of the Observatory in 2011 and concomitant loss of access to these data. Given the difficulties described in the literature, it appears that arriving at an accurate prevalence estimate for ME-CFS in Scotland will be as difficult in 2020 as it was in 2010.

In summary, a brief scoping search of the epidemiological literature published since the 2010 ScotPHN report indicates that little has changed in terms of diagnostic criteria, case definitions and estimates of (and methodologies for estimating) prevalence. There is some evidence that estimates of prevalence are dependent on the study methodology, inclusion criteria and the case definition which underpins it[45,46,47,48,49]; Collin et al[50] further suggest that there has been a dip in ME-CFS diagnoses since the emergence of clear diagnostic criteria for fibromyalgia, finding that ‘the incidence of CFS/ME diagnoses declined over the period 2001-2013 whereas FM [fibromyalgia] diagnoses…showed an overall increase’. This poses an

interesting question around whether this is due to clear diagnostic differences between the two diseases or whether it can be attributed to fashions in diagnostic labelling; the study authors note that ‘the steady decline in CFS/ME diagnoses is perplexing. In the absence of curative treatments and, given that we have no reason to suspect underlying trends in the causal agents or risk factors…we cannot discount a trend in diagnostic labelling’.

It should be noted that there is still no Scotland-specific epidemiological study which would support more accurate evidence of ME-CFS prevalence in the Scottish population; the BPSU study is likely to go some way towards addressing that deficit (at least in children and young adults) taking as it does a whole UK and Ireland perspective but an epidemiological study focusing explicitly on the Scottish population would be useful. Such a study may also help to address the continuing absence of epidemiological data assessing the severity of the condition. From a public health perspective this makes the task of assessing health and social care needs at the population level more problematic and impacts on the ability to translate assessed need into planning the necessary services to identify and manage care packages and provide treatment and care to individuals, many of whom will be cared for in home settings. Moving forward, building a clearer picture of the current state and quality of service provision in Scotland will be reliant on foregrounding patients’ lived experience. It is likely that any recommended service improvements will centre around breaking down barriers to accessing care and ensuring care and support services are focused on improving patients’ lived experiences by supporting them through their most troubling presenting symptoms.

The COVID-19 pandemic has raised interesting questions about potential links between long term effects of the virus and ME-CFS and it is likely that the research community will explore this further in the weeks and months to come. At the time of writing, however, there is no clear evidence to suggest a causal link, although it is becoming accepted that the virus is capable of causing numerous deleterious effects to a variety of organ systems.

Summing up

An initial literature search has demonstrated that, certainly in terms of epidemiology, little has changed since the publication of the 2010 ScotPHN report. Worldwide, incidence and prevalence remain contested, as do case definitions (despite their overall similarity). The UK ME Observatory has closed, with the loss of access to all the data collected there, and there is still no Scotland-specific study of the epidemiological aspects of ME-CFS. The condition does not appear to be mentioned in the Scottish Government's Long Term Conditions strategy[51], and there is nothing publicly available (and thus easily accessible to patients) on individual NHS board websites. As such it is difficult to conclude other than that there has been little to no progress on ME-CFS diagnosis and treatment and care pathways in Scotland since 2010. Some new guidelines have emerged in the intervening decade (ICC and SEID), and a proposed update to the NICE 2007 guideline has been significantly delayed (publication now expected in April 2021). None of these updates and amendments indicate that any new evidence has emerged which would significantly undermine the recommendations made in the 2010 ScotPHN report.

Bearing that in mind, the recommendations of the 2010 ScotPHN report remain broadly valid, developments in the policy landscape over the past decade notwithstanding. A list of these recommendations is provided in **Appendix A** for reference.

Given the disruption to health and social care services caused by the global COVID-19 pandemic, it is unlikely that Scottish Government (SG) colleagues will be able to proceed as planned with a board by board review of practices and service provision. In light of this, and in the context of the current focus on post-COVID-19 remobilisation of healthcare services, it is recommended that SG should gather together, and give consideration to, the original HNA recommendations, the findings of the Health and Social Care Alliance Scotland gathering views exercise, the NICE guideline review, and the findings of the rehabilitation framework in order to define next steps in developing and improving services and support for adults and children with ME-CFS in Scotland.

