

## **Report of the Task and Finish Group on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)**

### **INTRODUCTION**

There is very limited evidence to support how CFS/ME should be assessed, diagnosed and treated. The National Institute for Clinical Excellence (NICE) published Guidelines for the Management and Diagnosis of CFS/ME on 22 August 2007 which set out the general principles of care and diagnosis and initial management. These have been heavily contested by some patient groups and a Judicial Review was mounted. This was overturned in court.

The Map of Medicine has been procured by Informing Healthcare for all NHS Wales staff. It is an online clinical knowledge resource designed and developed by healthcare professionals to provide specialist level information to the right person at the right time. Map of Medicine provides 24/7 access to evidence-based clinical pathways grouped into broad areas of clinical practice, via an intuitive web-based interface. Each local Health Board can localise with colleagues across primary and secondary care to manage their own localised version of the tool, ensuring that Executives sign off this process locally. The Map of Medicine currently has a care pathway on CFS/ME, which has been developed by Royal Colleges and experts from across the UK known as an 'International status' care pathway.

The NHS has made little progress in implementing the NICE guidelines, which may be partly because of the lack of consensus and patient numbers are considered to be very small.

The Minister for Health and Social Services asked that a task and finish group be set up to support efforts to improve services for CFS/ME. To tackle the lack of consensus and to promote service development, the Minister was keen to secure agreement on a care pathway which could be implemented across Wales to ensure consistency and equity of access.

The Minister also wanted the task and finish group to comment on whether people with or suspected of having fibromyalgia should be referred and managed in a similar way to people with CFS/ME.

On 28 August 2009, the Chief Executive of the NHS wrote to the Chief Executives of the new Local Health Boards (LHBs) informing them of the Minister's decision to establish a task & finish group and asking each LHB to undertake a baseline assessment, based on the NICE guidelines, of the services provided to people with CFS/ME within both acute and community settings by 30 November 2009.

### **Baseline Assessments**

A summary of these assessments is at out in appendix 1. It is apparent from these assessments that services for CFS/ME are either very limited or not available at all.

## **Task and Finish Group**

The terms of reference for the Task and Finish group for CFS/ME were as follows:

1. To provide a written report to the Minister for Health and Social Services by the end of March 2010 which:-
  - Recommends a care pathway for implementation locally across Wales.
  - Recommends how existing services could develop and improve to comply with the proposed care pathway to meet needs of children, young people and adults with CFS/ME in Wales in a clinically and cost effective way.
2. As part of the report, comment on whether people with or suspected of having fibromyalgia should be referred and managed in line with the NICE guideline on CFS/ME.
3. In fulfilling this task, the Group must ensure that there is adequate service planning and multi disciplinary clinical input in to the work of the Group including children's and adolescent services and engagement with the third sector patient groups.
4. To take account of:
  - Related and relevant WAG policy, such as work to manage people with chronic conditions more effectively
  - The latest evidence and clinical practice relating to diagnosis and treatment for patients with CFS/ME
  - Existing model care pathways
  - The role of Map of Medicine
  - The outcome of the LHB baseline assessments of existing services against the NICE guidelines
  - The current and forecast financial pressures on other NHS services.

Membership of the Group included:

Mr Peter Lawler (Chair)	Deputy Director of Community, Primary Care & Health Services Policy, WAG
Dr Sarah Watkins	Senior Medical Officer, WAG
Mrs Shona Sullivan	Medical Director, Cwm Taf HB
Jan Smith	Therapies Director, Aneurin Bevan HB
Paul Hollard	Planning Director, Cardiff & Vale HB
Nigel Monaghan	Public Health Wales
Carol Shilabeer	Nursing Director, Powys HB
Ann Noyes	Children's Health Branch, WAG
Cathy White	Major Health Conditions, WAG
Matthew Thomas	Secretariat, Major Health Conditions, WAG

The Group invited written views, information & evidence from the following organisations:

WAG Advisory Structure

Welsh Medical Committee  
Welsh Nursing & Midwifery Committee  
Welsh Dental Committee  
Welsh Optical Committee  
Welsh Pharmaceutical Committee  
Welsh Scientific Advisory Committee &  
Welsh Therapies Advisory Committee

NHS Organisations

LHBs  
Welsh Ambulance Trust

Service User Groups

Welsh Association of ME Support (WAMES)  
Fibromyalgia Society  
Cerebra  
Action for Young People with ME

**Methodology**

A questionnaire was designed around the terms of reference and sent out to relevant organisations. A summary of the responses to the questionnaire are at appendix 2. In analysing the responses, the Group noted that there was frequent support for the Map of Medicine care pathway.

The Group also received a verbal presentation from the Welsh Association of ME Support (WAMES). A copy of this is at appendix 3.

The Group issued a further questionnaire asking for comments on the strengths and weaknesses of the Map of Medicine care pathway and whether there was support for the development of a Welsh Map of Medicine CFS/ME pathway. A summary of the responses to this is at appendix 4, and most of the responses were supportive of using the existing 'international status' Map of Medicine care pathway for CFS/ME and developing it further as an NHS Welsh care pathway for CFS/ME.

Responses received on fibromyalgia were mixed. The Fibromyalgia Society did not support managing people with fibromyalgia in line with those who have CFS/ME because it sees the needs of fibromyalgia being unique to this condition.

## **Recommendations**

The Task and Finish Group on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) would recommend the following:

### CFS/ME

1. The Welsh Assembly Government should formally endorse the existing 'International Status' Map of Medicine Care Pathway for CFS/ME
2. The Welsh Assembly Government should task Informing Healthcare as procurer of the Map of Medicine in Wales to adapt and develop the existing 'International status' Map of Medicine care pathway for CFS/ME into a 'NHS Wales status' care pathway. This process must be led by clinicians in consultation with patient groups and supported by planners.
3. The Welsh Assembly Government should task Local Health Boards as follows:
  - With immediate effect – to develop primary, community, secondary and tertiary services in line with the existing 'International Status' Map of Medicine care pathway
  - Overtime, to develop services further in line with the proposed 'NHS Wales status' Map of Medicine care pathway and to adapt the 'NHS Wales status' care pathway at LHB level to reflect local protocols and referral pathways.

### Fibromyalgia

4. In recognition of the specific needs of people with or suspected of having fibromyalgia, the Welsh Assembly Government should mirror the recommendations set out above for CFS/ME separately for fibromyalgia. A separate 'NHS Wales status' care pathway can be created on Map of Medicine to reflect this.

Summary of Baseline Assessments

LHB	Assessment
Cwm Taf	<p>There are no therapeutic services for this type of patient, clinicians would refer them back to primary care.</p> <p>There are patients attending in whom this diagnosis is eventually made, usually by physicians. The LHB is unable to provide any treatment or ongoing support for them because the only evidence based treatment shown to have any effect in CFS/ME is Cognitive Behavioural Therapy, which is a psychologically based treatment. The service has not been funded historically and as such, the LHB does not have the service leads.</p> <p>However, symptomatic patients will be referred to the appropriate clinician, e.g. neurology, if it is believed that this would be of benefit.</p>
Abertawe Bro Morgannwg	<p>There is no existing service within secondary care in the LHB. Elements of such a service are being developed on a small scale such as:</p> <ul style="list-style-type: none"> <li>• Condition Management Programme (CMP) team are currently exploring the possibility of developing a Fatigue Management Module which is not aimed at CFS/ME patients but is intended for anyone for whom fatigue is a problem.</li> <li>• Service Chronic Pain Management Group for patients is being piloted at Princess of Wales Hospital by the Physiotherapy Department.</li> <li>• In Primary Care the only services available are those provided on an ad hoc basis by interested GPs.</li> </ul>
Cardiff and Vale	<p>At present within the LHB there is no formal agreed care pathway for the care of people with CFS/ME that individual practitioners conform to. Current referrals are addressed in a 'stand alone' appointment; if the paediatrician identifies that inputs from other professionals are required then they will refer on.</p>

	<p>The LHB would aspire to the implementation of the NICE guidance, however they do not have the resources to deliver such a quality multidisciplinary service for this group of patients.</p>
Betsi Cadwaladr	<p>The existing service in North East Wales has a dietician and a physiotherapist for one half day per week, plus a psychologist for one full day. In consequence the primary intervention is an illness-management programme delivered to a group of 12-14 patients at a time. The psychologists remaining half day is then used to provide individual therapy on a limited basis, either for people for whom the group is in some way not appropriate, or as additional input for those requiring it.</p> <p>Children are not catered for at all by the existing service and neither is there any kind of outreach provision for individuals too disabled to attend the clinic.</p>
Hywel Dda	<p>The LHB currently does not have any core services specifically for patients with CFS/ME. There are few people who will see patients with this condition but the service that they are offered varies widely.</p>
Powys	<p>The LHB currently commissions all secondary care services for patients with suspected CFS/ME from a number of external providers. It is often these providers who establish a CFS/ME or Fibromyalgia diagnosis and, as a result the Health Board will not be able to submit any baseline information regarding this acute care.</p> <p>However, the Health Board has an established Pain and Fatigue Management Centre based at Bronllys Hospital. The Centre provides inter-disciplinary pain and fatigue management service on an all-Wales basis for many conditions including those patients living with CFS/ME and Fibromyalgia (adult service only).</p>
Aneurin Bevan	<p>The Health Board currently has a low baseline of designated services available for patients with this condition.</p> <p>A patient who attends their GP practice with symptoms would initially receive counselling and any appropriate medication, with onward referral if necessary to a Consultant Physician who has an interest in fatigue. If it is a child they would be referred to a paediatrician.</p>

**CFS/ME Task and Finish Group Questionnaire Responses****Question 1**

	<b>Question 1: Which current published care pathway would you recommend for implementation locally across Wales?</b>
<b>Betsi Cadwaladr University Health Board</b>	The Map of Medicine pathway seems to be both comprehensive and to have the potential for the creation of a tailored programme for the individual.
<b>Betsi Cadwaladr University Health Board (Extra Questionnaire from Simon Neal, Consultant Clinical Psychologist)</b>	<p>I do not know of any. The NICE guidelines have limitations; they are not supported by the majority of patient organisations; They also advocate the use of interventions such as GET which are said by a significant proportion of sufferers to make people worse (See action for ME survey 2008). At best GET and CBT require high levels of skill and expertise in their application, which is not generally available.</p> <p>See <a href="http://www.nzgg.org.nz/guidelines/0084/040518_matrix.pdf">http://www.nzgg.org.nz/guidelines/0084/040518_matrix.pdf</a> for a comparison of international guidelines, which might give rise to some consensus.</p>
<b>Public Health Wales</b>	The National Public Health Service reviewed the available care pathways for CFS/ME in August 2009 and would recommend the Map of Medicine care pathways. These pathways, for suspected CFS/ME and the management of CFS/ME, are formulated from the NICE CFS/ME guidance and are freely available for the NHS in Wales. The pathways are clear and provide easily accessible supplementary information for each step of the process and were updated in October 2009 by the Map of Medicine.
<b>Cardiff and Vale University Health Board</b>	<ul style="list-style-type: none"> <li>• At present within Cardiff and Vale UHB there is no formal agreed care pathway for the care of children and young people with CFS/ME that individual practitioners conform to.</li> <li>• There is informal sharing of guidance and advice between consultant paediatricians.</li> <li>• Current referrals are addressed in a “stand alone” appointment; if the Paediatrician identifies</li> </ul>

	<p>that inputs from other professionals are required then they will refer on.</p> <p>We would aspire to the implementation of the NICE guidance produced in August 2007, however we do not have the resources to deliver such a quality multidisciplinary service for this group of patients.</p>
<p><b>Cardiff and Vale University Health Board 2<sup>nd</sup> Questionnaire (Peryn Morgan)</b></p>	<p>I believe current NICE guidelines are comprehensive and it is a well structured pathway . However the limitations are due to lack of knowledge of what is available and how we utilise services that are in place to fit into the pathway. For instance exercise referral scheme, EPP Walk for health schemes Employment advisors and Gateway Workers.</p>
<p><b>WAMES (Welsh Association of ME &amp; CFS Support)</b></p>	<p>WAMES is not aware of a published care pathway which fully meets the needs of people with neurological ME. The NICE guidelines, the RCPCH's guidelines and the Department of Health's <i>Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME) National Service Framework for Children, Young People and Maternity Services exemplar</i> have serious failings in the diagnostic and treatment guidance. WAMES' statements on the NICE guidelines are attached.</p> <p>The documents that could provide a basis for care pathways include the Canadian guidelines (1), Drs Shepherd &amp; Chaudhuri's guidelines (2), and Dr Franklin's <i>Doctor's guide to ME in children and Young People</i> (3).</p> <p>(1) Carruthers, Bruce M. &amp; van de Sande, Marjorie I <i>A Clinical Case Definition and Guidelines for Medical Practitioners: An Overview of the Canadian Consensus Document</i>  <a href="http://www.mefmaction.net/documents/me_overview.pdf">http://www.mefmaction.net/documents/me_overview.pdf</a></p> <p>(2) <i>ME/CFS/PVFS an exploration of the key clinical issues: prepared for health professionals and members of the public</i> by Dr Charles Shepherd MB MBS &amp; Dr Abhijit Chaudhuri DM MD MRCP. ME Association: 2008</p> <p>(3) <i>The Doctor's guide to ME in children and Young People</i> by Dr Alan Franklin FRCPCH DCH. Tymes Trust, <a href="http://www.tymestrust.org/pdfs/drguide.pdf">www.tymestrust.org/pdfs/drguide.pdf</a></p>
<p><b>Aneurin Bevan Trust</b></p>	<p>NICE Clinical Guidelines 53 (August 2007)</p>
<p><b>Powys LHB</b></p>	<p>There isn't one pathway which meets the requirements of a fully biopsychosocial approach that is</p>

