5 December 2022

Dear

**ATISN 16836 – Chronic Fatigue Syndrome Steering Group**

Thank you for your request to the Welsh Government for information under the Freedom of Information Act (2000) received on 04 November 2022. You have requested the following:

- *All documentation around the Welsh Government Department of Health and Social Care's M.E/C.F.S steering group. This should include the dates the group was created/ended, minutes of the meetings and a list of attendees.*

## Our Response

I am able to confirm that Welsh Government does holds the information that you are requesting, please see Document 1. However, we have decided that this is to be exempted from disclosure under Section 40(2) – Personal Information of the Freedom of Information Act. The reasons for applying this exemption are set out in full in Annex 1.

## Next steps

If you are dissatisfied with the Welsh Government's handling of your request, you can ask for an internal review within 40 working days of the date of this response. Requests for an internal review should be addressed to the Welsh Government's Freedom of Information Officer at:

Information Rights Unit,
Welsh Government,
Cathays Park,
Cardiff,
CF10 3NQ

or Email: Freedom.ofinformation@gov.wales

Please remember to quote the ATISN reference number above.

You also have the right to complain to the Information Commissioner. The Information Commissioner can be contacted at: Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF.

However, please note that the Commissioner will not normally investigate a complaint until it has been through our own internal review process.

Yours sincerely,

## Annex A

### S.40 (2) – Personal information about others

‘Personal data’ is defined in sections 3(2) and (3) of the Data Protection Act 2018 (‘the DPA 2018’) and means any information relating to an identified or identifiable living individual. An identifiable living individual is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of the individual.

We have concluded that, in this instance, the information requested contains third party personal data.

Under Section 40(2) of the FOIA, personal data is exempt from release if disclosure would breach one of the data protection principles set out in Article 5 of the GDPR. We consider the principle being most relevant in this instance as being the first. This states that personal data must be:

*“processed lawfully, fairly and in a transparent manner in relation to the data subject”*
The lawful basis that is most relevant in relation to a request for information under the FOIA is Article 6(1)(f). This states:

*“processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child”.*

In considering the application of Article 6(1)(f) in the context of a request for information under FOIA it is necessary to consider the following three-part test: -

- **The Legitimate interest test**: Whether a legitimate interest is being pursued in the request for information.
- **The Necessity test**: Whether disclosure of the information/confirmation or denial that it is held is necessary to meet the legitimate interest in question.
- **The Balancing test**: Whether the above interests override the interests, fundamental rights and freedoms of the data subject.

Our consideration of these tests is set out below:

### 1. Legitimate interests
Welsh Government recognises that there is a lot of interest at the moment regarding COVID-19 and Long COVID and your legitimate interest in this information. However, releases under the Act are made to the world at large and published on the Welsh Government’s disclosure log.

### 2. Is disclosure necessary?

As stated above, in considering the release of this information we have to bear in mind that the information will not just be provided to the requester. Whilst release may be necessary in the context of your research, we have to consider the release in the wider context of public disclosure and the necessity for that. In that context, we do not believe it is necessary to release the names of junior members of staff that sat on the steering group.

**3. The balance between legitimate interests and the data subject's interests or fundamental rights and freedoms**

Welsh Government believes that those that provided information to formulate Welsh Government policy would not have any reasonable expectation that their names would be disclosed to the public and that to do so would not be fair and transparent within the meaning of the first data protection principle. In the absence of compelling legitimate interests in the publication of this information, we have decided it is exempt from release under section 40 of the Freedom of Information Act.

Section 40 is an absolute exemption and not subject to the public interest test.

## Document 1

**CFS – ME and FM Implementation group meetings:**
**Meeting - 11 November 2015**
**Attendees:**

| | |
|---|---|
| Chair: | Professor Jonathan Richards, Locality Clinical Director, Cwm Taf UHB |
| Deputy Vice Chair: | Jan Russell, Chair, WAMES |
| Owen Hughes | Head of Pain & Fatigue Management, Powys Teaching HB |
| Dr Simon Neal | Consultant Clinical Psychologist, Betsi Cadwaladr UHB |
| Clare Clark | Clinical Lead, Occupational Therapy, ABM UHB |
| Jo Hampson | Consultant Clinical Psychologist, Chronic Pain Programme, Cardiff and Vale UHB |
| Laura Lloyd-Davies | Project Support Officer, Hywel Dda UHB |
| Karin Phillips | Deputy Director, Major Health Conditions, Welsh Government |
| WG Officer 1 <redaction s40(2)> | Head of Older People & Chronic Health, Welsh Government |
| WG Officer 2 <redaction s40(2)> | Major Health Conditions, Welsh Government |
| WG Officer 3 <redaction s40(2)> | Major Health Conditions, Welsh Government |

**Notes of meeting:**

### 1. Welcome and introductions

Professor Jonathan Richards introduced himself and welcomed everyone to the meeting.

### 2. Apologies

- Dr Nicholas Brace, Pain Management Programme Clinical Lead (ABM UHB)
- Alison Shakeshaft, Director of Therapies and Health Science (Aneurin Bevan UHB)
- Maddy Piper, Consultant Rheumatologist (Aneurin Bevan UHB)
- Carol Ross, Fibromyalgia Wales
- Claire Hurlin, Strategic Head of Community & Chronic Conditions, Hywel Dda UHB
- Jane Boyd, Clinical Director, Psychology & Counselling Services, Cardiff & Vale UHB

### 3. Minutes of the meeting of 22 July 2015

The minutes were agreed.

### 4. Discussion

- **Report back on peer review of plans**
  The health board representatives provided a report on their plans and this identified a variation in progress to date. Simon Neal informed the Group that whilst he had drafted the North Wales report, he advised that progress was likely to be slow due to significant resource shortage, both financial and human. In regard to the peer review, Simon advised the main gap was the lack of baseline data which meant it was difficult to measure change and performance, which was a recurring theme through all plans.

  Jan Russell advised Hywel Dda's action plan had been signed off by the Executive Board.

  Clare Clark advised that ABMU was extending its pathway and considering a pilot project, although there were shortages in physiotherapy and psychological support. Some patients had been referred by their GPs to the service.

  Owen Hughes peer reviewed the ABMU plan and it was felt that, in common with other plans, more work was required.

- **Identification of common themes, models and challenges**

  Common themes included:
    - referrals for graded exercise,
    - Targeting GP education,
    - Coding (ICD10 International Classification of Diseases?),
    - Primary care pathway,
    - Outcome measures

  WG Officer 1 <redaction s40(2)> advised the Group's role is to agree "Once for Wales" measures, whether these are process, intervention, functional or outcome based.

  The Group agreed it was important to ensure ME – CFS and Fibromyalgia was included in their respective health board Integrated Medium Term Plans. The Group agreed training and awareness should also be included as a common theme.

  The Group was informed that Powys Teaching Health Board had established a service and was developing an online tool with presentations to GPs planned.

  Jo Hampson informed the group there was an ME – CFS/ Fibromyalgia pathway in Cardiff and Vale University Health Board and work was underway to identify individuals to develop a service which would start within primary care.

  It was agreed a workshop would take place mid December for LHB representatives to discuss how health boards can work jointly across borders, share good practice to help shape action plans with a view to them being ratified and included in IMTPs prior to publication. Meeting arranged for 16 December.

  In closing, WG Officer 1 summarised:-
- Health board plans needed further refinement on timescales, transition care, prudent healthcare and co-production, with partnership between patients and their families, health services and social services. Welsh Government to consider writing to Executive Leads regarding final completion of action plans and ratification by UHBs at Board level
    - Cross health board boundary working and sharing draft plans was encouraged

  There was no other business and the chair thanked the Group for their time.