The inclusion of social care, and of ME-CFS in children and young adults, within the remit for this update, represents a considerable extension to the scope of the 2009 healthcare needs assessment. These were not considered in the recommendations of the earlier report directly and, due to the current circumstances, have not been considered in this briefing. These areas do warrant further consideration, especially as part of the work to remobilise health and social care services following the pandemic.

Appendix A

Recommendations from the 2010 ScotPHN report with suggested amendments

Recommendation 1

It is recommended that the clinical, symptomatic definition of ME outlined in the Canadian Guideline be adopted in Scotland.

Comments: Consideration should be given to updating this recommendation in light of the emergence of two more recent new case definitions (ICC, 2011 and SEID, 2015) and the pending publication of updated NICE guidance on the diagnosis, care and treatment of ME-CFS.

Work on this should await publication of the updated NICE guideline, expected in April 2021.

Recommendation 2

It is further recommended that a symptomatic definition of CFS based on that proposed in the NICE guideline be adopted in Scotland.

Comments: Consideration should be given to updating this recommendation in light of the emergence of two more recent new case definitions (ICC, 2011 and SEID, 2015) and the pending publication of updated NICE guidance on the diagnosis, care and treatment of ME-CFS.

Work on this should await publication of the updated NICE guideline, expected in April 2021.

Recommendation 3

a) There is an urgent need for a sound epidemiological study of ME and CFS in Scotland; in which regard consideration should be given to including ME and CFS within the Scottish Health Survey.

b) Routine reporting of ME and CFS should be considered within the context of developing information systems for Long Term Conditions monitoring under the Quality and Outcomes Framework (QOF).

Comments: The need for a sound epidemiological study is greater now that it was in 2010.

The Long Term Conditions strategy, which the Scottish Government published in 2009, is no longer current. The more recently published Neurological Care and Support Framework, while not condition specific, encompasses ME-CFS within its approach.

Development of information systems would now need to be considered within the context of the Scottish Digital Health and Care Strategy.

Recommendation 4

It is recommended that to meet these expressed needs, health boards in Scotland should develop a specific tiered ME-CFS service that provides: rapid and accurate diagnosis and assessment; supportive care and treatment of presenting symptoms; and provides access to wider social and economic support.

Comments: This recommendation remains valid.

Where services can already meet these needs, Consideration should be given to mandating that Boards make this information publicly and easily accessible both via their websites and other media which take account of the impact of socio-economic inequalities (for example, digital exclusion) on patients' lives.

Recommendation 5

It is recommended that the characteristics of such services would include a local management of care, provided by the primary care team at its heart and supported by a specialist team that can facilitate diagnosis and assessment, and plan care on both a clinic and outreach basis.

Comments: This recommendation remains valid.

Ensuring effective care management for people with ME-CFS should be a key element within the long term condition approaches for primary and community care within IJBs.

Recommendation 6

At the present time there is insufficient research evidence on which to base a SIGN ME-CFS Guideline for Scotland. However, a clinical guideline which supports effective diagnosis, signposts people with ME-CFS towards appropriate medical and therapeutic assessment and service, and provides the basis for ongoing care management is desirable. It is suggested that this is in keeping with the Scottish Good Practice Statement on ME-CFS.

Comments: It would be appropriate to assess if this remains a valid conclusion with SIGN.

Consideration should be given to the need for a revision to the Scottish Good Practice Statement within the context of Realistic Medicine, the Neurological Care and Support Framework, and the updated NICE clinical guidance once it is published.

Recommendation 7

(See also Recommendation 4)

It is recommended that the tiered model for services proposed by the CMO's Short-Life Working Group be used as a basis for ME-CFS service development in Scotland.

Comments: This recommendation remains valid, though the tiered model should be consistent with more recent Scottish clinical strategies.

Recommendation 8

It is recommended that a dedicated helpline and website to provide information and support for people with ME-CFS and those who care for them be established in Scotland.