	<p>currently published although the NICE guidance is fairly comprehensive. Key to dealing with the condition is the development of self-management strategies which are not sufficiently emphasised in the NICE guidance which focuses on professional-led interventions.</p> <p>The Welsh Pain Advisory Board, under the management of the Welsh Pain Society, is currently producing a primary care pathway for the management of pain. This is currently out for consultation and the significant work already undertaken by the WPAB may provide a framework for considering a pathway for CFS/ME. This was in response to WAG document on Pain which included CFS/ME within its remit.</p> <p>Map of Medicine has also produced a useful pathway for the management of suspected CFS/ME. Pathways produced by English NHS Trusts would often not be realistically applicable to the very rural and sparsely populated situation in many parts of Wales but due to the geography of Powys they are often used.</p>
<p><b>Welsh Therapies Advisory Committee (WTAC)</b></p>	<p>As a consequence of accurate diagnosis by medical practitioners:</p> <ul style="list-style-type: none"> <li>ÿ Use of “Map of Medicine” as basis for the core pathway but also using</li> <li>ÿ Leeds and West Yorkshire CFS/ME Service Care pathway and</li> <li>ÿ The National Essex Neurosciences CFS Care Pathway for additional information.</li> </ul> <p>Map of Medicine could be tailored to suit local services</p>
<p><b>Cerebra</b></p>	<p>I do not have the in-depth knowledge of the CFS/ME specialist organisations on this question, and have not studied every available pathway. I know they intend to respond separately. However, thinking of children and their families specifically, I agree with the view of the draft prepared for the Scottish Public Health Network (Phil Mackie et al, May 2009) which says “Different care pathways and services need to be developed for groups with particular requirements such as children and young people; the severely affected; housebound and bed-bound patients; and those living in remote or rural areas. Where the patient group is small, such as in remote and rural areas, it may be necessary to develop services for CFS/ME integrated with the management of other chronic diseases, or to work in partnership with other NHS Boards.” I would want to add before the word</p>

	<p>“chronic”, the words “neurological and”. Also I agree with that draft in its view that separate thought needs to be given to the pathway for young people in the process of transition between children’s and adult services.</p> <p>The English NSF CFS/ME exemplar (2004, about “Megan”) encourages joined-up working between services. Sometimes it does not go very deeply into the service mechanism through which help will be given, for example it considers the guidelines on medical needs in education and broadly the Disability Discrimination Act, but seems not to take in the codes of practice on SEN and specifically the Special Educational Needs and Disability Act; also it does not specify who gives Megan the information about relevant voluntary services in Transition – in practice, signposting (and/or information prescription containing signposts) is very sporadic and when it occurs, is not always effective. What is done in the exemplar, to signpost straight to the specialist organisations for CFS/ME (in Wales, in our case), I think is good. In terms of its more clinical recommendations, I believe the specialist organizations will comment. In terms of other official documents, some of these are a bit different in Wales. The (imaginary) GP says that the CFS/ME group of conditions are not serious, but they can have life-changing consequences.</p> <p>Services in general, not only for CFS/ME, tend to have more administrative difficulty with people who move in and out of them as a result of conditions that have different effects at different times. I think it would be useful to have, within the framework, defined ways in which both children and adults could move in and out of types of service provision without fearing that if they improve enough to sign off from a service (OT, for example) they will experience delay or difficulty getting the service back again when they need it.</p>
<b>Abertawe Bro Morgannwg LHB</b>	Map of Medicine pathways for CFS that are based on NICE Clinical Guideline 53 (2007)
<b>Condition Management Program (Response from Cwm Taf LHB)</b>	
<b>Fibromyalgia</b>	I would suggest an Integrated Care pathway, with Multidiscipline, as there are lots of areas that need

<b>Support Group</b>	<p>to be addressed and covered within Chronic Conditions.</p> <p>All Wales Neuroscience, Care Pathways with living with long term neurological conditions. Community Health and Community Social Care need to be included.</p>
<b>The Young ME Sufferers Trust (Tymes Trust)</b>	<p>There is no published care pathway that we know of, which we would recommend.</p> <p>We recommend GP management supporting self-management, under consultant where needed, but not where the person is managing their illness well. GP support for practical measures such as benefits, practical home aids and home/virtual tuition are vital.</p> <p>Clinics supplying psychological therapies for ME have in our experience generally proved a disaster in England and we would not like to see Wales going the same way.</p> <p>We carried out a grant-funded exercise in what young people and their families want from a specialist clinic, where the health authority is setting one up. Virtually none of their views have been met. The link is:  <a href="http://www.tymestrust.org/pdfs/ourneedsourlives.pdf">www.tymestrust.org/pdfs/ourneedsourlives.pdf</a></p> <p>In terms of official care pathways: The children's chapter of the Dept of Health Report of 2002, which we assisted to write in our capacity as key members of the Chief Medical Officer's children's panel, comes closest to what we would recommend, out of everything published so far.</p>
<b>The ME Association</b>	<p><b>Please note that most of my comments to the questions below contain very similar observations and recommendations to those that are contained in the (December 2009) preliminary report on the Inquiry into NHS Service Provision for people with ME/CFS that has been produced by the (Westminster) All Party Parliamentary Group (APPG) on ME. I have already forwarded an electronic copy of this APPG report.</b></p> <p>I am not aware of any 'published care pathways' for ME/CFS that I would like to recommend.</p> <p>I am, however, aware of a number of ME/CFS referral services whose approach I would be happy to</p>

	<p>recommend.</p> <p>In particular, I suggest you approach Dr Abhijit Chaudhuri, Consultant Neurologist, Essex Centre for Neurosciences, Queen's Hospital, Romford, Essex to find out about their multidisciplinary ME/CFS service, which is neurologist led and includes in patient facilities for the assessment and management of severely affected patients.</p>
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Question 2

	<p><b>Question 2: How do you think existing services could develop and improve to comply with NICE guidelines and proposed care pathway to meet the needs of children, young people and adults with CFS/ME in Wales, in a clinically and cost effective way?</b></p>
<p><b>Betsi Cadwaladr University Health Board</b></p>	<p>The existing service in North East Wales has a dietician and a physiotherapist for one half day per week, plus a psychologist for one full day. In consequence the primary intervention is an illness-management programme delivered to a group of 12-14 patients at a time. The psychologist's remaining half day is then used to provide individual therapy on a limited basis, either for people for whom the group is in some way not appropriate, or as additional input for those requiring it.</p> <p>The first improvement that could be made is more time for additional 1:1 input by physiotherapist and dietician (in line with the NICE recommendation for individualised treatment – portions of the overall intervention still being in a group setting), ongoing assessment of new patients rather than this taking place between groups, and for service and staff development.</p> <p>Children are not catered for at all by the existing service and neither is there any kind of outreach provision for individuals too disabled to attend the clinic. Clearly to begin to provide services for these individuals would require considerable investment and planning since the existing provision is not more than adequate for the mobile adult population.</p>
<p><b>Betsi Cadwaladr University Health Board (Extra Questionnaire)</b></p>	<p>The catch is in the question.</p> <p>If cost effective means cost neutral, then the NICE guidelines could not be adopted in North Wales. In my own services – covering half of the Health Board area, resources are currently 2 sessions (1 day) of Clinical Psychology 1 session of Physiotherapy and 1 session of Dietetics. In our locality there are no specialist diagnostic services and no consultant or GPwSI interest in providing these. We are referred</p>

<p><b>from Simon Neal, Consultant Clinical Psychologist)</b></p>	<p>about 60 people per year from a small group of GP's who consider CFS/ME to be a recognised condition. Individual assessment and individual therapy as proposed by NICE could not be provided by current resources. At the moment we provide an 8 week group based symptom management programme with very limited follow-up. Domiciliary services are not and could not be provided.</p> <p>Compliance with NICE guidelines should not be the aim per se. The NICE Guidelines suffer from a considerable limitation in scope. The NICE guidelines failed to address the issue of aetiology of CFS and also failed to adequately address issues around diagnosis, for example compare the Oxford Criteria with the Canadian Criteria. NICE also addressed treatment of CFS as if it were investigating the efficacy of a drug and limited it's evidence base to RCT. Helping people who suffer from Chronic Fatigue is an art as well as a science, it is multifactorial in nature and requires a breadth of skills and interventions, including, most importantly, a good grounding in the theory of illness perceptions and health related behaviour. The fact that CBT and GET are advocated is an indication of the poverty of research in the area rather than an indication of the strength of outcomes for these interventions.</p> <p>In our area the development of a broad range of service would require:</p> <ul style="list-style-type: none"> <li>• Systematic education of GP's about the validity of the diagnosis and strategies for it's management that go beyond prescribed exercise and referral to mental health services</li> <li>• The development of extensive networks and pathways of care between Neurology, Rheumatology, Psychiatry, Chronic Pain and Paediatric services.</li> <li>• The appointment or identification of a specialist physician</li> </ul> <p>The development of the specialist service currently provided, both in terms of time and speciality – e.g. inclusion of an Occupational Therapist with an interest in Vocational support.</p>
<p><b>Public Health Wales</b></p>	<p>A mapping exercise performed in 2006 by the Welsh Association of ME and CFS Support (WAMES) group estimated a prevalence of 11,830 adults and children with CFS/ME in Wales. The survey found that less than 176 CFS patients had been treated each year in Wales i.e. 1.5% of the CFS/ME population in Wales. <sup>1</sup> The authors also reported on existing services in Wales. There were 2 clinics in North Wales that offer a management service, but no diagnostic service and an inpatient service at Bronllys Hospital in Brecon that offers group cognitive behavioural therapy (CBT), graded exercise therapy (GET) and relaxation therapy. It would appear therefore that there is considerable unmet need for these patients and services for diagnosis and treatment should be increased.</p>

The Welsh Assembly Government (WAG) has devoted considerable effort into developing strategies to improve the care of patients with long term conditions. The service improvements recommended by the Assembly are relevant to the care of CFS/ME patients. The WAMES survey <sup>1</sup> indicated that there were good results from CFS/ME patients who had attended the Expert Patient programme, developed as part of the chronic conditions strategic framework.

Effective services in Wales must be in place to fulfil the following recommendations from the guidelines and care pathways for CFS/ME:-

- Early effective diagnosis with prompt referral to a paediatrician within 3 months for children and young persons, or referral after 4 months to a specialist for adults. It has been demonstrated that early diagnosis has a positive impact on prognosis.
- Healthcare professionals, particularly in primary care should have appropriate skills and expertise in the diagnosis and management of CFS/ME; this may require training programmes to be developed.
- Development of individualised patient centred management plans.
- Assignment of a named healthcare professional to the patient, particularly those severely affected.
- There are reports of severely incapacitated patients unable to access healthcare services for years. There is therefore a need for development of specialist services to deal with the severely affected patients and this may require domiciliary services.
- More specialists are needed. A 'champion' with interest and specialist knowledge in CFS/ME is required in Wales to lead service development.
- Adequate and timely provision of services providing CBT, GET and pacing.
- Despite the lack of existence of high quality evidence for the effectiveness of alternative therapies, some patients find such treatments helpful.
- Planned and managed transitional care. There are reports of patients who are abandoned once they reach the age of 16.
- It is vital that the knowledge and experience of the few specialist paediatricians and consultants is disseminated throughout the NHS with CFS/ME being included in GP training.
- Planned reintegration to education for children and young adults.
- Adequate provision of wheel chairs and other aids.
- Therapists delivering any treatment, but particularly GET and CBT should be receptive to