**Meeting - 09 March 2016**
**Attendees**:

| | |
|---|---|
| Carol Ross | Vice Chair of Implementation Group and Chair, Fibromyalgia Wales |
| Jan Russell | Deputy Vice Chair of Implementation Group and Chair, WAMES |
| Dr Jo Hampson | Chronic Pain Service, Cardiff and Vale UHB |
| Dr Simon Neal | Consultant, Clinical Psychologist, Betsi UHB |
| Clare Clark | Clinical Lead, Occupational Therapy, representing Powys and ABMU UHBs |
| Alison Shakeshaft | Director of Therapies & Health Science, Aneurin Bevan UHB |
| Claire Hurlin | Strategic Head of Community & Chronic Conditions – Hywel Dda UHB |
| WG Officer 1 <redaction s40(2)> | Major Health Conditions, Welsh Government (WG) |
| WG Officer 2 <redaction s40(2)> | Major Health Conditions, WG |
| | |
| Michelle Price | Consultant Therapist for Stroke & Neurorehabilitation Powys Teaching HB |
| WG Officer 9 <redaction s40(2)> | Delivery & Performance, WG |

**Notes of meeting:**

## 1. Welcome and Introductions

Carol Ross welcomed everyone and explained she was chairing the meeting as Professor Jonathan Richards retired from Cwm Taf UHB on 29 February.

## 2. Apologies

- Professor Jonathan Richards, Cwm Taf UHB (retired)
- John Palmer, Cwm Taf UHB
- Sue Jeffs, Aneurin Bevan UHB
- Maddy Piper, Aneurin Bevan UHB
- Owen Hughes, Powys Teaching UHB

## 3. Note of the meeting of 11 November 2015

The notes were agreed with the following amendments:

- Karin Phillips, Deputy Director, Major Health Conditions, Welsh Government attended the meeting
- Jan Russell advised Hywel Dda's action plan had been signed off by the Executive Board.
- Jo Hampson informed the group there was an ME – CFS/Fibromyalgia pathway in Cardiff & Vale UHB
- Welsh Government to consider writing to Executive Leads regarding final completion of action plans and ratification by UHBs at Board level

**Action**

- Note to be amended as above
- WG to write to Executive Leads re completion of action plans. **(Done)**

## 4. Nominations for Chair of Implementation Group

- Claire Hurlin (Hywel Dda UHB) volunteered to Chair the Group.

## 5. Stocktake of recommendations

- WG Officer 2 <redaction s40(2)> gave a brief presentation showing progress by each health board against the ME – CFS and Fibromyalgia report recommendations. Overall, good progress has been made by all health boards in a relatively short period of time. Some health boards are more advanced than others, depending on their starting point and structure.
- Aneurin Bevan has got a Fibromyalgia group but recognise they need to increase their expertise on ME - CFS. They do not have an ME - CFS specialist and need to establish a multi disciplinary team to provide advice on treatment.

- There are a number of self management learning programmes available including Education Programmes for Patients (EPP).

**ACTION**

- Carol Ross agreed to resend the link to the electronic programmes for distribution to members. **(Done)**

## 6. PROMS/PREMS

- Michelle Price and WG Officer 9 <redaction s40(2)> joined the discussion by telephone and explained developing PROMS and PREMS are priorities in both the Stroke Delivery Plan and the Neurological Conditions Delivery Plan. Funding has been set aside to instigate these measures. ME – CFS and Fibromyalgia will be represented.
- A PREMS questionnaire is being developed and will be tested with patients and patient groups by the end of March including those with ME – CFS. The Welsh Neurological Alliance and WAMES are engaged in the process.
- Work is developing on the PROM and health boards are being asked to support clinicians' involvement in developing and testing PROMS. There is no perfect outcome measure. For ME – CFS a measure may be developed to establish whether patients are improving and how content they are with life.
- Final PROMS and PREMS are expected to take some time to achieve following a process of drafting, testing, adapting, testing again and sharing with wider groups.

**ACTION**

- Simon Neal agreed to share his contact details with Michelle Price. **(DONE)**

**General Discussion**

- Simon Neal requested WG write to Betsi UHB seeking an Executive Lead replacement for Professor Matthew Makin who has left the health board. (**Done)**
- Following the reorganisation at Betsi UHB it has been agreed pathway developments will sit under the neurological network subject to resources being forthcoming.
- The ME – CFS/FM pathway draft for ABM UHB will be considered shortly by the Long Term Conditions Board. The pathway will be piloted in ABM UHB and outcomes will be looked at after one year.
- Aneurin Bevan UHB held a successful meeting with the FM steering group and Primary Care and proposes to keep management of the condition within Primary Care if possible. As far as ME – CFS is concerned plans are in place to make further progress with the pathway and action plan although engagement with patient representatives is required.
- The plan for Hywel Dda has been passed by the lead executive – meetings are held every month to generate interest and update the plan. They are considering the use of PocketMedic which is a digital platform allowing clinicians to send short self management films to patients to help manage their chronic disease. The licence fee for the health board is about £20k.
- WAMES is developing brief electronic information sheets for online use.
- Cardiff & Vale's action plan has been passed by the Clinical Lead of the Board and is on the agenda for the Executive Board's consideration
- Hywel Dda is planning to put their action plan on their website.
- ME Awareness week is taking place nationally between 11 and 17 May.
- Fibromyalgia Awareness week is taking place later this year – further information will be provided in due course.
- It was agreed an update of the work of the group would be submitted to the Minister in the summer.

**ACTION**

- WG to write to Betsi Chief Executive requesting an Executive Lead replacement for Professor Matthew Makin who has left the health board. **(Done)**
- Carol Ross and Jan Russell agreed to provide support network contact details to Alison Shakeshaft **(Done)**
- Jan Russell will provide links to resources, guides, patient information, on-line learning and patient stories for publication during ME awareness week (11-17 May). **(Done and published on GP One website)**
- WG to write to Executive Leads seeking an update/progress report on what has been achieved in each LHB.
  **(Done)**

**Date of Next Meeting**

- To be agreed - future meetings to commence at 13.30pm

**Meeting - 20 July 2016**

**Attendees:**

| | |
|---|---|
| Claire Hurlin (Chair) | Strategic Head of Community & Chronic Conditions – Hywel Dda UHB |
| Nick Brace | Pain Management Programme Clinical Lead - Abertawe Bro Morgannwg UHB |
| Simon Neal | Consultant, Clinical Psychologist, Betsi Cadwaladr UHB |
| Dr Jo Hampson | Chronic Pain Service, Cardiff & Vale UHB |
| Clare Clark | Clinical Lead, Occupational Therapy, Powys THB |
| Alison Shakeshaft | Director of Therapies & Health Science, Aneurin Bevan UHB |
| Jan Russell | Deputy Vice Chair of Implementation Group, Chair WAMES |
| Karin Phillips | Deputy Director, Major Health Conditions – Welsh Government |
| WG Officer 4 <redaction s40(2)> | Head of Older People's Health and Chronic Conditions Team – Welsh Government |
| WG Officer 2 <redaction s40(2)> | Senior Policy Officer, Older People's Health and Chronic Conditions Team – Welsh Government |
| WG Officer 5 <redaction s40(2)> | Policy Officer, Older People's Health and Chronic Conditions Team – Welsh Government |

**Notes of Meeting:**

**1. Welcome and Introductions**

1.1 Introductions were made around the table. Karin Phillips thanked Claire Hurlin for agreeing to take over the role of Chair of the Group following the retirement of Professor Jonathan Richards. Karin also advised the Group that WG Officer 2 <redaction s40(2)> would be retiring on 28th July and thanked her for all her hard work.