Comments: This recommendation remains valid, though should be updated in the context of the Scottish Digital Health and Care Strategy.

Rigorous efforts should be made to ensure that those who are significantly disabled as a result of ME-CFS, or those where socio-economic inequalities might affect involvement, are not excluded from participation in this work.

Recommendation 9

A broadly constituted stakeholder group should be established to:

a) create a national, core information set which can be used for people with MECFS and their carers;

b) create a national, core information set which can be used for health and social care professionals; and

c) explore appropriate ways of making such information widely available.

Comments: This recommendation remains valid, in that delivering the outputs from such a group is still needed. These outputs would need to take into account the Scottish Digital Health and Care Strategy.

Rigorous efforts should be made to ensure that those who are significantly disabled as a result of ME-CFS, or those where socio-economic inequalities might affect involvement, are not excluded from participation in this work.

Recommendation 10

NHS Boards in Scotland should develop formal, care pathways for the diagnosis, assessment and management of people with ME-CFS as outlined in the report of the CMO's Short Life Working Group. These local pathways should be compatible with the Scottish Good Practice Statement on ME-CFS.

Comments: This recommendation remains valid, though the approach to developing care pathways should take into account the work of the Scottish Access Collaborate report on neurology and current Modernising Patient Pathways work.

Ensuring that the barriers to health, social and community care access raised by socio-economic inequalities should also be a priority.

Recommendation 11

NHS Boards in Scotland should formally identify ME-CFS within their long term conditions plan or strategy. Management of ME-CFS should be carried out in line with local arrangements for other long term conditions, where appropriate.

Comments: This recommendation remains valid.

The Long Term Conditions strategy, which the Scottish Government published in 2009, is no longer current. The more recently published Neurological Care and Support Framework, whilst not condition specific, encompasses ME-CFS within its approach.

Development of information systems would now need to be considered within the context of the Scottish Digital Health and Care Strategy.

Recommendation 12

When developing local approaches to long term conditions management, NHS Boards should ensure that: a) assessment and review mechanisms are in place for people with ME-CFS, including domiciliary assessments /review where needed; and b) appropriate referral mechanisms for people with ME-CFS to receive appropriate supportive therapies are in place; and c) appropriate referral mechanisms for people with ME-CFS to access services that can meet specific, symptomatic needs are in place.

Comments: This recommendation remains valid.

Appropriate resources should be available to ensure services to which people with ME-CFS are referred, or are accessing on a self-referral basis, have sufficient capacity to cope with demand.

Recommendation 13

When developing local approaches to long term conditions management, NHS boards should ensure that both rehabilitation services and specialist, symptom specific services have sufficient capacity to support people with ME or CFS in addition to the many other people with long term conditions for whom they will be providing care.

Comments: This recommendation remains valid.

Delivery of this recommendation should take into account the Scottish Government's Recovery and Rehabilitation Framework, which makes a commitment to develop once for Scotland Rehabilitation Strategy.

Care should be taken to ensure that ‘rehabilitation’ in this context is not limited to self-management and that rehabilitation is recognised as including treatment and care services.

Recommendation 14

Local arrangements for transition to adulthood should be extended to cover the needs of young people with ME-CFS. These arrangements should be included in local care pathways.

Comments: This recommendation remains valid, though the approach to transition should be in line with Commitment 5 of the Neurological Care and Support Framework.

Recommendation 15

NHS Boards in Scotland should develop, or facilitate the development of, self-management programmes to support people with ME-CFS.

These programmes should be subject to appropriate quality assurance:

a) for the NHS, such quality assurance should be provided by NHS Quality Improvement Scotland; and

b) for the independent or third sectors, guidance on quality assurance should be developed on a wide, partnership basis.

Comments: This recommendation remains valid, though the approach to self-management should be in line with the Neurological Care and Support Framework’s Commitments 1 and 11.

Care should be taken to ensure that the approach to self-management for people with ME-CFS is appropriate to meeting their needs.

Healthcare Improvement Scotland's General Standards for Neurological Care (published in 2019) should be explored as the mechanism for delivering this recommendation. This would be consistent with Commitment 11 of the Neurological Care and Support Framework.