	<p>patients' wishes and should be trained in CFS/ME management.</p> <p><sup>1</sup> Welsh Association of ME &amp; CFS Support. <i>More tortoise than hare. A report on health services for adults and children with ME &amp; CFS.</i> Cardiff: WAMES; 2007.</p>
<b>Cardiff and Vale University Health Board</b>	<ul style="list-style-type: none"> <li>• A small number of joint appointments occur, but these are <i>ad hoc</i>. They require “good will” and flexibility between colleagues e.g. joint paediatric appointment with CAHMS or Psychology or Physiotherapy. The current system that is based on waiting list drivers does not facilitate this process. In previous years there was a community based clinic developed locally in conjunction with Physiotherapy and Psychology. This clinic was never formally resourced and was dependent on flexibility. This flexibility was lost with the emergence of waiting list initiatives and Physiotherapy then Psychology input was withdrawn. The clinic ceased in 2004.</li> <li>• This suggests that any low cost local option would require adaptation of existing waiting list initiatives. This will not occur as the waiting list driver is a national WAG strategy.</li> <li>• This means that a ring fenced resource must be identified to address this pathway, and this would have implications for a wide group of staff with different professional backgrounds. To achieve this we would require a high level agreement within the UHB.</li> <li>• The same staff groups provide services to vulnerable children with complex and statutory needs e.g. educational statements and children with complex disability. It would be inappropriate to dilute resource to these children hence new resource will be required</li> <li>• The reality is that the majority of these children are lost within general outpatient services, and therapy provision is virtually non-existent. There are no existing services to develop and improve and so any care pathway in Wales would have to be built from a very low baseline. MDT services can be clinically efficient and cost effective if they are managed in the correct way,</li> <li>• We would support consideration of the development of a managed clinical network</li> </ul>
<b>Cardiff and Vale University Health Board 2<sup>nd</sup> Questionnaire (Peryn Morgan)</b>	<p>For me it is about working in Partnership and networking so agencies are continually updated what is available out there. In order that we make use of services out there instead of trying to invent new ones . for instance in Cardiff there is a voluntary scheme called pedal power and this client group could use that as a form of graded exercise. It is also available for all ages .</p> <p>I am also aware of Cardiff and Vale voluntary sectors have directories which services could add to.</p> <p>What I have discovered having worked in primary care is that different areas do things difficulty it would be good to access a site which has a matrix of what’s on offer in each locality throughout Wales.</p>

<p><b>WAMES (Welsh Association of ME &amp; CFS Support)</b></p>	<p>There are no existing services which cater specifically for adults, children or young people with neurological ME. There are no domiciliary services. Severely affected patients and those with mobility problems or those who are in relapse are often even refused home visits by the GP or nurse when they are unable to attend the surgery.</p> <p>There are no diagnostic services.</p> <p>The 2 <b>North Wales CFS Clinics</b> offer treatments for people with chronic fatigue in line with the NICE guidelines. WAMES does not believe that these services are appropriate for people with ME – they do not take enough account of the ongoing biomedical dysfunction in many of the body’s systems, relying on treating faulty illness beliefs and physical deconditioning. Patients undergo a strict selection process which does not appear to be based on the nature of the illness, but on a much more pragmatic assessment related to how they get their funding. Some patients have valued the pacing theory, meeting with other patients and exchanging experiences &amp; information about treatments and learning about stress reduction, relaxation etc, but many past patients report that they have felt alienated by the attitude to their illness, have relapsed after being encouraged to avoid daytime rests and do more than they can sustain. Many patients have been encouraged to return to work at the expense of all family and social life, and have not seen long term improvement in their ability to function, if anything they have experienced a worsening of their condition due to inappropriately being encouraged to go back to work full time when they are simply not well enough to cope and they can then get no help from the benefits system.</p> <p>WAMES is concerned that there has been no longitudinal study of the clinics’ work and no published results that indicate anything more than a small improvement in function. Their assessment or procedures do not appear to have taken account of recovery from other factors. They have not used control groups or quantitative and double blind verification. We acknowledge that people with some fatigue conditions might find the clinics’ approach helpful but they are suitable for only a very small number of people with ME, and who are well enough to participate. Many patients are too unwell to attend such courses – the travelling, length of sessions, and sensory overload can lead to relapse. WAMES questions the cost effectiveness of such a ‘one size fits all’ approach to an ill-defined group of patients, and is particularly concerned in light of the findings of the assessment of the Belgian CFS</p>
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centres (7).

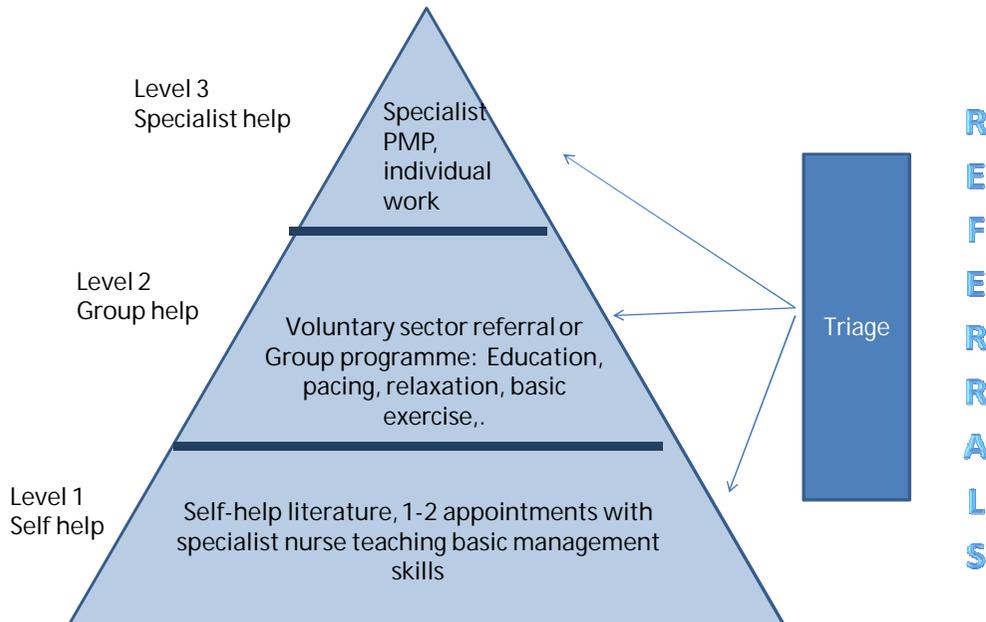
The **Bronllys fatigue and pain service** caters for only a small group of potential patients, due to the need for people to be well enough and mobile enough to cope with the course, the travelling, lengthy sessions in a busy day and lack of lifts in the building.

A new approach needs to be developed which will give early diagnosis and management advice to patients close to home. A small proportion of people with ME and CFS could be managed at Level 2 of the **WAG CCM** model: the 'Practice based' CCM Programme, but a significant proportion would need the support offered at level 3: 'Network based' CCM services. This would need to be underpinned by thorough education of the participating GPs, district and community nurses and therapists in order to avoid the current situation of diagnoses being given by untrained therapists, the lack of understanding of low energy levels and post-exertional symptoms, inappropriate advice being given about rest, exercise, education etc. and accusations of abuse or neglect being made about parents of ill children. Being able to share GPwSI services and neurology nurses & therapists with other neurological conditions would make the development of services to people with ME more cost effective.

A past survey has estimated that 25% of adults and children with ME are severely affected and could have complex diagnostic and care needs. Not all would need hospital admission as hospitals can be very stressful places for severely affected patients. Level 4 support: 'Case managed services' would be required. Because the stresses of travel can lead to a worsening of symptoms, it would not be desirable for such patients to be transported to England for treatment, especially children, who particularly need their family support network. A clear referral system would also need to be created as there are currently no neurologists or general consultants within Wales with a special interest in ME or overlapping conditions. There are also few in England, and as the WAG policy is to improve the quality of care closer to the patients' home, identification of clinical champions would appear to be a matter of priority. With appropriate training and support severely affected people with ME who need specialist tube feeding or nursing care can be managed at home, thus avoiding problems from the noise, light and odours in a hospital setting.

According to the English CMO's 2002 Report on CFS/ME the number of patients estimated to have ME could be as high as 0.4% of the population, or 11,974 patients (Figures relate to 2008 Mid Year

	<p>Estimates of the Population taken from this link  <a href="http://wales.gov.uk/topics/statistics/headlines/pop2009/hdw20090827/?lang=en">http://wales.gov.uk/topics/statistics/headlines/pop2009/hdw20090827/?lang=en</a></p>
<b>Aneurin Bevan Trust</b>	<p>There is experience in England from the establishment of specialist units. By looking at these I think the model to follow is from Barts.</p> <p>Their website is <a href="http://www.bartscfsme.org">www.bartscfsme.org</a> and is full of useful information and handbooks for exercise.</p>
<b>Powys LHB</b>	<p>Chronic conditions such as CFS/ME can be effectively and efficiently managed through a biopsychosocial approach. Such an approach sometimes needs to be delivered in a specialist, secondary care setting. However, early intervention with this approach (rather than with a purely biomedical one) can prevent people from becoming entrenched in 'medical dependency' and from ever requiring this secondary level of care.</p> <p>Within Powys we are currently developing Local Enhanced Services (LES) for the management of chronic pain which may also be an efficient and cost-effective model for serving people with CFS. Whilst still in its development stage, these LESs are intended to be arranged around groups of current GP practices. Under the guidance of a GP with a special interest or responsibility within that group, services will be provided, within existing premises, to all patients served by that group. By drawing on central expertise for training and/or consultancy (in Powys, the Bronllys Pain &amp; Fatigue Management Centre) local staff can take primary responsibility in a cost-effective way whilst avoiding the duplication of services and also being confident that they have remote access to experienced clinicians. Each group of practices can develop services as appropriate to their local needs but a model of its possible constituents is below:</p>

	 <p>Level 3 Specialist help</p> <p>Specialist PMP, individual work</p> <p>Level 2 Group help</p> <p>Voluntary sector referral or Group programme: Education, pacing, relaxation, basic exercise,.</p> <p>Level 1 Self help</p> <p>Self-help literature, 1-2 appointments with specialist nurse teaching basic management skills</p> <p>Triage</p> <p>R E F E R R A L S</p> <p>It may be necessary for a specific pathway to be developed for children that is triaged through, for example, 'Women's and Children's' services. Children would benefit from this being delivered through school and education, rather than conventional medical, routes.</p>
<p><b>Welsh Therapies Advisory Committee (WTAC)</b></p>	<p>As current services are patchy and fragmented for CFS/ME sufferers at present, it is unlikely that reliable services can be established without some investment. A range of actions would have a positive impact:</p> <ul style="list-style-type: none"> <li>• Undertake a baseline assessment to identify where and to what extent current services are established e.g. therapists with existing specialist knowledge delivering an adhoc CFS/ME</li> </ul>

	<p>service.</p> <ul style="list-style-type: none"> <li>• Establish effective triage systems</li> <li>• Establish GPs with a special interest</li> <li>• Consider a “Hub and Spoke” model with central specialist unit and outreach local teams to ensure reliable access across a geographical area.....</li> </ul> <p>.....utilising mainstream services in a more co-ordinated and structured way e.g. community multi-disciplinary teams to deliver some of the “spoke” roles.</p> <ul style="list-style-type: none"> <li>• Utilising a therapeutic group approach for example for Lifestyle Management is as a cost-effective way to deliver services to people with a mild to moderate presentation.</li> <li>• 1:1 work with severely affected clients by therapists using bio-psychosocial model</li> </ul> <p>A shared care approach with care co-ordinator or key worker role.</p>
<b>Cerebra</b>	<p>In view of the differential diagnosis, the other conditions that have to be excluded when someone is showing signs of having CFS (such as chronic heart disease, psychiatric illnesses, thyroid disease, connective tissue diseases, chronic anaemia, neoplastic disease, chronic infections, endocrine diseases, inflammatory bowel disease, other chronic illnesses, and drug abuse), it would seem to be something that, for children has to go to someone with specialised knowledge initially. An understanding among other professionals that a child showing signs associated with these conditions, such as extreme tiredness, might have a medical condition would help, so that the child can reach a specialist who is able to give a differential diagnosis. In view of the tendency among some professionals to prejudge conditions as “all in the mind” or “all in the parenting skills” (or even, “all in the parent’s mind”) if they have no definitive diagnostic test, I think it is important that the specialists should be professionals sympathetic to the understanding of this group of conditions as organic. The gatekeepers such as GPs would also need enough of this perspective, and not, again, to prejudge or dismiss the family’s concerns. In this respect, CFS/ME conditions seem to be where AD(H)D and ASD were a few years ago. In my helpline work, even today I still come across the occasional professional who believes that AD(H)D and / or ASD do not exist. The other problem that CFS/ME is likely to share with these other two groups of conditions is of delayed and / or borderline diagnosis. Clinicians do not necessarily see this as a problem, but the trouble is, it can have knock-on effects to other services and the stresses that families find themselves under. It will happen by definition with CFS/ME because under the Guidelines the child must have had symptoms for three months. I have sometimes found that although a child is having difficulties with schoolwork, for example, the illogical conclusion that is reached by some services is that</p>

the child and family should not receive help because the child has not been given a diagnosis, or because it has been defined as something like “ASD characteristics” rather than “ASD”. This is in spite of the fact that the underlying legislation, entitling children to assessment for services, does not exclude those who have practical and functional needs, whatever the cause. I wonder if some mechanism like a provisional note, for example that a child’s condition is to be investigated in 3 months’ time, might help to get other services in place in the initial stages. Also, parents need information that will reassure them that they are not being judged, and that explains any delays in the processes of putting help in place, and of what is involved in differential diagnosis.