**2. Apologies**

Sue Jeffs, Aneurin Bevan UHB
Maddy Piper, Aneurin Bevan UHB
John Palmer, Cwm Taf HB
Owen Hughes, Powys Teaching UHB
Nick Smith, WAST
WG Officer 6 <redaction s40(2)>, Social Services Welsh Government
Carol Ross, Fibromyalgia Wales

**3. Note of the meeting on 9 March 2016 and matters arising**

3.1 The minutes of the last meeting were agreed with the slight amendment that Simon Neal is not Dr.

3.2 An update was provided by Alison Shakeshaft on agenda Item 6 from the last meeting – PROMS/PREMS. The updates were:

- Both Stroke and Neurological Conditions Implementation Groups have agreed patient reporting outcomes.
- Michelle Price has been doing group work on PREMS/PROMS. Michelle has been working with Jonathan Hewitt on a grid to test the patient relating outcome measures on stroke and neurological conditions.
- PROMS is being tested in stroke patients in Cwm Taf and Aneurin Bevan.
- Options need to be considered to take forward the PREMS work. They may bid for Stroke money to move this forward.
- Hopefully data will start being collected from October.

**4. Feedback following Karin Phillips letter of 30 June to Executive Leads regarding the progress report on action plans and future development plans.**

4.1 WG Officer 2 <redaction s40(2)> advised the Group three updates had been received from Cardiff & Vale, Powys and Hywel Dda. Cwm Taf have contacted WG Officer 2 <redaction s40(2)> and advised they will be sending their update through shortly.

4.2 Clare Clark joined the meeting.

4.3 The Group provided a verbal update on the work in their areas. A synopsis of these updates were:

- Aneurin Bevan are much further forward with their work on FM than CFS/ME. They will review their action plan by the next meeting and will draft pathways for both conditions.
- Hywel Dda published their plans on 11th May but they need to be updated. The first draft of their management pathway is currently out for consultation and they are hoping they will be able to discuss feedback in October. They are also trying to find money to work with pocketmedic to produce films which run for 3-5mins. GPs will be able to sign patients up via email and then send them the films either in bulk or weekly.
- Cardiff & Vale action plans and pathways have been agreed. They are exploring a pilot group in 2017 to develop within the existing self-management work. They have also launched the 'Bold Improvement Goal Programme'. It is likely that musculoskeletal services may be included which will probably include CFS/ME.
- Powys THB has further development plans which include an online programme and text support. They are also establishing transitional links with the paediatricians and raising awareness to GPs.
- Betsi Cadwaladr will have a new executive board lead in October. In the interim Mark Williams will be covering following the departure of Matt Makin.
- Abertawe Bro Morgannwg UHB has drafted a pathway which has highlighted some resource problems. The Long term Conditions Board will provide some resource to deliver a new expanded pathway. They have also identified a shortage in psychological and physiotherapy access.

4.4 A question was raised relating to the Cabinet Secretary's views regarding improving the services for patients with ME-CFS and FM. Karin advised his views had not been sought but once a response had been received from each of the Executive leads they would be able to update the Cabinet Secretary.

**ACTION**

Executive leads to respond to Karin Phillips letter of 30 June.

**ACTION**

Karin Phillips to write to Mark Williams, Betsi Cadwaladr interim Executive Board Lead, regarding lack of progress on publishing action plans and progress reports.

## 5. Roundtable discussion on suggestions to raise awareness in primary care re:

- RCGP on-line learning module for ME-CFS
- Timely diagnosis
- Effective management of children and adults
- Identifying gaps

### RCGP on-line learning module for ME-CFS

5.1 Jan Russell advised that WAMES were not able to support the RCGP ME on-line module due to a number of reasons including the psychosocial pathway. Jan added that WAMES had concerns about the assessment element which focussed on fatigue, even though many patients don't necessarily recognise fatigue as a symptom, instead just reporting that they are feeling generally unwell. WAMES also felt that there needs to be much more balance within the module and highlighted the reference to the fine trial, which hadn't proved a resounding success.

### Timely diagnosis

5.2 Dr Jo Hampson informed the group she will be attending a meeting which involves 30 patients coming together to discuss the type of service that they want. This follows a number of complaints received by the Care Council.

5.3 The group agreed there was no one way approach to diagnosis and there has to be ability for patients to have access to a range of services. Other suggestions to support a timely diagnosis included:

- Exclusion process, where you exclude conditions such as sleep apnoea and MS.
- Having a range of training options available, not just e-learning.
- Using clustering to identify the needs of the population.
- Writing to GPs to ask for their views.

**ACTION**
Claire Hurlin to draft a questionnaire on behalf of the Group to send to GP Practice Managers about whether GPs feel confident diagnosing ME-CFS and FM, who would they turn to for advice, what screening/guidance is required for diagnosis, treatment options, where would they refer patients etc. This is to be agreed by the Group before dissemination.

**Effective management of children & adults** - to be discussed during the next meeting due to time constraints.

**Identifying Gaps** – to be discussed during the next meeting due to time constraints.

**6. Update on Me-CFS and FM and the Neurological Implementation Group**

Agenda item covered during other agenda items.

**7. Update on fibromyalgia Wales is supporting LHB pathways for Fibromyalgia**

Agenda item covered during other agenda items.

**8. Update from Welsh Association of ME & CFS**

Agenda item covered during other agenda items.

**Any other business**

Dates for next meetings to be agreed and added to diaries.

**Action Log**

| | **Action** | **By who** | **Update** |
|---|---|---|---|
| 1. | Executive leads to respond to Karin Phillips letter of 30 June. | Executive Leads | |
| 2. | Karin Phillips to write to Mark Williams, Betsi Cadwaladr interim Executive Board Lead, regarding lack of progress on publishing action plans and progress reports. | Karin Phillips | |
| 3. | Claire Hurlin to draft a questionnaire on behalf of the Group to send to GP Practice Managers about whether GPs feel confident diagnosing ME-CFS and FM, who would they turn to for advice, what screening/guidance is required for diagnosis, treatment options, where would they refer patients etc. | Claire Hurlin | Draft questionnaire has been forwarded to the group on 01/09/2016. |

## Meeting - 29 November 2016

**Attendees:**

| | |
|---|---|
| Karin Phillips **KP** (acting Chair) | Deputy Director, Major Health Conditions, Welsh Government |
| Dr Jo Hampson **JH** | Chronic Pain Service, Cardiff & Vale University Health Board |
| Clare Clark **CC** | Clinical Lead, Occupational Therapy, Powys Teaching Health Board |
| Dr Owen Hughes **OH** | Consultant Psychologist, Powys Teaching Health Board |
| Jan Russell **JR** | Deputy Vice Chair of Implementation Group, Chair WAMES |
| Dr Maddy Piper **MP** | Consultant Rheumatologist, Aneurin Bevan University Health Board |
| Nick Brace **NB** | Pain Management Programme Clinical Lead, Abertawe Bro Morgannwg, University Health Board |
| WG Officer 7 <redaction s40(2)> | Senior Policy Officer, Older People's Health & Chronic Conditions Team, Welsh Government |
| WG Officer 5 <redaction s40(2)> | Policy Officer, Older People's Health and Chronic Conditions Team, Welsh Government |

**Apologies:**

| | |
|---|---|
| Claire Hurlin (Chair) | Strategic Head of Community & Chronic Conditions, Hywel Dda University Health Board |
| John Palmer | Director of Primary, Community & Mental Health, Cwm Taf Health Board |
| Simon Neal | Consultant, Clinical Psychologist, Betsi Cadwaladr University Health Board |
| Sue Jeffs | Deputy Director of Therapies and Health Science, Aneurin Bevan University Health Board |
| Nick Smith | Head of Service, Non-emergency transfers, Wales Ambulance Service Trust. |
| Carol Ross | Fibromyalgia Wales |

## Notes of meeting:

### 1. Welcome and Introductions

**1.1** Introductions were made around the table. KP explained that Claire Hurlin had sent her apologies just before the meeting due to an accident on the M4 and asked if there were any objections to her standing in to chair the meeting. There were no objections.

