

PE1690/H

Scottish Public Health Network submission of 11 July 2018

1) General comments

Thank you for requesting the views of the Scottish Public Health Network (ScotPHN) in relation to PE1690. We note that this is a petition made by an individual on behalf of the organisation *#MEAction Scotland* which we understand to be the local group within the wider, international *#MEAction* advocacy movement.

In November 2010 ScotPHN published a healthcare needs assessment on Myalgic Encephalomyelitis – Chronic Fatigue Syndrome (ME-CFS). This document, and its supporting appendices are still available on the [ScotPHN website](#). This work was commissioned by the Scottish Government. As the report notes, the objective of any Health Care Needs Assessment (HNCA) is to specify services and other activities which impinge on health care relating to a specific disease or diseases. In general, the principal activities involved in HNCA are:

- an assessment of incidence and prevalence;
- an analysis of the effectiveness and/or cost-effectiveness of services; and
- establishing the existing service baseline to help guide service development and redesign (ScotPHN 2010, Pg. 21)

Within this context, the major focus of the work was to understand the number with people who experience ME-CFS for the first time or on a continuing basis for whom the NHS (and wider social care services) in Scotland could need to provide diagnostic and supportive care. Further to this is sought to specify the way in which existing services could be developed or helped to operate differently to improve the services.

As a result not all elements of the petition were considered by the report.

2) Comments on the specific petitions

Investing in biomedical research and creating a centre of excellence for ME

This was considered as part of the report – specifically in the context of wider infrastructure around the service model proposed (see Section 12.3). This consideration underpinned a specific recommendation that:

“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.”
(ScotPHN 2010, Pg.106)

The ScotPHN healthcare need assessment would support this element of the petition.

Ensuring healthcare professionals' training and education materials reflect the latest scientific evidence

This was considered as part of the report (See Section 12.2). Two recommendations were drawn from this section:

“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.” (ScotPHN 2010, Pg.105)

“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.” (ScotPHN 2010, Pg.106)

The ScotPHN healthcare need assessment would support this element of the petition.

Providing specialist care for patients and discontinuing the harmful treatments graded exercise therapy (GET) and cognitive behavioural therapy (CBT)

The provision of specialist NHS care – within the context of a wider tiered model of care that also included primary, community and social care provision – forms the main considerations of the healthcare need assessment. (See Section 11). This was informed by the evidence considered relating to service design and effectiveness both from ME-CFS services and more broadly based approaches to effective service models across health care systems. Recommendations 9 to 22 within the report all relate to the model of service proposed, though it should be noted that these are more broadly based than simply what may be termed “specialist” services. This is because a specialist service does need to operate within the context of wider service provision.

The ScotPHN healthcare need assessment would support this element of the petition; though it would note implementation on those recommendations relating to “specialist” services in isolation may not provide an effective, holistic service response.

The healthcare need assessment did not consider the clinical effectiveness of specific treatments or treatment regimes. Rather, it assessed the similarities and differences between the published clinical guidelines that were available prior to 2010 with a view to establishing the scope for clinical guidance for Scotland. (See Section 8). This consideration led to a single recommendation that:

“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.”
(ScotPHN 2010, Pg. 70)

Since the publication of the ScotPHN healthcare need assessment, considerable further work has been published that could inform clinical guidance, not least of which has been the publication of – and challenge to – the **P**acing, **G**raded **A**ctivity, and **C**ognitive Behaviour Therapy; a Randomised **E**valuation (PACE) trial.

Making recommendations regarding specific therapeutic approaches was beyond the scope of the health care need assessment, so ScotPHN has no view on this part of the recommendation.

ScotPHN is not in a position to assess if the evidence base has developed sufficiently to now allow a SIGN guideline to be developed.

3) Comments on the verbal evidence presented to the Committee

ScotPHN has reviewed the wider discussion which formed the basis of the verbal evidence taken by the Petitions Committee. We note that queries were raised by Committee members regarding the recommendations contained in the healthcare need assessment and why they were not implemented in the period after 2010.

These are not issues on which ScotPHN has a view. However, we would commend the overall healthcare need assessment, rather than consider specific elements of, or recommendations from, the report in isolation.