Admittedly I have only come across it rarely, but there have been helping professionals who have refused to accept the diagnosis of a specialist clinician. One was a psychotherapist in a CAMHS service whose influence on the child was profound, and the ensuing battle was very difficult for the family, as well as costly for the hospitals involved. I think there is a potential for this to happen with CFS/ME because of the historical schools of thought, one of which says it does not exist, although I am not quite sure what can be done about it. Having the NICE Guideline should be useful in this respect (although I understand from WAMES that, as a guideline for treatment, it is less useful). So perhaps as well, it would be useful for the Care Pathway to be attached to the description of the effects of CFS/ME conditions, and not only to the diagnostic labels and the academic acceptance of their existence. I think what could also help with this is if a leaflet or a factsheet could be produced for information to patients and carers, as the guideline suggests, and if this leaflet acknowledges the reality of the condition.

Perhaps it would also help if things were easier for LEAs and schools to maintain the flow of a child’s education when they have to have a lot of time out of school. Children in these circumstances seem to get very little education unless parents choose to home-educate, even though in theory the service is there, as in the NSF exemplar. I am not sure what the issue is, whether it is just about resources – a shortage of home tutors, for example. LEAs, once again, would need understanding of the condition particularly in cases where a child has a Statement of Special Educational Needs and therefore according to the Code of Practice the LEA has to be asked before the family can choose to educate, themselves, at home.

Someone who can advise in practical ways about the day-to-day management of a child’s medical issues, and the low spirits that can set in with a long-term and tiring condition, could be valuable to

families – such as a nurse or counsellor, maybe, with additional CFS/ME-specific training. We know that having a member with additional needs affects the whole family, also that some of the stresses on families of children with additional needs (again, not just CFS/ME) come from their interactions with professionals. (A member of Cerebra’s telephone stress counselling service, Prof. Ann Edworthy, has written a book “Managing stress for carers” which makes use of the results of research on this.) In conditions where there is disagreement among professionals, with some believing entirely in nurture and not at all in nature, this can be accentuated. Those of us in voluntary organisations should hold up our hands here, perhaps, and say that we have not done enough to raise awareness of these conditions within society as a whole.

When it comes to the stage of transition to adult services, college etc., parents of children whose education has been interrupted, or whose development is slow, often feel that they have not had the same chance as other children to reach their potential and want this milestone to be delayed educationally. This applies to a range of conditions, not only CFS/ME. The transition support process from age 14 onwards with options, information and help finding resources and switching over to adult services, is officially only offered to children and their families where there is a Statement of Special Educational Needs in place. Although some others can access it if they request it, they need to know they can do that. I think it would be helpful if some kind of transition support – even just through one professional, rather than necessarily a team - was made proactively available to children and families where they have missed out on some of their education for medical reasons, whether or not they have a Statement. (In an ideal world, it would be good if young people who have missed large amounts of education could be funded to do some more learning later. I suppose one difficulty with that is that their school place will have been funded, even when they were not there.) On the medical front, to be transferred to an adult system that continues to recognise that the young adult has CFS/ME, and gives them an assurance of continued access to services when they need them, would be reassuring to families who feel that they as yet cannot give each other independence because of continued needs. At some stage, the Jobcentre and employers are also likely to need understanding about the effects of these conditions.

In terms of the NICE recommendation about referral to specialists, and looking at the pattern that has developed in neurological and other services in Wales, it would seem useful for children not to have to travel so far to see a specialist. At the moment, I understand that at least some children from Wales go

to an already overstretched service based in Bath, which is quite expensive as well as tiring. An alternative to families travelling might be a combination of domiciliary and remote assessment and services (NICE guideline section 1.1.1.3). This might tie in with some of the other ideas currently being discussed in Wales in terms of telemedicine and neurorehabilitation.

I feel a bit concerned about the therapies mentioned by NICE. Anecdotal comments (not specifically about CFS/ME) suggest that cognitive behavioural therapy is very variable in quality, and seems to help some people and not others who are referred for it. Exercise therapy seems to have a bad press among users and I wonder if this is because (as I am told) in England, CFS/ME and some other conditions are being treated as if they are all the same. If exercise is done in the best way it could be, perhaps then it could be of help. I am only guessing here, but people who apply exercise therapies, such as physiotherapists, usually tend to push patients to exert themselves a little bit beyond what they think they can do, in order to build up strength, function etc. If this idea is applied too enthusiastically to someone with CFS/ME, it could lead to relapse. Good diagnosis coupled with awareness and a personalised approach might be one way of making sure this does not happen, also making clear what it says in the NICE guideline, that people should not be refused services because they have not consented to a particular approach being used, and by extension in the case of children, if their parents have not; also that these therapies should be offered, not necessarily given. I have heard of a practice in hospital of placing a child's food in another part of the room so that they have to get up if they want to eat. I would regard this type of thing as a subversive form of a therapy they might otherwise refuse, and as such, I am uncomfortable with it. I note also that the guideline itself (page 59) says that these interventions, which have been researched with adults who have mild to moderate CFS/ME, may not be the same for children or for anyone with severe CFS/ME. There is some indication that nutritional advice would be helpful, and I wonder if this ought to be looked into a bit more – the guideline (p.45) says that nutritional supplements may be part of a self-management strategy, and that some patients may have to deal with nutritional deficiencies, but that there is not much evidence on it. Also in terms of research, I wonder whether newer fMRI techniques could shed more light on what is going on – again I think research, to be most useful, would need to differentiate between these overlapping conditions rather than putting them all together as the NICE guidance tends to do. Also I wonder whether some other approaches that are recommended for stress may be helpful. The guideline is apparently due for review late in 2010, and perhaps new research evidence will come to light as well.

<p><b>Abertawe Bro Morgannwg LHB</b></p>	<p>There is no existing service within secondary care in ABMU that could be developed or improved. Elements of such a service are being developed on a small scale, such as:</p> <p>The Condition Management Programme (CMP) team are currently exploring the possibility of developing a Fatigue Management Module. This is not aimed specifically at patients with CFS/ME or fibromyalgia but is intended for anyone for whom fatigue is a problem. Up to now the CMP has been using elements of the NICE guidelines when working with people with CFS and fibromyalgia on a 1:1 basis. There is Psychology Services into the CMP which is based on the cognitive behavioural approach as recommended by the NICE guidance.</p> <p>At the Princess of Wales Hospital, Physiotherapy has been piloting a Physiotherapy Service Chronic Pain Management Group for patients who have presented to Physiotherapy on numerous occasions with chronic pain and/or fibromyalgia. This is not a multidisciplinary group.</p> <p>Stand alone physiotherapy is not considered to be an appropriate intervention, rather a biopsychosocial MDT community-based approach with a suitably trained physiotherapist as part of the team. The model should be able to provide patients with a choice of easily accessible 1:1 or group interventions.</p> <p>In Primary Care the only services available are those provided on an ad hoc basis by interested GPs. One suggestion put forward from Primary Care is that a computer-based education resource be provided for primary care teams, publicised through protected learning sessions, and access to a management course delivered via a website for patient use in the same way as is done with <a href="http://www.livinglifetothefull.co.uk">www.livinglifetothefull.co.uk</a> for depression and anxiety. If this were to be commissioned and developed at a national level it should be cost-effective for mild to moderate cases. Exercise elements could be delivered as part of the National Exercise on prescription Scheme.</p>
<p><b>Condition Management Program (Response from Cwm Taf LHB)</b></p>	<p>Earlier identification and management of symptoms by GPs and routine referral into 'management programmes' (not just prescription of medication) such as the CMP (for adults), to promote proactive self-management of the condition would prevent a further onset of secondary symptoms and would reduce the extent of focus on reversing chronicity of symptoms. CFS/ME services would subsequently be working with clients with less engrained behaviours and beliefs and could therefore focus on promoting function and occupational outcomes and preventing an increase in chronic fatigue/ME related symptoms.</p>

	<p>Such prevention of chronicity through involvement with clients in the early stages of emerging symptoms meets the 'prevention rather than cure' objective set out by DoH (2006a).</p> <p>Improved GP support could assist with stages 9 – 11 on map of medicine beyond the remit of CMP.</p>
<b>Fibromyalgia Support Group</b>	<p>Self Help would be a start on some areas of the care pathway, so patients can manage their own conditions, along with their Carers and family members knowing how to deal with looking after a patient living with a chronic condition, as each day is sometimes different on their ability to carry out day to day tasks or continue to be in employment.</p> <p>Employers also need information on assisting their staff member who has a chronic condition, and to retain them in a working and social network environment.</p> <p>Both of the above would offer a cost effective way to manage the services existing.</p>
<b>The Young ME Sufferers Trust (Tymes Trust)</b>	<p>NICE has also been a disaster and we would not wish to see the NICE Guidelines used in Wales. It is bad enough here in England. Children are routinely being referred for graded activity and in our experience are routinely relapsing as a result. I refer you to my Witness Statement for the Judicial Review of the NICE Guideline at <a href="http://www.tymestrust.org/pdfs/brief2009-3.pdf">www.tymestrust.org/pdfs/brief2009-3.pdf</a> and to our original evaluation of NICE where we listed the best aspects, as well as the problems, on pages 18/19 of Vision available at <a href="http://www.tymestrust.org/pdfs/vision2007-2.pdf">www.tymestrust.org/pdfs/vision2007-2.pdf</a>.</p> <p>We would be grateful if you would check with these references. Possibly the most important helpful aspect of NICE was its reminder that patients have a right to decline treatment. In practice, they don't understand until it is too late, that CBT and GET typically makes classic ME patients worse. It appears to us from our personal and professional experience that only those who are substantially recovered, or who did not have classic ME to start with, but some other fatiguing illness coming within the wide CFS net, are helped by these therapies. Where GET therapists allow patients to stop an activity that is making them feel bad, and respond to their symptoms, this is not in fact GET, but pacing. Patients find that pacing themselves is the most helpful form of management. This is confirmed by many expert physicians, though not those of the GET school of thought.</p>
<b>The ME Association</b>	<p>The ME Association does not believe that the NICE guideline on ME/CFS is fit for purpose because (a) it places far too much emphasis on the alleged benefits of cognitive behaviour therapy (CBT) and graded</p>

	<p>exercise therapy (GET) and (b) it is very inadequate when it comes to providing information and recommendations on a whole range of other important options (pacing in particular) and aspects of ME/CFS management.</p> <p>All the surveys of ME/CFS patient opinion that have been carried out indicate that people with this illness are opposed to the NICE guideline and do not want to see referral services that simply 'comply with the NICE guidelines', especially in relation to the recommendations regarding CBT and GET.</p>
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Question 3

	<p><b>Question 3: Do you think people with or suspected of having fibromyalgia should be referred and managed in line with the NICE guideline on CFS/ME?</b></p>
<p><b>Betsi Cadwaladr University Health Board</b></p>	<p>Fibromyalgia, in its most severe manifestation, overlaps very considerably with CFS and can be difficult to distinguish from CFS. These patients should be managed using the same pathway as CFS patients. However the pathway would require medical input, since medication plays a major role in the management of fibromyalgia, in contradistinction to CFS.</p> <p>The milder versions of the condition, allowing higher function in sufferers, can be readily managed in physiotherapy departments, on a 1:1 basis using a pathway comprising exercise, sleep regulation and relaxation training alongside the prescription of appropriate evidence-based medication (Amitriptyline, Gabapentin, Duloxetine or Tramadol) by their GP.</p> <p>A screening tool of some description (perhaps the Fibromyalgia Impact Scale) would be necessary to select the two populations.</p>
<p><b>Betsi Cadwaladr University Health Board (Simon Neal, Consultant Clinical Psychologist)</b></p>	<p>No: Existing services would be swamped. The intervention of choice for people with Fibromyalgia is different; People with Fibromyalgia, who reach specialist services, are much more likely to have co-morbid mental health problems; They are more likely to respond to pharmacological interventions; They are more likely to respond to graded exercise. These people should be assessed and managed by properly resourced Chronic Pain Services.</p>

<b>Public Health Wales</b>	<p>No. Fibromyalgia is considered to be a chronic pain syndrome and whilst there is some overlap for services required for management, there are European evidence based guidelines <sup>2</sup> for the diagnosis and treatment of fibromyalgia.</p> <p>2. Carville SF, Arendt-Nielsen S, Bliddal H, et al. EULAR evidence-based recommendations for the management of fibromyalgia syndrome. <i>Ann Rheum Dis.</i> 2008; 67:536-41.</p>
<b>Cardiff and Vale University Health Board</b>	<ul style="list-style-type: none"> <li>• Referrals are made by GPs, health professionals such as School health nurses, therapists, CAMHS expressing a wide range of concerns that may be united under the “umbrella” of CFS.</li> <li>• Fibromyalgia may be addressed in a similar manner</li> <li>• A scoping exercise may assist in identification of related conditions that may benefit from this approach</li> </ul> <p>Colleagues in therapies support this approach</p>
<b>Cardiff and Vale University Health Board 2<sup>nd</sup> Questionnaire (Peryn Morgan)</b>	<p>Yes I do</p>
<b>WAMES (Welsh Association of ME &amp; CFS Support)</b>	<p>Fibromyalgia is a condition with overlapping symptoms but it is not the same condition as ME. Fibromyalgia has historically been classed as a disease of the musculoskeletal system and connective tissue (WHO ICD10 M79.7) but we understand it is increasingly being treated as a neuromuscular condition. It is possible for people to have both conditions, making diagnosis more difficult, but we believe it is important that both conditions have their own clinical pathway as there are differences in the triggers, diagnosis and management. It would be perfectly possible however for both to share some services, along with other neurological conditions.</p>
<b>Aneurin Bevan Trust</b>	<p>Yes, one manages in the community. It is nothing to do with hospitals.</p> <p>The only medical assessment is the need to exclude other diseases, but this requires guidelines, not a new clinical service in the hospital. The guidelines could be implemented by GP's.</p>