### 2. Purpose of the Group

**2.1** Referring to paper MECFSFM 1 – Terms of Reference of the Group, KP asked for comments regarding potential overlap with other groups. She also asked about the peer support and challenge role and what that should mean in regard to health board plans and reports. She pointed out that a number of plans still had not been published on the relevant health board website and/nor received by Welsh Government as requested in KP's letter dated 30 June 2016.

**2.2** KP outlined the work being taken forward by the Persistent Pain Steering Group, to develop a Persistent Pain Framework. She advised that there would be opportunity for this Group to feed into the Framework.

**2.3** The Group shared their views.

- Some thought the work of the Group could be absorbed within the work of the Persistent Pain Steering Group. However, concerns were expressed that if that was to happen, there would be a danger that specific conditions could get overlooked such as ME.
- Different health boards manage ME/CFS & FM differently. For example Aneurin Bevan does not include FM within the pain pathway, the condition sits in rheumatology. In Abertawe Bro Morgannwg ME/CFS & FM all sit within Pain Services. It was agreed this should not be an issue.

- There needs to be a new commitment for taking this work forward. The current system is not working; this is evident in the lack of response producing annual plans.
- 2 presentations per meeting from different health boards would be a useful way of understanding what is happening in different health boards, offer opportunity to share good practice; identify gaps; and seek Group's view on proposals.
- Plans for work on CFS/ME &FM should be fed into the IMTP process to help ensure this work is 'on the agenda'.
- Primary care representative to be invited to meetings when appropriate.

**ACTION: WG Officer 5 <redaction s40(2)> to adjust Terms of Reference to reflect comments.**
**ACTION: WG Officer 5 <redaction s40(2)> to ensure that the IMTP review process included assessing coverage of CFS/ME and FM.**

### 3. Good practice

**3.1** The Group shared good practice within their Health Boards:

- Powys – using technology to engage with service users, e.g. Skype is being made available for patients who are unable to attend groups to ensure they can still be part of discussions.
- Cardiff & Vale – The Executive Board and JH recently met a large patient group to seek their views on the service required. CFS/ME is now part of the pain service in Velindre.
- Abertawe Bro Morgannwg – Rheumatologists are developing a screening tool to diagnose FM in Primary Care. They are also piloting a service where GP clusters have access to Occupational Therapists. CFS/ME & FM groups will be separated with the groups being tailored to these conditions. Evaluation will take place over the next 12 months.
- Aneurin Bevan – Currently delivering the three branches of multimodal care in the community - National Exercise Referral Scheme, 'Activate your Life' courses and stress courses. They have met with GPs and will be working in communities within the next 12 months. One in three rheumatology referrals are FM patients so they are looking how they can deliver to the community. FM patients are not seen by the Pain Team.
- Hywel Dda – draft management guidelines for GPs are out for consultation but little response to date. There is a CFS working group in Hywel Dda but no FM group.

**ACTION: WG Officer 5 <redaction s40(2)> to forward draft Pain Framework when available and to include an agenda item at the subsequent meeting.**

### 4. GP Questionnaire

**4.1** CC informed the Group the questionnaire will be circulated to GPs. KP suggested it may be useful to reference the questionnaire in the newsletter that is circulated to GP clusters from Grant Duncan, Deputy Director of Healthcare Policy within Welsh Government. This was agreed

**ACTION: WG Officer 7 <redaction s40(2)> to ask Grant Duncan to include information on the questionnaire in his next newsletter.**

### 5. Effective Management of children and adults

**5.1** CC advised there are gaps in all Health Boards whilst patients are transitioning from child to adult services. KP indicated that the refresh of the Neurological Delivery Plan next year would cover transition.

### 6. Identifying Gaps

**6.1** CC suggested any potential gaps could be identified within the progress reports completed by individual health boards. KP added identified gaps could be discussed in future meetings to share knowledge and expertise on how to overcome challenges.

### 7. Minutes

**7.1** The minutes were agreed with no amendments.

### ACTION LOG

| | **Action** | **Responsible owner** | **Progress** |
|---|---|---|---|

| | | | |
|---|---|---|---|
| 1. | To adjust Terms of Reference to reflect comments. | WG Officer 5 <redaction s40(2)> | Complete – ToR amended. |
| 2. | To ensure that the IMTP review process included assessing coverage of CFS/ME and FM. | WG Officer 5 <redaction s40(2)> | IMTP process concluded in March. As CFS/ME and FM is not a requirement of the IMTP process officials were unable to assess this area. However, a review of the IMTPs revealed that these conditions were not mentioned. |
| n3. | To forward draft Pain Framework when available and to include an agenda item at the subsequent meeting. | WG Officer 5 <redaction s40(2)> | Ongoing – Framework is currently being developed. A draft will be forwarded for comments when a near final version has been drafted. We anticipate this will be in the summer. |
| 4. | To ask Grant Duncan to flag the GP questionnaire in his next newsletter. | WG Officer 7 <redaction s40(2)> | Not completed. |

**Meeting - 12 April 2017**

**Attendees:**
Claire Hurlin (Chair) Hywel Dda University Health Board
Debbie Owen ABMU University Health Board
Clare Clarke – Powys teaching Health Board
Owen Hughes – Powys Teaching Health board
Jan Russell – WAMES
Jo Hampson – Cardiff and Vale University Health Board
WG Officer 4 <redaction s40(2)> – Welsh Government
WG Officer 7 <redaction s40(2)> – Welsh Government

**Apologies**

John Palmer – Cwm Taf University Health Board
Sue Jeffs – Aneurin Bevan University Health Board
Alison Shakeshaft – Aneurin Bevan University Health Board
Karin Phillips, Welsh Government
Carol Ross, Fibromyalgia Wales

**Notes of meeting:**

**1. Welcome and Introductions**

1.1 The Chair opened by welcoming attendees and introductions were made around the table.

**2. Minutes of the last meeting**

2.1 The minutes of the last meeting were agreed as a true record. There were several suggested amendments to the membership list of the revised terms of reference. These are attached at Annex 'A' to these minutes. WG Officer 4 <redaction s40(2)>asked if group members could send any further suggested amendments to the Welsh Government.

**3. Purpose of Group / where are we now**

3.1 WG Officer 4 <redaction s40(2)> informed the group that the Cabinet Secretary for Health, Well-being and Sport was being challenged, both in plenary sessions and via correspondence, about progress made with policy on CFS/ME/Fibromyalgia and that he was disappointed by a perceived lack of progress – for example very few plans had been published on health board websites. He told the group that the Cabinet Secretary would shortly be writing to all health boards seeking an update on progress.

3.2 This was welcomed by the group as they felt it would give drive and impetus from the top of their organisations – they felt it was useful to have a reminder that these policies are important.

**4. GP Questionnaire**

4.1 CH asked if anyone in the group had received responses to the GP questionnaire. CC said that they had sent it out via survey monkey in Powys but had not had any responses. CH advised that they will now engage with individual practices. JH advised that Cardiff and Vale had received a 16% response rate and CH advised that Hywel Dda had received 15 responses from the 53 practices surveyed. However, it was noted that this had been achieved by asking the Primary Care Locality Managers to work with the practices to get them completed. . It appeared that the responses did not reveal any surprises – patients with these conditions generally do not feel supported.