Recommendation 16

Consideration should be given to developing an appropriate regulatory framework for the provision of self-management programmes by independent or voluntary sector providers as for independent healthcare providers.

Comments: Healthcare Improvement Scotland's General Standards for Neurological Care (published in 2019) should be explored as the mechanism for delivering this recommendation. This would be consistent with Commitment 11 of the Neurological Care and Support Framework.

Recommendation 17

a) Consideration should be given as to how best to facilitate the development of consultant posts for ME-CFS at NHS Health Board or NHS Regional Planning Group level across Scotland. These consultants should lead multidisciplinary teams to provide services at Tier 3.

b) Consideration should be given as to how best to provide an appropriate skill-mix in medical provision as part of the multidisciplinary teams to provide services at Tier 3.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Recommendation 18

NHS Health Boards / NHS Regional Planning Groups should prioritise the development of consultant led services, supported by a Tier 3 multidisciplinary team for ME-CFS. Consideration should be given to a more detailed workforce plan in the medium term.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Delivery of this recommendation must be consistent with the Neurological Care and Support Framework's Commitments 16 and 17.

Recommendation 19

In establishing MDTs, the NHS boards or NHS regional planning groups should:

a) ensure that once staff are appointed, an appropriate period of staff training is funded to allow an effective service to be established; and

b) ensure that MDTs have a suitable lead in time to develop effective collaborative working arrangements with local services at Tier 2.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Delivery of this recommendation must be consistent with the Neurological Care and Support Framework's Commitments 16 and 17.

Recommendation 20

NHS health boards and NHS regional planning groups should develop managed clinical networks in order to ensure that there are effective clinical services to meet the health care needs of people with ME-CFS.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Recommendation 21

NHS health boards and NHS regional planning groups, working with key stakeholders, should decide how best to ensure the development of such clinical networks for ME-CFS both regionally and across Scotland.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Recommendation 22

NHS health boards should ensure that services which operate at Tier 2 for ME-CFS should have the opportunity and capacity to participate in the development and operation of the clinical networks at regional and national level.

Comments: This recommendation remains valid, but must be considered in the context of Re-mobilise, Recover, Re-design: the framework for NHS Scotland.

Recommendation 23

NHS Quality Improvement Scotland should work with all interested parties to develop service standards for ME-CFS services in Scotland. Consideration should also be given to developing specific standards for clinical networks as part of this development.

Comments: This recommendation remains valid.

Recommendation 24

NHS Education Scotland should work with independent ME-CFS organisations to develop solutions to ME-CFS issues which would be included within education packages. These should be fed into undergraduate, foundation and professional training of health care staff across Scotland.

Comments: This recommendation remains valid, though consideration should also now be given to the extension of such work to the education and training of those in social and wider care settings.

The work now under way with Scottish Medical Schools and NHS Education Scotland reported by the Cabinet Secretary for Health and Sport to the Scottish Parliament's Public Petitions Committee, and the funding provided under the Neurological Care and Support Framework to ME-CFS stakeholder organisations who are also engaging with NHS Education Scotland, needs to be used to implement sustainable changes in education and professional training.

Recommendation 25

The third sector and independent sector agencies that work with and for people with ME-CFS should explore how best they can develop educational support for health care providers modelled on the approaches of similar agencies.

Comments: This recommendation remains valid.

Work undertaken in response to recommendations 23 and 24 (above) should include the third and independent sectors in order to proceed on a once for Scotland basis and to ensure consistency across all and any educational packages and resources which are developed.

Recommendation 26

The existing research strategy in Scotland in relation to ME and CFS research should be reviewed by the Chief Scientist's Office and a new strategy developed, aimed at broadening the evidence base for ME-CFS. To ensure effective communication of the existing, diverse evidence base, consideration could be given to developing a Centre for Research Excellence and Dissemination.

Comments: This recommendation remains valid.

The funding provided by the Scottish Government to establishing a James Lind Alliance Partnership to identify the top 10 research questions on ME-CFS is welcome. Ensuring these priorities inform the delivery of this recommendation will be critical.

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