<b>Powys LHB</b>	<p>More focus needs to be given to the painful element of the condition for people with fibromyalgia than for CFS/ME, however, the approach to managing the condition should however be similar for the two conditions. People with chronic, non-malignant health conditions are generally best served by a biopsychosocial approach. Any guidelines that adopt this interdisciplinary approach (such as NICE) and promote self-management, rather than solely focus on medical investigation and treatment, will also provide good support for people with fibromyalgia. Clinical experience and outcome evidence from an interdisciplinary pain and fatigue management programme strongly indicates that CFS/ME and Fibromyalgia can be very successfully managed with the biopsychosocial approach.</p> <p>Furthermore, the General Management Strategies (NICE Guideline 53) regarding sleep, rest, relaxation, pacing, diet, independence, education and employment should be promoted early in a person's presentation, definitely pre-diagnosis, and will benefit people in the management of any long term condition. Assessment of an individual's current experience and behaviour in relation to the above is likely to be time-consuming and GPs may need to specifically allocate time for this or to train other practice practitioners in this assessment.</p>
<b>Welsh Therapies Advisory Committee (WTAC)</b>	<p>Currently some CFS services see people with fibromyalgia, as some management strategies are similar.</p> <p>However, as pain is the predominant feature of the condition it is generally considered to be preferable for this client group to be referred to pain management services or rheumatology rather than following the care pathway for CFS client/patients.</p>
<b>Cerebra</b>	<p>There are two ways of looking at this. One way might be to start all people with neurological conditions on the same pathway and then to diverge, bringing in different specialisms for comorbidities, etc. – such as neuromuscular services – as necessary. It might be difficult to distinguish between some neurological conditions to start with, and they are likely to have common features, so it might make sense to start the care pathway in the same way. I thought this was what was going to happen in Wales, according to meetings that have been held in connection with the review of neuro-services. However, now I understand that some people in Wales are being asked to produce separate care pathways for some of these conditions, so in view of that, probably it would be better to have a separate one for fibromyalgia, which might fit better into a rheumatic sort of pathway. The pathways could then converge in places where there is some overlap, rather than diverge where there are differences. Other factors to consider are, I do know that WNA colleagues involved with neuromuscular conditions are concerned about the resources available to them in Wales, and the loss of at least one specialist; that we have a smaller and</p>

	<p>more scattered population than some other parts of the UK; and that it is nice for people – particularly if they get very tired, with a variety of inconvenient symptoms – not to have to deal with multiple appointments in different places.</p> <p>I note that the European League Against Rheumatism has suggested guidelines for fibromyalgia treatment:  <a href="http://www.myalgia.com/Treatment/EULAR%20revommendations%20for%20treatment%202007.pdf">http://www.myalgia.com/Treatment/EULAR%20revommendations%20for%20treatment%202007.pdf</a>.  Not being medically qualified I cannot comment on these in detail, but I can see that again, the recommendations about exercise would not be the same.</p>
<b>Abertawe Bro Morgannwg LHB</b>	<p>There was a difference of opinion with Therapies colleagues supporting this approach whilst Primary Care’s response suggested evaluating the outcomes of patients with fibromyalgia who were managed by Rheumatologists to see if they were best managed by that specialty.</p>
<b>Condition Management Program (Response from Cwm Taf LHB)</b>	<p>CMP interventions with CFS/ME &amp; Fibromyalgia frequently overlap as intervention is based upon symptom management (both proactive and reactive management) and is tailored to individual need. However, we currently include a more specific focus on pain management with clients experiencing fibromyalgia involving clients in generic pain management groups in addition to tailored fatigue related advice.</p> <p>Subjectively, clients experiencing CFS/ME appear to request advice based upon managing and preventing post-exertional malaise more than clients diagnosed with fibromyalgia who frequently require more advice related to promoting improved sleep patterns. Although the end focus may be slightly different the advice provided is essentially the same (from an OT point of view).</p>
<b>Fibromyalgia Support Group</b>	<p>No I don’t think patients with fibromyalgia should necessarily be managed along the same lines as chronic fatigue or ME - more appropriate to be managed along the Pain Management Programme approach which may be similar but the pain issue in Fibromyalgia is a factor that needs to be considered.</p> <p>As Fibromyalgia has multiple symptoms and conditions linked with the condition, including symptomatic Fatigue, and is needed to take all the other symptoms into consideration when managing the condition.</p>

	Diagnosis and treatment would therefore be appropriate to the patients presenting at the surgery or clinic.
<b>The Young ME Sufferers Trust (Tymes Trust)</b>	We prefer not to comment on this, but leave it to organisations specialising in fibromyalgia.
<b>The ME Association</b>	No.  Although there are some similarities between ME/CFS and fibromyalgia I believe that once a firm diagnosis of fibromyalgia has been established those patients who require specialist advice on management should then be referred to a multidisciplinary service, possibly in a rheumatological department, that has specific expertise in the management of fibromyalgia.

#### Question 4

	<b>Question 4: What services do you consider should form part of the care pathway?</b>
<b>Betsi Cadwaladr University Health Board</b>	<p>Psychology – to help with the change to more recovery-promoting behaviours and attitudes. To aid the process of acceptance of and adaptation to a long-term disabling condition. To facilitate the development of a self-managing relationship with their condition.</p> <p>Dietetics – to help dispel myths about the use of certain supplements in the management of CFS and give a well-proportioned view on those that might have some value. To encourage a balanced, nutritious diet and a structured pattern of consumption to adequately fuel and energise the body while avoiding the misuse of short-term ‘stimulant’ foods. To address individual dietary related issues – e.g overweight linked to reduced ability to exercise , IBS , food intolerances and other conditions that may exist alongside CFS/ME – eg diabetes / hyperlipidaemia.</p> <p>Physiotherapy – to help with activity modification and the achievement of sustainable levels and patterns of activity. To assist with the progression of activity on this stable foundation. To help with musculoskeletal pain problems as required. To give advice and guidance on exercise selection, level and progression. To teach relaxation techniques.</p>

	<p>Medicine – to help with medication advice, prescription and modification. To advise on the further investigation and management of comorbidities impacting on their CFS.</p> <p>Employment advisor – to provide guidance on benefits, return to work, negotiating reasonable graded return schemes, negotiating sustainable levels of work, advising on issues of employment law.</p>
<p><b>Betsi Cadwaladr University Health Board (Extra Questionnaire from Simon Neal, Consultant Clinical Psychologist)</b></p>	<p>Specialist early medical assessment or as a minimum protocol driven assessment by GP with Special Interest.</p> <p>Specialist psychosocial assessment – Liaison Psychiatry or Clinical Psychology, to exclude significant mental Health problems and to assess illness beliefs and the like</p> <p>Early access to sleep study or home based nocturnal pO2 monitoring to exclude sleep apnoea.</p> <p>Delivery of symptomatic control strategies using a range of medications with adequate review/follow-up.</p> <p>Psychological therapy (Not necessarily confined to CBT - Therapy using an Acceptance and Commitment framework or Mindfulness based therapies are know to be helpful) addressing acceptance of Chronic Ill Health, Co-morbid or reactive mental health problems and strategies for adaptation/symptom management. Adult Mental Health Service actively exclude people with CFS or inappropriately label them as having somatoform disorders</p> <p>Group based or individual support/education/advice relating to symptom management provided by a multidisciplinary service.</p> <p>Occupational/vocational support including advocacy and work place based intervention and support.</p>
<p><b>Public Health Wales</b></p>	<p>Because of the complexity and range of needs within CFS/ME, various levels of care are required and the tiered model of care described by WAG for long term conditions is appropriate for service delivery for</p>

patients with CFS/ME. The tiered approach to service development should build upon care at primary care, specialist local support and where necessary, the ability to refer complex cases to more specialised services.

**Tier/Level 1**

The most important requirement at Tier 1 is for information for people with CFS/ME, their carers and for health professionals so that they fully understand the condition. Creating and providing such information will not be easy, but liaison between primary care information services and the voluntary sector will be required. Knowledge and successful implementation of care pathways will be vital. Such pathways may require modification to suit local needs.

**Tier/Level 2**

CFS/ME patients can generally be managed within primary care. The primary care team has a major role in ensuring that the measures recommended for the management of long term conditions and in the clinical guidelines are applied to CFS/ME patients. A key element in the management of people with CFS/ME is the provision of supportive care. Clear referral criteria for therapy services are therefore required in relation to physiotherapy and occupational therapy, access to mobility aids, nutritional advice, social care services, pain management and psychotherapy.

Self management is important in the treatment of CFS/ME and it is pivotal that the advice given by the primary health care team for this is informed and of a high standard. Such programmes must be subject to effective quality assurance and regulation. There should be a means within the NHS service for effective cooperation and liaison with the voluntary sector.

**Tier/Level 3**

There appears to be less agreement from the published literature as to what is required for effective Level 3 services for CFS/ME patients. There is consensus that essential to the Level 3 service is the multidisciplinary team (MDT). The MDT would be responsible for:-

- specialist diagnosis and assessment
- the planning of care for more complex cases
- supporting the community and primary health care services providing long term conditions

	<p>management within Level 2 services</p> <ul style="list-style-type: none"> <li>• providing education and training for Level 2 health care professionals</li> <li>• providing advice on self management programmes.</li> </ul> <p>The guidelines are not specific on what workforce requirements are required for Level 3 services. The Level 3 MDT is predicated on the existence of both local and regional managed clinical networking. The establishment of a national managed clinical network would ensure the sharing of expertise and experience, provide cross cover and permit a more focussed approach to research and evaluation of treatments.</p>
<p><b>Cardiff and Vale University Health Board</b></p>	<ul style="list-style-type: none"> <li>• We would recommend that a paediatrician with appropriate skills should see these referrals initially, this will probably be a General Paediatrician, however some referrals may be seen in a community based clinic especially if the origin of the referral was educational.</li> <li>• A primary care physician with appropriate skills in paediatrics may be in a position to provide the initial health screen- however this is where a paediatric pathway may divert from adult models</li> <li>• We would support local identification of a lead with specific interest and dedicated time to support pathway development and contributions to a “network”</li> <li>• The Paediatrician would be expected to identify if organic pathology is contributing to the presentation e.g. anaemia or thyroid dysfunction and investigate accordingly.</li> <li>• Local/network training schemes should be developed across disciplines to ensure a progressive service</li> <li>• These patients will need Psychology input for CBT</li> <li>• Physiotherapy for graded exercise prescription, equipment provision and monitoring of physical function over time.</li> <li>• They will need OT for functional activities and equipment provision</li> </ul> <p>They will require dietetics for nutritional support.</p>
<p><b>Cardiff and Vale University Health Board (Peryn Morgan)</b></p>	<ul style="list-style-type: none"> <li>§ List people who have a special interest in this area.</li> <li>§ Making a distinction between Primary care professionals and secondary Care professionals as diagnosis appears to be an issue</li> <li>§ Individual CBT is a scarce commodity in Primary care and although GP’s all have counsellors they are limited to 6 sessions</li> <li>§ In Cardiff we do have the stress management course and for a small part of Cardiff and Vale</li> </ul>

	<p>access to cCBT</p> <p>§ Exercise referral etc</p>
<p><b>WAMES (Welsh Association of ME &amp; CFS Support)</b></p>	<p><b>Diagnostic service</b> where history is taken, physical examination and laboratory tests are done in order to eliminate other possible conditions and identify viruses and dysfunctions in the body. This service should be ready to incorporate diagnostic tests as and when they become available (a number are being researched at the moment).</p> <p>The first priority is to identify professionals throughout Wales who have an interest in ME and are willing to undergo training to enable them to identify it and distinguish it from conditions with overlapping symptoms. Based on WAMES' experience with patients in Wales we would suggest that the conditions likely to lead to misdiagnosis include: MS; early MND; Lyme disease; FMS; a range of lesser known neurological conditions; allergies; toxic poisoning and food intolerances; sleep apnoea; post-polio syndrome, idiopathic chronic fatigue. Many more are possible and are recorded by ME clinicians round the world. A desire to give an accurate diagnosis is essential for specialists, whether they be GPs or consultants. Too many patients have experienced lacklustre attempts to find out what was wrong with them and have been given a 'dustbin' diagnosis of CFS, which has not always turned out to be correct. Many more have been misdiagnosed with depression, or had their co-existing condition of ME overlooked when there is also depression present.. A willingness to monitor patients long term is also essential. This is useful to both the patient, in picking up new symptoms which are not part of the ME and which can be treatable, and also to the doctor, as it increases their understanding of the illness. If a standardised system of recording was used, the information could be collated nationwide and used to inform the future development of services and research.</p> <p><b>Pharmacological prescription</b> for symptom relief and also for tackling the underlying disease process, when this becomes available (e.g. a number of antivirals are currently being trialled).</p> <p><b>Management advice</b> should be offered to all patients, enabling them to develop individualised management plans, covering, where relevant:</p> <ul style="list-style-type: none"> <li>- the principles of Pacing or activity management (not APT) which enables the patient to avoid stressing the body during the acute and chronic phases of the illness. This approach is outlined in</li> </ul>