4.2 There was some discussion around the need for a baseline to measure progress.

**ACTION – Members to extend the deadline for responses to the questionnaire to seek further responses.**

**5. See M.E. Project, Bristol**

5.1 The group discussed this project and it was noted that the project had received funding to pay the wages of a designated person to support people with these conditions.

5.2 It was noted that people with these conditions struggle to find and maintain appropriate work. Many did not tell their employer about their medical condition. It was agreed that we should ask the people from the Bristol project to present at the next meeting of this group.

**ACTION: CR/WG Officer 4 <redaction s40(2)> to contact Bristol See M.E. project to ask them to present at the next meeting.**

## 6. Presentations

6.1 MP informed the group about the letter that Aneurin Bevan sends to their GPs to help them diagnose fibromyalgia. There is a link at the bottom of the letter which GPs can click on for further information.

6.2. She also advised the group that in Aneurin Bevan they have a six week stress course and a four week mindfulness course which do not need referrals – anyone can just turn up for them. They also run the National Exercise Referral programme which has been useful.

6.3 MP further advised that hospitals want to place treatment for fibromyalgia in the community but patients are resistant to this as they want to see a specialist in a hospital environment.

6.4 CC informed the group about a telehealth project in Powys whereby patients are sent an options booklet which they fill in and return and are then offered either a face to face assessment, a telephone assessment or a Skype assessment. This was particularly useful for people with these conditions as it could negate the need to travel long distances in rural health board areas. 'Invest in your health' is a six week self management programme which has had positive feedback from service users. GP training was also provided using the Skype programme.

6.5 CC also advised the group about the 'fitbit' style devices they were trialling for people who wanted to improve their movement.

6.6 The group discussed the PACE trial and the fact that since the re-analysis of CBT and exercise treatment for ME there had been a movement to get the paper rescinded as it was beginning to be seen as 'bad science'.

6.7 WG Officer 4 <redaction s40(2)> asked if the group wished to put on some form of event to publicise the good work that is being done in this field. He said he would explore possible funding options if so. The group agreed but said that it would need to link to other subjects to gain wider interest. OH said it could possibly link to the proposed consultation events for the chronic pain work in the summer.

**ACTION: WG Officer 4 <redaction s40(2)>/CR to consider possible links with summer events.**

6.8 The group agreed that the update from health boards requested by the Cabinet Secretary could fulfil the annual reporting requirement for this year. It was agreed that there was a need to refresh the template for producing the CFS/ME/Fibromyalgia reports in future.

**ACTION: CH to produce a first draft of a new template and circulate to the group for comment.**

6.9 There was a discussion around webinars – 'Action for M.E.' was beginning a round of web-based training for GPs and the possibility of this group influencing what went into that training was discussed. It was also agreed that this group should publicise those webinars.

**ACTION: JR to send information on webinars to the group.**

6.10 The group agreed that Debbie Owen should present good practice from ABMU at the next meeting and that the Bristol project and the revised reporting template should form the rest of the agenda.

| Action | For | Progress |
|---|---|---|
| Extend deadline for questionnaire return to allow further time for responses | All | |
| Contact Bristol SEE M.E. project to ask them to present at the next meeting | CR/WG Officer 4 <redaction s40(2)> | |
| Investigate links with other events to promote good practice in CFS/ME/Fibromyalgia | WG Officer 4 <redaction s40(2)>/CR | |
| Produce new draft of reporting template | CH | |

| | | |
|---|---|---|
| Provide information on ME Webinars | JR | |
| Report on good practice at next meeting | DO | |

## Membership

| | |
|---|---|
| Chair | Claire Hurlin, Strategic Head of Community and Chronic Conditions |
| Abertawe Bro Morgannwg UHB | Hamish Laing, Medical Director and Executive Lead<br>Debbie Owen, Pain Management Programme Clinical Lead |
| Aneurin Bevan UHB | Alison Shakeshaft, Director of Therapies and Health Science and Executive Lead<br>Sue Jeffs, Consultant anaesthatist<br>Maddy Piper, Consultant Rheumatologist |
| Betsi Cadwaladr UHB | Dr Simon Neal, Consultant Clinical Psychologist |
| Cardiff and Vale UHB | Dr Jo Hampson and Dr Bethan Jones Chronic Pain Service<br>Dr Fiona Jenkins, Executive Director of Therapies |
| Cwm Taf UHB | John Palmer, Interim Director of Primary, Community and Mental Health and Executive Lead |
| Hywel Dda UHB | Jill Patterson, Interim Executive Director of Strategy & Integration/ Therapies & Health Sciences and Executive Lead |
| Powys Teaching HB | Dr David Murphy, Director of Therapies and Health Sciences and Executive Lead,<br>Owen Hughes, Head of Pain & Fatigue Management<br>Clare Clark, Clinical Lead, Occupational Therapy |
| Welsh Ambulance Services Trust (WAST) | Nick Smith, Head of Service, Non-emergency transfers |
| Fibromyalgia Wales | Carol Ross, Chair, Fibromyalgia Wales and Vice Chair of Implementation Group |
| Primary Care | As required. |
| Welsh Association of ME & CFS Support | Jan Russell, Chair, WAMES and Deputy Vice Chair of Implementation Group |
| Welsh Government | WG Officer 4 <redaction s40(2)>, Head of Older People's Health & Chronic Conditions Management<br>Redacted WG Officer 7 <redaction s40(2)>, Senior Policy Officer, Older People's Health & Chronic Conditions Management Branch |

**Meeting - 13 September 2017**
**Attendees:**
Claire Hurlin (Chair), Hywel Dda Local Health Board
Bethan Jones, Hywel Dda Local Health Board
Fiona Jenkins, Cardiff and Vale University Health Board
Jo Hampson, Cardiff and Vale University Health Board
Gareth Jordan, Cwm Taf University Health Board
Simon Neal, Betsi Cadwaladr University Health Board
Owen Hughes, Powys Teaching Health Board
Clare Clark, Powys Teaching Health Board
Maddy Piper, Aneurin Bevan Health Board
WG Officer 4 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

Jan Russell, WAMES (Via teleconference)

**Apologies**

Hamish Laing, Abertawe Bro Morgannwg University Health Board
Alison Shakeshaft, Aneurin Bevan University Health Board
Jill Paterson, Hywel Dda Local Health Board
David Murphy, Powys Teaching Health Board
Debbie Owen, Aneurin Bevan University Health Board
Carol Ross, Fibromyalgia Wales
WG Officer 7 <redaction s40(2)>, Welsh Government

**Meeting notes:**

## 1. Welcome and Introductions

1.1 The Chair welcomed attendees and introductions were made around the table.

## 2. Presentation from Action for ME on the See M.E pilot project.

2.1 Tom Owen, Director of Services and Development, Jonah Grunsell, Chair of Trustees, Action for M.E. and Fiona Wright, North Bristol NHS Trust attended and gave a presentation on the work of the See M.E project.

2.2 JG advised that Action for ME is a charity that takes action to end the ignorance, injustice and neglect faced by people with M.E. He advised that they do this by meeting need now to improve the lives of people with M.E. while taking action to secure change for the future. Alongside providing information, support and advice to people to help improve their health and well-being, Action for M.E. works with professionals to enhance the care and support that people with M.E. receive and funds pilot research projects to advance knowledge of the illness.

2.3 JG further advised that they were a small, dedicated team that employs 18 part-time and full-time staff and two sessional workers in Scotland. They are supported by around 70 volunteers, working with them in their Keynsham and Scotland offices and at home to deliver their vital services. The majority of their Trustees have had M.E. themselves, and most of the remainder have experienced it as carers.

2.4 FW advised that the North Bristol NHS Trust see around 500 people a year for ME, mainly direct referrals from GPs. FW informed the group that the pilot project, called Support, Empower, Employ M.E. (See M.E.), was delivered by the charity Action for M.E. in partnership with the Bristol CFS/ME Service at North Bristol NHS Trust. The project, launched on 4 June 2015, ended in October 2016, and was open to people living with CFS/ME within Bristol, Gloucestershire and North Somerset. See M.E. was funded by the National Lottery through the Big Lottery Fund, the Henry Smith Charity, Lloyds Bank Foundation, Rayne Foundation, Denman Charitable Trust and the Dame Violet Wills Trust.

2.5 FW advised that See M.E. was an innovative pilot project that transformed employment outcomes for people with M.E. in the South West. By responding directly to the needs of people with M.E., and those that support them, See M.E. provided crucial tailored and expert support, empowering people with M.E. to stay in, return to or leave work well.
The project employed specialist employment support staff with experience of M.E, embedding them within the specialist Bristol NHS M.E. clinic, where they worked with more than 120 people with M.E. over 12 months between 2015 and 2016.
2.6 TO advised that an independent evaluation of the project found that 72% of See M.E. clients achieved their employment goal, including:

- successfully returning to their job after lengthy sickness absence
- starting a new job
- achieving their best possible exit from unsustainable employment
- achieving more sustainable existing employment
- starting volunteering or a training course.

2.7 The project also demonstrated significant value for employers and clinicians:

- 60% of clinicians said See M.E. freed up clinical time previously spent supporting patients with their employment needs. This time saving of two hours per week equates to £24,000 per annum.
- 83% employers or union representatives said See M.E. made a positive difference to their anticipated case outcome.

2.8 TO informed that group that three toolkits had been developed, one for the employer, a guide for the individual and one for clinicians which had been downloaded by the NHS.
2.9 TO advised the group that further information was available at the following link.
https://www.actionforme.org.uk/living-with-me/managing-work/see-me-project/

## 3. Minutes of the last meeting

3.1 The minutes of the last meeting were agreed as a true record. WG Officer 4 <redaction s40(2)> asked if the membership was now up to date and there were a few minor changes suggested and agreed.

## 4. Letter from the Cabinet Secretary for Health, Well-being and Sport

4.1 WG Officer 4 <redaction s40(2)> thanked the group for their responses to the Cabinet Secretary's letter and advised that consideration needed to be given to what the priorities would be for the group moving forward. FJ suggested that the action plans be extended to 2020 to bring them in line with the major health conditions delivery plan timescales. WG Officer 4 <redaction s40(2)> added that they would also need to be updated if they were going to be extended. The group agreed this was a good suggestion and WG Officer 4 agreed to seek the Cabinet Secretary's agreement to this.

**ACTION: WG Officer 4 <redaction s40(2)> to speak to the Cabinet Secretary about extending the group to 2020.**

4.2 JR suggested that a greater focus needed to be given to educating primary care to aid faster diagnosis. GJ agreed that a GP pathway would be helpful to GPs to support faster diagnosis. He also advised that CFS/ME and FM had little or no coverage in GP training.

4.3 FJ asked if there was already a pathway in place for GPs and if so suggested that the group review and update it. OH advised that there was an existing pathway and that he would circulate it to the group for it to be discussed at the next meeting.

**ACTION: OH to circulate GP pathway to group members. Secretariat to agenda the pathway for discussion at the next meeting.**

4.6 FJ asked if CH as chair of the group could communicate to health boards the need to include CFS/ME & FM in their IMTPs. CH agreed.
**ACTION: CH to write to health boards about including CFS/ME and FM in their IMTPs.**

## 5. New reporting template

5.1 The reporting template was discussed and several suggested amendments were made and agreed around the table.

**ACTION: CH to send amended template to the group for information.**

## 6. GP Questionnaire

6.1 The GP Questionnaire was discussed CH advised that the main outcome form Hywel Dda was the request for education and training in primary care either face to face or e-learning. Consideration to how this happens will be discussed at next meeting when reviewing the pathway.

**ACTION: Discussion on way forward to be tabled at next meeting**

## 7. Sharing best practice

7.1 JR spoke about good practice and mentioned the ‘Unrest Film’ which will be shown in the National Assembly for Wales – no date has yet been confirmed. The film is part of the 2018 campaign and is funded by local people.

7.2 JR also referred the group to a paper she had prepared for the meeting, highlighting a number of self help programs and self management courses that were available.

## 8. AOB

8.1 CH said that she would be resigning as Chair due to a change in her portfolio. Members agreed that in the first instance a request seeking expressions of interest to take up the chair would be sent to all members with the minutes of the meeting. CH agreed to chair one more meeting to enable a smooth handover to the new chair.

**ACTION: Secretariat to seek expressions of interest for a new Chair when circulating the note of the meeting.**

**Meeting - 15 December 2017**
**Attendees:**
Owen Hughes, Powys Teaching Health Board
Gareth Jordan, Cwm Taf University Health Board
Clare Clark, Powys Teaching Health Board
Maddy Piper, Aneurin Bevan Health Board
Christine Roach, Public Health Wales
Carol Ross, Fibromyalgia Wales
WG Officer 7 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

**Apologies**

Bethan Jones, Hywel Dda Local Health Board
Fiona Jenkins, Cardiff and Vale University Health Board
Jo Hampson, Cardiff and Vale University Health Board
Simon Neal, Betsi Cadwaladr University Health Board
Claire Hurlin (Chair), Hywel Dda Local Health Board
Hamish Laing, Abertawe Bro Morgannwg University Health Board
Alison Shakeshaft, Aneurin Bevan University Health Board
Jill Paterson, Hywel Dda Local Health Board
David Murphy, Powys Teaching Health Board
Debbie Owen, Aneurin Bevan University Health Board
Jan Russell, WAMES

**Notes of Meeting:**

**1. Welcome and Introductions**
1.1 The Chair welcomed attendees and introductions were made around the table.

**2. Minutes of last meeting**
2.1 The minutes of the last meeting were agreed as a true record. Claire Rooke spoke about the action from the last meeting on Gareth Hewitt seeking agreement from the Cabinet Secretary for extending the group to 2020 and advised the briefing was in hand and the action would be completed in the coming weeks.

**3. Recent correspondence**
3.1 WG Officer 7 <redaction s40(2)> spoke about the recent correspondence which has been sent to each health board from WG Officer 4, Welsh Government and Claire Hurlin, outgoing Chair of the CFS/ME and FM Implementation group. WG Officer 7 explained that WG Officer 4 <redaction s40(2)> wrote to each health board for an update on the progress that had been made to implement the recommendations of the CFS/ME and FM report and Claire Hurlin wrote to each health board to ask for their support in advocating CFS/ME and FM to their IMTPs. WG Officer 7 <redaction s40(2)> asked the group to provide a short update in response to the letter from Claire Hurlin to advise Welsh Government if it is at all possible for CFS/ME and FM to be included for the next round of IMTPs. Gareth Jordan advised that CFS/ME and FM was in the first draft of Cwm Taf IMTP.

**ACTION:** Group to provide short update on whether CFS/ME and FM has been included to the IMTP for their health board for this year.
**ACTION:** Group to advocate for CFS/ME and FM to be included in next year’s IMTP.

**4. Review of existing pathway**
4.1 Owen Hughes advised the group that the existing pathway had been circulated. MP agreed to circulate the Aneurin Bevan 2015 pathway and Carol Ross also agreed to send the fibro myalgia

pathway for WG Officer 8 <redaction s40(2)> to circulate. The group agreed to discuss the pathway at the next meeting when the majority of the group is present.