	<p>the Pacing leaflet on the WAMES website document page;</p> <ul style="list-style-type: none"> <li>- management of relapses;</li> <li>- management of sleep disturbance, which will be different depending on the phase of illness;</li> <li>- relaxation techniques;</li> <li>- diet, nutrition, allergies and intolerances;</li> <li>- help with Benefits, employment and education issues;</li> <li>- management of pain;</li> <li>- management of cognitive dysfunction;</li> </ul> <p><b>Rehabilitation services</b> offered to those who wish and need it</p> <ul style="list-style-type: none"> <li>- assessment by OT to look for ways to save energy, including provision of aids and adaptations</li> <li>- advice from Physiotherapist on improving functioning without causing post-exertional relapses</li> </ul> <p><b>Mental health assessment</b> should not be automatic but only offered to the small percentage who actually exhibit signs of depression. If a patient is having difficulties coming to terms with the diagnosis or coping with the condition they should be referred, with the patient's consent, to the counselling service which is attached to all GP practices or other relevant counsellor for help with coping strategies.</p>
<p><b>Aneurin Bevan Trust</b></p>	<p>Similar to Barts. Inviting one of their Physiotherapists or OT's to give evidence would be very useful and I'm sure they learned the hard way from their mistakes.</p>
<p><b>Powys LHB</b></p>	<p>Essential to the pathway is a full biopsychosocial assessment. Therefore medicine, physical therapy and psychology should all form part of the service in addition to social interventions which help the individual reengage with their community.</p> <p>The overall pathway, including that for severe presentation, should include:</p> <p>GP Rheumatology Health Psychology Occupational Therapy Physiotherapy</p>

	<p>Occupational Health  Chronic Conditions Management  Specialist Interdisciplinary Programmes  Immunology  Dieticians  Nursing in ward based care  Education  Return to work  Social Services</p> <p>Very rarely, psychiatry or liaison psychiatry may have a role to play.</p>
<p><b>Welsh Therapies Advisory Committee (WTAC)</b></p>	<p>A multi-disciplinary team is essential, and should ideally consist of:</p> <ul style="list-style-type: none"> <li>• CBT practitioner</li> <li>• Consultant/specialist GP</li> <li>• Dietician</li> <li>• Occupational therapist</li> <li>• Physiotherapist</li> <li>• Psychologist</li> <li>• Speech and language therapist</li> </ul> <p>As all the statutory committees have been approached for comment, this response will focus on the role of the professions represented by WTAC</p> <p><b>CBT/OT Practitioner</b> to address:</p> <ul style="list-style-type: none"> <li>• Thoughts and feelings</li> </ul> <p><b>Dietician:</b></p> <ul style="list-style-type: none"> <li>• To educate on healthy eating and ensure adequate nutrition</li> </ul> <p><b>Occupational therapists</b> using the Bio-Psychosocial model, and Cognitive Behaviour Therapy (CBT)</p>

principles

It is envisaged that these OTs will be working in a community setting and will primarily be involved in group work for mild to moderately affected clients, and 1:1 work in client's own home for those who are more severely affected, or those who are unsuitable for group work. OTs will have a knowledge and experience of working with patients/clients with physical and mental health conditions.

The group and 1:1 work will cover the following topics:

- Pacing
- Graded activity
- Goal setting
- Memory and concentration
- Relaxation and breathing techniques
- Sleep
- Setbacks

**Physiotherapist:**

- Core balance and posture
- Breathing
- Graded exercise therapy, activity modification and progression of activity
- Musculoskeletal pain

**Speech and Language Therapist**

- Voice

**Return to Work**

Any return to work plans should follow NICE guidelines.

These plans should involve the following:

- Occupational health departments
- Disability employment advisers

	<ul style="list-style-type: none"> <li>• Jobcentre Plus whose advisers might then be in a position to offer such programmes as Condition Management Programme and Access to Work etc.</li> </ul> <p>Health professionals can also fulfil the role of signposting clients on to other services, such as “Expert Patient Programme”.</p>
<b>Cerebra</b>	<p>GP – as a gateway, if no specialist knowledge at the practice  Diagnostician with specific CFS/ME knowledge/training (or specialist service for adults), domiciliary if possible  Expert analysis of tests and communication of results  Personalised care planning – analyse issues, wider than clinical. Discussion about the implications of the condition that has been identified  Any specialists / other professionals needed, who may be for comorbid conditions, pain control, equipment such as wheelchairs, physical and mental advice as necessary, including possibly counselling and stress management for carers as well as the person with the condition, if they want it.  Obviously also, continued treatment if necessary of anything that has triggered the onset of symptoms, such as a virus, side-effects of treatments that may have been given for that, and management of any pain.  Possibly dietary and nutritional advice, if testing shows nutrient levels either out of range, or within range but rather low.  Nutritional help. If there are signs of allergy or food intolerance, it may be helpful if GP or other diagnostician were free to consider prescribing special foods, such as gluten free or lactose free foods. (I know that these are prescribed sometimes with other conditions, and they are expensive for families otherwise.)  Sleep advice. I would feel more comfortable about sleep advice based on the attempt to understand an individual's patterns, than about an attempt to automatically standardise sleep. There has been more research recently into the patterns of sleep of (general) adolescents, showing that they actually need some of their strange patterns!  Information provision including management, services available and the CFS/ME organisations.  Someone in the community for home-based practical advice, positive support (specialist nurse or counsellor?) and general help with symptoms as they arise  School / education planning and information, including home education, home tutoring or E-learning as</p>

	<p>possibilities. (I wonder how things might develop in Scotland for E-learning, because it is already done for children – any children – who live remotely there.)</p> <p>Assessment for social support e.g. respite, again for carers as well as the children with disabilities team, and aids, especially if care needs go on for a long time</p> <p>Assessment for home adaptations if appropriate</p> <p>Welfare / financial advice, or signposting to this, with appropriate support from clinician(s). Advice and support for parents at work / carers with employers.</p> <p>Holistic ongoing care and opportunities to re-enter services (including later education if possible).</p>
<b>Abertawe Bro Morgannwg LHB</b>	<ul style="list-style-type: none"> <li>• Accelerated access to Neurology and appropriate imaging and other investigations to exclude alternative diagnoses</li> <li>• Multidisciplinary team of specialists covering health and non-health agencies (GP, Physiotherapy, Occupational Therapy, Psychology, Lifestyle Counselling, Social Services, Education Services, Occupational Support, Voluntary Sector Patient Support Groups etc) trained and experienced in Cognitive Behavioural Therapy, graded exercise, pacing etc</li> <li>• Access to inpatient care, appropriate to their age group, for moderate to severe patients</li> <li>• Clear guidance with regard to appropriate secondary care specialty best placed to provide care for these patients</li> </ul>
<b>Condition Management Program (Response from Cwm Taf LHB)</b>	<p>For adults of a working age:</p> <p>OT</p> <p>Physiotherapy</p> <p>CBT</p> <p>Health Promotion</p> <p>GP Input</p> <p>Jobcentre plus advisor/DEA</p> <p>Links with secondary health, work and wellbeing support services such as Prescribed Exercise Scheme, Expert Patient Programme, Book prescription scheme, Volunteering organisations, Action for ME.</p> <p>Education and support to reinforce helpful messages to relatives &amp; carers.</p>
<b>Fibromyalgia</b>	Better understanding of the symptoms and conditions, making diagnosis quicker and support offered

<b>Support Group</b>	more consistent across the geographical areas.
<b>The Young ME Sufferers Trust (Tymes Trust)</b>	<p>Domiciliary support and support for home tuition/virtual education, in which we have experience, is vital for children with classic ME. School attendance is typically one of the biggest causes of relapse. The other, in our experience, being general over-activity including GET.</p> <p>Please also see our comments on the care pathway in our first question.</p>
<b>The ME Association</b>	<p>As noted in the APPG Inquiry Report, and in the ME Association guidelines for health professionals, ME/CFS referral services should:</p> <ol style="list-style-type: none"> <li>1 Be physician led</li> <li>2 Be situated in a part of a hospital that is suitable for people with substantial mobility and cognitive problems</li> <li>3 Not be situated within a mental health department</li> <li>4 Be multidisciplinary</li> <li>5 Cater for children and adolescents</li> <li>6 Regard those who are severely affected as a high priority and offer both in-patient facilities and a domiciliary service</li> <li>7 Offer a range of management options, including activity management based on the approach known as pacing</li> <li>8 Offer help and support with a range of non medical aspects of management – including benefits and employment</li> <li>9 Not use the CDC/Fukuda research criteria as an inflexible screening tool in deciding who should, or should not, be referred to the service from primary care.</li> </ol>

Question 5

	<p><b>Question 5: Are there any specific issues/guidance that you feel the Task and Finish Group should take account of in the development of their advice?</b></p>
<p><b>Betsi Cadwaladr University Health Board</b></p>	<p>The most important thing to acknowledge is the widespread resistance of patient groups to Graded Exercise Therapy and Cognitive Behavioural Therapy. The insistence upon use of these methods by can easily be seen as paternalistic and can sour relationships with local groups. Whilst both methods have evidence to support use their inclusion, proportion and timing need to be decided in negotiation with the individual patient, remaining cognizant of their needs, capacities, and stage of recovery.</p> <p>Secondly, the NICE guidelines emphasise individual therapy but the benefits of group work for validation of patients' experience, engendering confidence and determination for difficult behaviour changes, and encouraging a problem-solving stance should not be overlooked. The group aspect of our own intervention is something that many of our patients state as having been of use to them.</p>
<p><b>Betsi Cadwaladr University Health Board (Simon Neal, Consultant Clinical Psychologist)</b></p>	<p>Whatever pathway of care is developed it needs to be evidence based, acceptable to the Client/patient group and appropriately resourced. This is not a specialist service that can be developed from within current resources – there are none.</p>
<p><b>Public Health Wales</b></p>	<p><b>Somatisation</b> The patients with CFSME are particularly sensitive about what they perceive as a lack of belief by the medical profession about the true nature of their illness.</p> <p><b>Recommendation for CBT and GET</b> There are vociferous patient action groups that have challenged the recommendations of the guideline development groups (GDG). The NICE guideline was the subject of a judicial review mounted by CFS/ME patients that was ultimately rejected in the high court. The basis for the legal case was the recommendation by NICE for CBT and GET and the constitution of the GDG.</p>

	<p><b>Psychosocial aspects</b> The CFS/ME patients would like less emphasis on the bio-psychosocial model for CFSME. Documents from patient groups frequently emphasise that CFS/ME is classified in ICD 10 under Diseases of the Nervous System at G93.3 and is not considered as a mental health condition.</p> <p><b>Development of local care pathways</b> Local care pathways and services may need to be developed for groups with particular requirements, such as children and young people; the severely affected housebound and bedbound patients and those living in remote or rural areas. The transition from paediatric care to adult services also requires clear pathways.</p>
<p><b>Cardiff and Vale UHB</b></p>	<ul style="list-style-type: none"> <li>• There is no specialist provision for CFS in Cardiff and Vale. Adoption of NICE guidelines requires the identification of new resource</li> <li>• The task force could look at undertaking a robust scoping exercise to try to determine how many patients require such a service and how big exactly is the gap in MDT provision. This should then inform any advice that they provide to WAG.</li> <li>• The task force could scope the clinical course of the patient group. With existing services a group of patients (no data for scale) recover, those that do not seek further specialist support and requests are received for referrals to Dr Crowley in Bath. It is likely that access to a tertiary service may still be requested by some individuals, it would be important to scope this element of uncertainty</li> <li>• The process for these external referrals is unclear in the new UHB structure and there is no agreed gatekeeper for this process. This introduces an element of stress to communication which is potentially therapeutically disadvantageous to this patient group</li> </ul> <p>There is an overlap with referrals for eating disorders that need to be examined in view of new tertiary provision for eating disorders in South Wales</p>
<p><b>Cardiff and Vale University</b></p>	<ul style="list-style-type: none"> <li>○ Make it succinct as possible</li> <li>○ Make it user friendly</li> </ul>

<b>Health Board (Peryn Morgan)</b>	<ul style="list-style-type: none"> <li>○ Ensure you have the right people on the task and finish group</li> <li>○ Or you may well loose the message</li> </ul>
<b>WAMES (Welsh Association of ME &amp; CFS Support)</b>	<p><b>Status of ME and CFS</b>  ME (or CFS) is currently not considered to be a long term or chronic condition by all health professionals. This could partly be because of the emphasis on unexplained fatigue (which is not the main symptom for all patients), and because it is often assumed to be of psychological origin. It could also be because the full range of research findings showing ongoing biomedical dysfunction is not made known to them - well over 4,000 papers have been published. The fact that there are few pharmaceutical interventions, other than those for symptom relief, might also add to it's low status. ME was not mentioned by name in the Profile of Chronic Conditions, and in many other WAG publications in the past it has been linked with somatic or psychological conditions. Few doctors also probably don't realise how many patients are affected by the condition. It would be helpful if ways of raising the profile of the illness in the general healthcare community could be explored.</p> <p><b>Terminology &amp; sub-groups</b>  There needs to be a greater understanding of the many different ways that the term CFS is used within the medical profession and the fact that a lot of confusion arises when the terms CFS, chronic fatigue and ME are used interchangeably. Recent research by Kerr and others has highlighted the existence of different subgroups of patients currently given the 'diagnosis' of CFS and the likelihood is that not all subgroups will respond to the same treatments, as has already been observed in the ME community.</p> <p><b>CBT &amp; GET</b>  These therapies have been promoted as the 'evidence based' intervention for ME. The research evidence for their effectiveness is poor however and even the NICE guidelines acknowledges this. No evidence has ever been presented for the widespread existence of muscle deconditioning' or 'faulty illness beliefs' in ME. A number of research projects have been published over the years which indicate they are not the best interventions, including those which show:</p> <ul style="list-style-type: none"> <li>- counselling and support is as effective and cheaper (4);</li> <li>- the existence of exercise intolerance in people with ME/CFS (5);</li> <li>- increasing activity is not linked to higher performance (6);</li> </ul>

- provision of CBT & GET in Belgian CFS centres '*is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS*' (7)

WAMES believes that not only are CBT and GET potentially harmful to many people with ME, they are also not cost-effective.