**ACTION:** Maddy Piper to send the AB pathway from 2015 to WG Officer 8 <redaction s40(2)> to circulate.
**ACTION:** Carol Ross to send the FM pathway to WG Officer 8 <redaction s40(2)> to circulate to the group.

## 5. Sharing best practice

5.1 Owen Hughes asked the group on its thoughts of each health board presenting at future meetings with which models work well in their individual health boards. Clare Clark agreed and added that she thought the presentation from Action for M.E was interesting and also that there are useful links on Action for M.E's website which health boards might be interested in using.

5.2 Maddy Piper asked whether it would be helpful for each health board to provide an update at future meetings on what's been going on in the individual health boards. The group agreed that it would be helpful and Owen Hughes said that it would be good for the group to think about how is best to use future meetings.

5.3 Christine Roach provided a short update on the EPP programme.

**ACTION:** Future meetings to have an update from each health board on the agenda. WG Officer 7 <redaction s40(2)>/ WG Officer 8 <redaction s40(2)> to arrange this.

Owen Hughes asked the group its thoughts on looking at additional recommendations. Maddy Piper said that it would be good for the group to support local communities. Carol Ross agreed and the group discussed identifying and pulling together community resources. There was also a discussion around a move towards more of a community focus which should translate into more action on the ground. The group considered including this in their local pathways so that GPs are aware of what is happening.

The group had a conversation around which organisations would be helpful to attend future meetings. It was agreed that colleagues from NERS, social prescribing, DWP and mental health be invited to the next meeting.

**ACTION:** Christine Roach to provide details of a NERS representative.
**ACTION:** WG Officer 7 <redaction s40(2)>/ WG Officer 8 <redaction s40(2)> to invite NERS, social prescribing, DWP and mental health colleagues for the next meeting.

## 6. AOB and date of next meeting

6.1 Owen Hughes asked the group if anyone had any other business that they wished to discuss. Clare Clark spoke of the peer support group at Powys and the health boards plan for transition from child to adult. Maddy Piper spoke of the pilot which was going ahead in January at Aneurin Bevan. Carol Ross spoke of the work going on at ABMU on setting up an implementation group for neurological conditions and looking at getting FM and ME further up the priority list and that the health board is looking to develop a system which is easier for patients/carers, a telemedicine route and also education awareness for fibro myalgia.

6.2 The group agreed that the agenda should include looking at pathways and sharing best practice for the next meeting. WG Officer 8 agreed to send out a doodle poll with dates for a next meeting in April.

**ACTION:** WG Officer 8 to issue doodle poll for the next meeting in April.

**Action table**

| Action | Who for | Complete by |
|---|---|---|
| Group to provide short update on whether CFS/ME and FM has been included to the IMTP for their health board for this year | Group | Next meeting |
| Group to advocate for CFS/ME and FM to be included in next year's IMTP | Group | |
| MP to send the AB pathway from 2015 to HW to circulate | Maddy Piper | Completed |
| CR to send the FM pathway to HW to circulate to the group | Carol Ross | Completed |
| Future meetings to have an update from each health board on the agenda. CR/HW to arrange this | WG Officer 7 <redaction s40(2)> / WG Officer 8 <redaction s40(2)> | |
| CR to provide details of a NERS representative | Christine Roach | Completed |
| To invite NERS, social prescribing, DWP and mental health colleagues for the next meeting | WG Officer 7 <redaction s40(2)> / WG Officer 8 <redaction s40(2)> | |
| To issue doodle poll for the next meeting in April | WG Officer 8 <redaction s40(2)> | 6 weeks prior to next meeting date |

**Meeting – 25 May 2018**
**Attendees:**
Owen Hughes, Powys Teaching Health Board
Gareth Jordan, Cwm Taf University Health Board
Clare Clark, Powys Teaching Health Board
Maddy Piper, Aneurin Bevan University Health Board
Wayne Jepson, Public Health Wales
Carol Ross, Fibromyalgia Wales
Cerydd Muller, Abertawe Bro Morgannwg University Health Board
WG Officer 7 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

**Apologies**

Debbie Owen, Abertawe Bro Morgannwg University Health Board
Fiona Jenkins, Cardiff & Vale UHB
Simon Neal, Betsi Cadwaladr University Health Board
Christine Morrell, Abertawe Bro Morgannwg University Health Board
Nick Smith, WAST
Jan Russell, WAMES
Christine Roach, Public Health Wales
Tom Owen, Action for M.E

**Meeting notes:**

**1. Welcome and Introductions**

1.1 The Chair welcomed attendees and introductions were made around the table.

**2. Minutes of last meeting**

2.1 The minutes of the last meeting were agreed as a true record with minor amendments to the attendee list. The actions of the last meeting were discussed; Cwm Taf and Powys confirmed that CFS/ME and FM had been included within their IMTPs. The group agreed to pick up with other health boards at the next meeting. All other actions had been noted as completed.

**3. Issued raised in WAMES email**

3.1 OH informed the group that Jan Russell, WAMES had written to the Cabinet Secretary in April about the difficulties that patients with ME and CFS have when trying to access help from the NHS and asked the group to review the letter to agree what can be done going forward.

3.2 There was a discussion around where services for CFS/ME/Fibro patients sit within health boards. None of the health boards present stated that they currently operate these services under the Neurological Conditions banner but they report via their neurological reporting systems. Carol Ross said that ABMU Health Board have their services under a neurological pathway.

3.3 The group discussed and agreed that it would be useful to contact health boards to seek interest from clinicians on CFS/ME and FM as this would help to move forward within health boards. Powys had approached GPs when the survey was previously sent out and offered training but there was limited uptake.

3.4 The group discussed GP training and GJ advised that it may be beneficial if the conditions are included within undergraduate training for GPs. The group discussed what training resources are currently available for the conditions and CRoss advised that there has been an e-learning module created for fibromyalgia, CC mentioned the useful resources available on the Action for M.E website. The group agreed to look at what resources are available and publicise to GPs. WG Officer 7 <redaction s40(2)> suggested that WG could signpost available resources within the regular GP newsletter. CRoss also informed the group about healthy living sessions the voluntary sector have set up with GP practices within ABMU to give presentations on the conditions, CRoss agreed to present at other GP practices if useful. GJ agreed to access the MARS website to find out what CFS/ME training modules are available.

3.5 The group discussed using Jan's email to contact health boards to seek an update on what they have in place for the conditions and agreed to issue a survey monkey for members of the group to discuss locally and complete ahead of the next meeting.

3.6 OH mentioned that there had been a recent FOI request on CFS/ME which should be available on health board websites and could contain relevant information.

**Action:** Seek other opportunities for GP training
**Action:** Issue survey monkey to health boards
**Action:** GJ to check MARS website – GJ has confirmed that Fibromyalgia Wales jointly developed 'Understanding Fibromyalgia CPD' and this is available on MARS website
**Action:** Secretariat to trawl FOI requests on health board websites.

## 4. All Wales pathway

4.1 OH spoke about the two pathways which are currently available (CFS/ME and Fibromyalgia) and asked the group for its thoughts on updating them and adding the resources which are now available such as EPP and Action for M.E. OH asked the group to agree what needs to be included within the pathway and look how they are represented locally. MP spoke about the 'Fibromyalgia options booklet' which is handed out to patients from rheumatology and GP practices within ABUHB.

**Action:** Group to discuss the All Wales pathway at next meeting
**Action:** MP to circulate the Fibromyalgia options booklet to the group

## 5. AOB and date of next meeting

5.1 OH asked the group if they had any other business they would like to discuss. MP agreed to speak with David Milton regarding GP training, CC mentioned that Powys are using Skype for patients to attend GP appointments. WG Officer 7 <redaction s40(2)> advised that the pain document would be going out for consultation on 4 June if the group wished to respond.