### **Self management programmes**

While the EPP can be helpful to some people with ME, the course leaders do not always have enough knowledge about the potential harm that exercise can have for people with ME, which makes participants who don't follow the exercise recommendations look uncooperative. Many people with ME are not well enough to attend the course but still need guidance in self management. There is a need for condition specific self management programmes to be developed, including those that can be used online and in other formats at home.

**The Care Pathway** should include:

- A Functional Capacity Measurement Tool designed for people with ME such as the EIPS (8)
- Pathways for different subgroups and the severely affected, children and young people
- guidance for carers:
  1. Carers should be entitled to, without them having to request it, an assessment of their needs by Social Services under the statutory legislation.
  2. Carers should, if assessed as needing services, receive those services as designated in their assessment.
  3. Carers should also be advised about their rights under Employment Law and also advised about benefits to which they may be entitled.
  4. Carers should be offered respite care to enable them to continue caring
  5. An acknowledgement that carers should be able to ask for help without fear of being suspected of harming their child.
- the possibility of Telecare and telephone advice to supplement surgery or hospital visits

### **English Clinics**

WAMES has concerns about the way that some of the clinics have developed in England, which mirrors to some extent what has happened with some Welsh clinics. There have been reports that people have felt the clinics do not understand ME, include people with other fatigue conditions and call all conditions

CFS, treat everybody the same, refuse management advice if the programme based on CBT and GET has been refused by the patient, and steer people away from patient support groups unless they actively support the treatment being offered by the clinics. In this way some of the general principles of care and respect outlined in the NICE guidelines have been ignored, and this should be guarded against in Wales.

**Failures of i) care ii) the patient centred approach and iii) treatment which acknowledges human rights** and is compliant with all the relevant legislation such as the Geneva Convention on the Rights of the Child, the Human Rights Act etc. – such failures are too common for people with ME in Wales.

Children are not always:

- listened to, believed, and their point of view taken on board.
- able to access health care where they are not treated in a demeaning nor abusive fashion.
- given appropriate referrals to other specialisms depending on their needs in a setting which is appropriate for them.
- given an appropriate education given their age and health, and are sometimes forced back to school before they are ready or refused home education.
- given a community care assessment of their needs under Section 17 of the Children Act without it progressing inappropriately to a Section 47 investigation. Disputes between parents and doctors and even between medical practitioners should not be considered sufficient evidence to suspect harm.
- given appropriate health care whether this be in their home or in a hospital or GP setting.
- given home visits from appropriate health professionals.
- allowed to refuse 'Consent to treatments', as is their right.
- provided with appropriate aids and adaptations to their homes, including provision of a wheelchair.
- given appropriate support to enable them to claim benefits.

Transition:

- transfer between children's and adults services in both health and social services, and other services, is difficult and stressful and is not always carried out with the agreement of the young person.
- If the young person has reached the age at which compulsory education ceases but have missed a large chunk of their education, they are seldom enabled to continue in education (part time or online etc, whatever is appropriate for them) whether this be 6<sup>th</sup> form, or university level. Funding should continue until the young person has reached their goal.

- they need appropriate help and support to enable them to claim benefits in their own right.
- little help and support is given to enable young people with ME to live independently from their parents/carers if desired.

Adults:

- have difficulties accessing health care in a setting which is appropriate to them (e.g. in the home if they are severely affected and suffer relapses if taken out of the home)
- sometimes experience abuse, disinterest or are treated in a demeaning fashion as if they were deliberately wasting doctors' time with imagined complaints.
- sometimes are refused referrals to other specialisms.
- do not always receive a community care assessment of their needs and have those needs met in a timely and appropriate fashion.
- are often not offered or are refused aids and adaptations which could increase their functioning.
- need help and support to enable them to complete forms, gather evidence etc in order to claim benefits to which they are entitled.
- can not easily access help with employers i.e. sick notes etc

(4) Ridsdale L, Godfrey E, Chalder T, et al. **Chronic fatigue in general practice: is counselling as good as cognitive behaviour therapy? A UK randomised trial.** *Br J Gen Pract* 2001;51:462:19-24

(5) S. Pierce & P.W. Pierce **The physiology of exercise intolerance in patients with myalgic encephalomyelitis (ME) and the utility of graded exercise therapy**

[www.investinme.org/Documents/PDFdocuments/The%20physiology%20of%20exercise%20intolerance%20in%20patients%20with%20myalgic%20encephalomyelitis.doc](http://www.investinme.org/Documents/PDFdocuments/The%20physiology%20of%20exercise%20intolerance%20in%20patients%20with%20myalgic%20encephalomyelitis.doc)

(6) [Bazelmans E](#), [Bleijenberg G](#), [Voeten MJ](#), [van der Meer JW](#), [Folgering H](#). **Impact of a maximal exercise test on symptoms and activity in chronic fatigue syndrome.** *J Psychosom Res.* 2005 Oct;59(4):201-8.

(7) Twisk FNM, Maes M. **A review on Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) in Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS): CBT/GET is not only ineffective and not evidence based, but also potentially harmful for many patients with ME/CFS** in *Neuro Endocrinol Lett.* 2009 Aug 26;30(3):284-299

(8) Lerner, Dr Martin Energy Index Point Score: A Functional Capacity Measurement Tool for CFS

	<p>Patients</p> <p><a href="http://www.cfsviral-treatment.com/energy_index_score/index.html">http://www.cfsviral-treatment.com/energy_index_score/index.html</a></p>
<b>Aneurin Bevan Trust</b>	<p>There are enormous pressure groups that will try to hijack the whole system. These have various theories such as Chronic Viral Infection that have no basis in actual Clinical practice.</p> <p>Sticking with the NICE guidelines should stop this counter-pressure, and allow a practical system to be set up.</p>
<b>Powys LHB</b>	<p>At present there is a serious shortage in the skills required to deliver biopsychosocial interventions in Wales therefore significant investment will be required in training as well as services although services are in place which we Commission.</p> <p>Many clinicians, including GPs, lack confidence in diagnosing CFS/ME or Fibromyalgia. Fear of 'missing something', compounded by patients' anxiety, results often in over-medicalisation of the condition and initiates dependency on medical services from an early stage. GPs (also physiotherapists and OTs) require adequate training in:</p> <ul style="list-style-type: none"> <li>• Assessment and diagnosis</li> <li>• how to communicate helpfully with a patient with a long term condition - including explanations for any investigations that are recommended</li> <li>• basic understanding of the psychosocial/behavioural elements that maintain symptoms</li> </ul> <p>People who could potentially be highly productive members of the workforce are often unable to return to work because of the inflexibility of employers and of the state benefits system.</p> <p>Graded Exercise Therapy (GET) has recently received 'bad press'. Many people referred for GET are now anxious about its possible detrimental effects and may be reluctant to even accept the referral. Physiotherapists require adequate training in GET <u>as appropriate to CFS</u> to ensure an individualised, patient centred approach is provided.</p> <p>CFS/ME is highly variable with symptoms ranging from mild to severe. It is important to be aware that those, minority of, people with severe symptoms may be bed bound and require at least a period of ward based care. Staff caring for people in this situation need training and/or access to expert advice to</p>

	<p>ensure satisfactory care. Likewise, any clinicians providing home-based care for long term severe presentation, eg, District Nurses, need adequate training.</p> <p>There is no recognised network of clinicians interested in CFS/ME and therefore publicity of, and contribution to, the work of the Task &amp; Finish Group may be difficult to secure. Care needs to be taken that appropriate individuals are identified and consulted on the development of service delivery plans.</p>
<p><b>Welsh Therapies Advisory Committee (WTAC)</b></p>	<ul style="list-style-type: none"> <li>• It is the primary goal of health professionals to enable people with CFS/ME to self-manage their condition. Interventions should be instrumental in helping their clients/patients to achieve this.</li> <li>• Client/patient groups have indicated that there is widespread resistance to the concept of Graded Exercise Therapy and CBT. It is important to consider how health professionals can help to overcome these preconceptions (possibly a training issue) and engage such clients in therapy.</li> <li>• The use of an agreed range of standardised outcome measures is essential to ensure a consistent service and to gather data.</li> <li>• NICE guidelines emphasise individual work, but the effectiveness of group work should not be overlooked</li> <li>• As there are very few clinicians currently working in the field of CFS/ME throughout Wales; development of a service should be structured to ensure training, mentoring and supervision is available to staff within mainstream services.</li> </ul> <p>A “hub and spoke model” would ensure consistent clinical standards across Wales.</p>
<p><b>Cerebra</b></p>	<p>Common to many long-term and possibly debilitating conditions, a need to access recurrent rehabilitation / therapy appointments close to home.</p> <p>In the case of more centralised hospital appointments, a “one-stop-shop” approach might work well, as already operates successfully for some other medical conditions (i.e. a seamless flow between different elements that are needed – seeing consultants, tests, etc.)</p>

	<p>An occasional need for special equipment.</p> <p>A need for schoolwork at home, if school-based.</p> <p>Acknowledgement of the need for carer support, particularly if a lone parent.</p> <p>Supporting people with long-term conditions (about personalised care planning),  <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354</a></p>
<b>Abertawe Bro Morgannwg LHB</b>	<ul style="list-style-type: none"> <li>• Lack of specialist multidisciplinary services</li> <li>• Lack of knowledge of the conditions and their management amongst Primary Care teams</li> <li>• Restricted access to Cognitive Behavioural Therapy (CBT) across the ABMU HB area. It is suggested that the possibility of integrating CBT for these conditions into the planned expansion of Psychological Services being developed for patients with anxiety and depression be considered.</li> <li>• Review of outcome data from inpatient and outpatient/community Based specialist services provided elsewhere</li> <li>• It is felt that it is important that these services are not delivered as an 'add on' to an existing role, but a defined team with set aims and criteria covering the whole Health Board area.</li> </ul>
<b>Condition Management Program (Response from Cwm Taf LHB)</b>	<p>With limited resources and a limited timeframe, the CMP has had to engage with community services to promote a context for 'rehabilitation' which can be sustained after discharge. Despite the disadvantage of limited clinical supervision being available to the client, we feel this approach is: cost-effective, it empowers the client and it promotes meaning and transferability of skills (if rehabilitation is not limited to a clinical environment). It also buffers against depression through decreased social isolation in addition to a reduced sick role. We would recommend a community-based element to your pathway.</p>
<b>Fibromyalgia</b>	<p>Finding out what services and support are currently available throughout Wales, and how to further</p>

<b>Support Group</b>	<p>develop the areas that are currently having no or limited support or services.</p> <p>This would then allow for training or refresher recognition, of Chronic Conditions within the Health Sector.</p> <p>Enabling consistency throughout the Region.</p>
<b>The Young ME Sufferers Trust (Tymes Trust)</b>	<p>Yes, and we have supplied links to the relevant documents in our answers to the other questions.</p> <p>We would also ask that you kindly read ‘Special problems of children with ME/CFS and the enteroviral link’ from the Journal of Clinical Pathology. The link is here:  <a href="http://www.tymestrust.org/pdfs/specialproblemsofchildrenwithmecfs.pdf">www.tymestrust.org/pdfs/specialproblemsofchildrenwithmecfs.pdf</a></p> <p>Should you wish to contact us directly, we shall be happy to discuss any matters with you and we sincerely hope that Wales can improve on the unhelpful English model.</p>
<b>The ME Association</b>	<p>I hope the Task Force will take serious note of:</p> <ol style="list-style-type: none"> <li>1 The conclusions and recommendations contained in the APPG report into NHS Service Provision for ME/CFS.</li> <li>2 The feedback provided by patients into the MEA survey of patient opinion on all aspects of management. This was completed by over 4,000 people with ME/CFS in the whole of the UK and represents the largest ever survey of patient opinion ever carried out. This data is still being analysed but we can supply an electronic copy containing all the preliminary results if required.</li> </ol>

**Presentation from WAMES (Welsh Association of ME & CFS Support)**



**WAMES Presentation to the CFS/ME Task & Finish Group  
Dated 26<sup>th</sup> JANUARY 2010**

Good afternoon all. Thank you for the opportunity to talk to you this afternoon.

We have been asked to speak about the issues (from a patient's perspective) which would affect the way that existing services could be improved and developed. In the short time available it is only possible to highlight some of the key issues, but I will answer any questions afterwards to the best of my ability. In addition I will refer to ME/CFS as ME throughout although this term encompasses the terms ME, CFS & PVFS.

The general principles of care for people with ME are overarching in that children, adolescents, adults and their carers should all be treated with respect and dignity. This does not always happen currently. The polarised views on the causes and management of ME should not affect the professional/patient relationship nor the ongoing care of the patient. However, ME, CFS and PVFS, which names are used interchangeably for this condition, are all tabulated in ICD10 at G93.3, conditions of the nervous system by the World Health Organisation and patients have been waiting for a long time for the NHS to acknowledge both this and the growing body of research that shows the underlying physical problems in many systems in the body.

We feel we must also draw to your attention the erroneous use of the term chronic fatigue in relation to ME. Chronic fatigue can be a symptom in many illnesses and is only one of a number of symptoms that needs to be present for a diagnosis of neurological ME to be made. The inability of doctors to recognise the collection of symptoms is one of the things that delays diagnosis for patients.

Initially a lot of work is going to be needed to be done by health professionals to reverse the damage and regain the trust of patients who have been disbelieved, neglected, isolated and misdiagnosed by them for so long.

The situation in Wales at present as we know it is :

There are no specialised services for children. As far as we can tell there are no Paediatricians who have a speciality in ME.

There are no transitional services for adolescents as there are no specific services for children to refer from.

There are no specialised services for adults that offer a diagnosis nor are there any Consultants who have a speciality in ME although there are 3 small rehabilitation clinics that include patients with ME who are fit enough to attend.

There are no services for the severely affected patients.

WAMES does not believe that improving or developing existing clinical settings is the best way forward because they cater for such a small number of patients and do not cater for children or those who are too ill to attend them.

Initially what is needed is to train existing primary care staff in the appropriate diagnosis and management of ME and to differentiate between ME and other conditions, and monitor patients long term.

Given the heavy workloads of doctors it would probably be necessary to appoint someone to oversee the ongoing education process. There's a need to :

- Identify local champions to develop appropriate services and to disseminate the latest biological and other research findings.

- The next step is to identify and train professionals in each area (such as practice or neuro nurses) to assist the GPs, paediatricians and Consultants in giving help with developing management plans, both to the mobile and to the severely affected housebound patients, which are tailored to individual needs.
- There may be a need to identify OTs, physios, dietitians and nutritionists to address needs in some patients, but first the numbers of patients requiring such help would need to be identified. Existing counsellors attached to GP surgeries could be used for patients who need them although they may need extra training to help ME patients.
- Neurologists need to be trained to diagnose and advise in complex cases and general consultants need to be more aware of the condition.

Patients have a low opinion of the NICE Guidelines believing that they do not offer specific enough information to help doctors diagnose accurately. Nor do they offer management advice which is appropriate for all in that GET & CBT are offered en masse to all mild and moderately affected people with ME. The applicability of this is doubtful as not one size will fit all patients.

The cost to treat each patient in Wales who is eligible according to NICE Guidelines, is **£4,228 for 16 sessions** of GET & CBT per patient . (Figures are from St Bartholomew's Hospital CFS Service). On top of this you have to consider the cost of training the doctors and therapists to administer these treatments. We have to ask if this is a cost effective way of delivering treatments which will not cure and that most patients will likely refuse and that could cause relapses in many, leading to legal action?.

When patients first present to their GPs with symptoms which may indicate ME they need to receive appropriate testing to preclude other conditions. Management advice suitable to their situation which could include how to pace their activities to prevent 'boom and bust' cycles. Appropriate management advice at this stage could prevent making their condition more severe thereby lengthening the likely time they will be ill.

Children will need an immediate referral to a Paediatrician who specialises in ME for confirmation or denial of the diagnosis.

Help with education by informing the school that the child is too ill to attend. If the child is expected to be at home for 15 days or more then the GP should also contact the LEA to ensure home tuition or e-learning is set up appropriate to the child's health needs.

This will ensure the child does not fall too far behind in their schooling nor become too isolated. GPs therefore need to understand the importance of patients not overdoing things in the early stages.

For adults it will mean providing proof to their employers that they are too ill to attend work.

For some adults referral to a Consultant who specialises in ME may be necessary because their condition does not follow a simple course or they may not improve as expected or they deteriorate for no apparent reason. Some GPs may not be comfortable in managing a more severely affected adult alone and want the backup of specialised services in managing the patient.

GPs or Consultants will need to provide information and advice to employers about making reasonable adjustments at work to accommodate their employee who may only be able to work part time, need a less physical role, need to work from home or may even be too ill to work at all.

For the severely affected child or adult it may be necessary for them to have domiciliary visits from GPs and hospital Consultants etc as they will be too ill to leave their homes without worsening their condition or relapsing.

Adults and children will need help to claim appropriate benefits relative to their needs. Adults who are too ill to work will need to access benefits to allow them to continue to live independently. They may also need to access benefits which help to cover the extra costs relative to their illness.

The parents of children may need help to claim benefits which help to cover the extra costs of having a child with additional health needs at home as well as for themselves if they have had to give up work or go part time to provide the care that their child needs. Persuading the Benefits Agency to give benefits to people with ME is becoming increasingly difficult and supporting information from a consultant is often crucial

Both adults and children may need support from Social Services with care, aids and adaptations such as wheelchairs, stairlifts etc which will make their lives easier. Assessments should be undertaken as quickly as is possible and receipt of necessary aids, adaptations and services should be input swiftly.

Carers should receive an assessment of their needs from Social Services and receive the necessary support to enable them to care for their loved ones as early as possible and to prevent parents from becoming exhausted and unable to cope.

Transition from children's to adult health and social care services should be carefully managed ensuring there is a seamless and stress free cross over of services. Referral at transition should be to a Consultant who specialises in ME and to the disability team within social services. It would be advantageous if joint working could be undertaken for some time before transition finally takes place. Education officials should also be involved at this stage due to home tuition/e-learning ceasing at the age of 16. If an adolescent wishes to continue in education but are too ill to attend school/college funding is stopped and the young person finds it almost impossible to find funding appropriate to their needs to continue their education from home.

I think my time must be up and there is a lot more I could say, but I'll be glad to answer any questions about this or our questionnaire response, thank you.

**CFS/ME Task and Finish Group Additional Questionnaire Edited Responses****Question 1**

	<b>What do you think are the strengths of the Map of Medicine Care Pathway? i.e that works well.</b>
<b>HPD3</b>	Need to know what is out there in Wales and how success these programmes are/have been.
<b>ABMU</b>	<p>Excellent, comprehensive guidance on all aspects of this difficult condition.</p> <p>The fact that it is a diagnosis of exclusion makes it particularly important for GPs to consider the differential diagnosis, and therefore the detailed summary of this is v helpful.</p> <p>The psychological aspects of this condition are well explained and their importance given, in my view, the appropriate weight. The inclusion of different antidepressants that can be useful (for different symptoms) is helpful.</p> <p>The details of the graded exercise programme are important so that patients can be informed of the likely management programme.</p>
<b>Betsi Cadwaladr</b>	<p>The guidance for the primary care in terms of pretty much establishing diagnosis at this level is very good. I think secondary care medical provision should be purely to further investigate the significance or otherwise of abnormal test results. Lots of CFS sufferers have B12, thyroid, testosterone levels that vary from normal levels but when corrected for this has no impact on their primary problem.</p> <p>If the onus on diagnosis is with the GP referral to secondary care can then be with a specific focus and aim. In this way existing medical services would suffice.</p>

<b>Hywel Dda</b>	<p>Having a clear pathway to follow is a strength in itself.</p> <p>The NICE guidelines for CFS/ME Diagnosis &amp; Management are incorporated throughout.</p> <p>The pathway presents as holistic in character i.e. has a biopsychosocial approach (although this is not explicitly stated) that takes into account the person's physical, emotional &amp; social issues. The pathway acknowledges the importance of regular review and the management of setbacks/relapse.</p> <p>The pathway acknowledges the importance of the doctor/patient relationship, with an emphasis on listening.</p> <p>The pathway makes references to the importance of family involvement/understanding.</p>
<b>Cerebra</b>	<p>My first impression is that the Map only seems to look at a narrow band of clinical aspects, which I don't feel would be optimally effective on its own – fair enough, it is a map of “medicine”. Like one of the people who has replied to you already, I like the Scottish one the best. Beyond that, I'm not able to contribute further at this time, but I take comfort in the fact that there are knowledgeable people on your mailing list.</p>
<b>Public Health Wales</b>	<p>It is essential that testing for viral infection in cases of CFS is done in a very considered and cost effective way. Numerous studies shows testing for viral infection by routine virology labs is unhelpful and uneconomic – for most viruses because there are no tests to distinguish ongoing symptomatic infection from past resolved asymptomatic infection. Lack of this understanding is what has led to the erroneous attribution of cause to various viral infections in the past.</p>
<b>Question 1 – later responses</b>	
<b>Public Health</b>	<p>Cannot comment about how well the overall algorithm works but I am very concerned about</p>

<b>Wales</b>	requests for increasing numbers of VIROLOGY tests which are inappropriate.
<b>NSAG Welsh Medical Committee</b>	It is a sensible and practical approach to aid the diagnosis of CFS
<b>Cardiff and Vale</b>	It is a simple algorithm defining the clinical pathway. It is easy to understand and follow by clinicians as well as carers and patients not familiar with the conditions.
<b>Fibromyalgia Support Group</b>	Self Management of symptoms. Investigations path, with the patients history and examination. As long as Health Professional follows the flow chart in the MoM, this whole structure should work well.
<b>Welsh Therapies Advisory Committee (Hywel Dda)</b>	<ul style="list-style-type: none"> <li>• It provides clear and concise guidance for the patient's physician in particular re diagnosis- step by step guidance</li> <li>• Also guidance for members of a primary care team re mangement.</li> <li>• Having a clear pathway to follow is a strength in itself.</li> <li>• The NICE guidelines for CFS/ME Diagnosis &amp; Management are incorporated throughout.</li> <li>• The pathway presents as holistic in character i.e. has a biopsychosocial approach (although this is not explicitly stated) that takes into account the person's physical, emotional &amp; social issues.</li> <li>• The pathway acknowledges the importance of regular review and the management of setbacks/relapse.</li> <li>• The pathway acknowledges the importance of the doctor/patient relationship, with an emphasis on listening.</li> <li>• The pathway makes references to the importance of family involvement/understanding.</li> <li>• Quick reference – clinicians</li> </ul>

<p><b>Powys LHB</b></p>	<p>Standardised, rigorous, early history taking and investigations validate and normalise patient's experience.</p> <p>Within the secondary care element, it recognises the requirement for a biopsychosocial management of the condition as recommended by the NICE Guidelines.</p> <p>It acknowledges that care should be shared between primary and secondary care.</p> <p>In acknowledging set-backs/ flare ups it accepts the requirement, particularly in adults, for long-term management rather than cure although greater emphasis could be placed on the self-management goal.</p>
<p><b>WAMES</b></p>	<p>WAMES believes that in principle the Map of Medicine could be a useful aid to doctors when diagnosing and managing ME and CFS but not in its present format. Much would need to be done to make this current pathway an effective tool and acceptable to patients and many health professionals who specialise in ME and below we highlight <b>a few</b> of the major problems. Because of the wide level of ignorance, misunderstanding and misdiagnosis of the condition among professionals, there are questions about whether such a pathway would be sufficient on its own. One way to increase its efficacy might be to include the links to GPs or consultants with a special interest in ME and CFS, who would be available for consultation during the assessment and diagnostic process, and links to sources of training materials. An ongoing education programme would also be needed.</p>
<p><b>WOC</b></p>	<p>Readily accessible, easy to use, and can be modified to suit local protocols.</p>
<p><b>Public Health Wales - Pharmacists</b></p>	<p>I can only comment in generic terms – can promote and support an evidence based and consistent approach to clinical care. Ability to adapt to local circumstances important and provides opportunity to develop Welsh specific pathways.</p>