5.2 The group agreed for a meeting to be set up at the beginning of July to discuss the All Wales pathway, videoconference facilities will be available.

**Action:** Secretariat to issue doodle poll for next meeting in early July.

## Action table

| Action | Who for | Complete by |
|---|---|---|
| Seek other opportunities for GP training | Group | |
| Issue survey monkey to health boards | WG Officer 7 <redaction s40(2)> / WG Officer 8<redaction s40(2)> | |
| GJ to check MARS website | Gareth Jordan | Completed. |
| Secretariat to trawl FOI requests on health board websites. | WG Officer 7 <redaction s40(2)> / WG Officer 8<redaction s40(2)> | |
| Group to discuss the All Wales pathway at next meeting | Group | |

|  |  |  |
|---|---|---|
| MP to circulate the Fibromyalgia options booklet to the group | Maddy Piper |  |
| Secretariat to issue doodle poll for next meeting in early July. | WG Officer 8<redaction s40(2)> | Completed. |

**Meeting – 6 July 2018**
**Attendees:**
Owen Hughes, Chair, Powys THB
Clare Clark, Powys THB
Maddy Piper, Aneurin Bevan UHB
Jan Russell, WAMES
Ruth Crowder, Therapies Advisor, Welsh Government
Christine Roach, Public Health Wales
Clare Ogden, Head of Communications and Engagement, Action for M.E
Debbie Owen, Abertawe Bro Morgannwg UHB
Cerydd Muller, Abertawe Bro Morgannwg UHB
WG Officer 7 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

**Audio:**

Fiona Jenkins, Cardiff & Vale UHB

**Apologies:**

Jo Hampson, Velindre NHS Trust
Christine Morrell, Abertawe Bro Morgannwg UHB
Carol Ross, Fibromyalgia Wales
Simon Neal, Betsi Cadwaladr UHB
Nick Smith, WAST
Wayne Jepson, Public Health Wales

**Meeting notes:**

### 1. Welcome and introductions

The chair welcomed the group and introductions were made around table.

### 2. All Wales Pathway

The chair advised the group that the meeting would be to discuss the three pathways two on CFS/ME and one on Fibromyalgia.
Fiona Jenkins said that this was a good time to re-look at the current pathways as they were created using the Map of Medicine software which is no longer in use in Wales. FJ suggested the group would need to be pragmatic between what is ideal and reality when developing a pathway and highlighted the need for agreement from the health boards that they are able to deliver what is being asked before sign off. FJ also suggested the need for a radical review which is evidence based as currently only one health board has a specialist service.
Owen Hughes and the group agreed and suggested including services which are currently available such as the EPP programme. Christine Roach offered to find out what services are currently available for patients which could be included within the pathway.
**Action:** Christine Roach to find out what services are currently available.
**ME/CFS pathway**
Jan Russell spoke about the updated NICE guidance on ME/CFS which will be published in 2020 and highlighted M.E patients are being misdiagnosed or not diagnosed at all with the current guidelines.
Clare Ogden agreed and spoke about the committee NICE have set up to review and update the current guidelines. Clare Ogden advised the *committee for ME/CFS guideline* are currently looking for lay members. Clare suggested contacting victoria.thomas@nice.org.uk if anyone is interested in applying. The committee is chaired by Dr Peter Barry, and the Vice Chair is Baroness Ilora Finlay
https://www.nice.org.uk/get-involved/our-committees/join-a-committee/lay-member--me-and-cfs

The group agreed to re-order the existing ME/CFS pathway and include more information on diagnosis and next steps after confirmed diagnosis.
The group discussed how is best for GPs to speak with patients after being diagnosed with ME/CFS. Clare Ogden offered to share a survey Action for M.E have sent to patients which includes questions on what patients find helpful after being diagnosed. The group agreed the need for GPs to be more aware of the condition and diagnosing.
The group discussed management once diagnosis had been confirmed. The group agreed and concluded:

- The need for a good health professional and patient relationship
- To create menu with options which are available for the patient
- A management plan the health professional and patient to agree; management plan must include all options and services available for the patient; offer guidance and assistance for the patient to complete the management plan.

Clare Ogden informed the group of the booklet Action for M.E have created for newly diagnosed patients which has been approved by NICE.
https://www.actionforme.org.uk/uploads/newly-diagnosed-booklet-dec-15.pdf
**Action:** Action for M.E and WAMES agreed to discuss together what should be included within the management plan.
Clare Clark informed the group of the Digital First project which is available in Powys. The project has been set up for bed bound patients or patients who are unable to attend clinic to have Skype consultations with health professionals. Clare said that the project has been proven successful in Powys.
Owen Hughes agreed to draft a framework with elements to be discussed at the next meeting.

**Fibromyalgia pathway**

The group discussed the Fibromyalgia pathway and agreed the revised guidelines need to be modernised.
Maddy Piper advised on importance of having CBT therapy after diagnosis as it has been proven to be the most effective treatment for patients.
The group agreed to use the same option for the Fibromyalgia pathway to create;

- Menu including available options
- Management plan with options and how patients can access these options

Maddy also informed the group of the Patient Options booklet Aneurin Bevan hand to newly diagnosed patients.
**Action:** Group to provide Owen with services which are currently available within their health boards for M.E, CFS and Fibromyalgia.
**Action:** Owen to speak with Gareth Jordan and David Minton for GP opinion on the Management Plan.

## 3. NICE guidance / M.E training

Jan Russell advised the group that Dr Nina Muirhead from Cardiff University is in discussion to provide formal teaching on M.E to trainee doctors at Cardiff Medical School and will be offering the students a variety of projects. These included a case study on a patient, looking at the daily challenges ME patients face or witnessing any ME patient undergoing elective surgery. This could potentially help students to be aware of difficulties surrounding this (getting up early/waiting in a seated waiting room/ post-exertional malaise from clinic appointments or pre-operative assessment/ differences with anaesthetics etc.)

## 4. Minutes of last meeting

The minutes of the last meeting were agreed as a true record. The group spoke about the survey monkey draft questions which had been sent out and agreed the questions would need to be reviewed to be more effective with questions focussing on health professionals rather than just GPs. WG Officer 7 <redaction s40(2)>, agreed to look in to whether WG can share the health boards summary of responses to the Cabinet Secretary’s letter to the group. Clare Ogden offered to share the FOI request Action for M.E undertook for the *Spotlight* report.

**Action:** Outstanding actions to be completed by next meeting

## 5. AOB and date of next meeting

The next meeting has been arranged for 11 September between 14.00-15.30pm at the Welsh Government building. The meeting will be to discuss the draft framework.

**Meeting – 11 September 2018**
**Attendees:**
Owen Hughes, chair, Powys THB
Clare Clark, Powys THB
Debbie Owen, ABMUHB
Clare Ogden, Action for M.E
Jan Russell, WAMES
Carol Ross, Fibromyalgia
Gareth Jordan, Cwm Taf UHB
WG Officer 7 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government
**Apologies:**
Fiona Jenkins, Cardiff & Vale UHB
Wayne Jepson, Public Health Wales
Jo Hampson, Velindre
Sue Jeffs, Aneurin Bevan UHB
Nick Smith, WAST
Ruth Crowder, Welsh Government
**Meeting Notes:**

1. **Welcome and apologies**

The chair welcomed the group and apologies were noted.

2. **Minutes of last meeting**

The group discussed and agreed the minutes of the last meeting as well as outstanding actions from the previous meeting.
**Action:** HB responses to Cabinet Secretary's letter to be circulated to the group and members to confirm the appropriate people are represented on the group.

3. **Framework Development**

Owen Hughes informed the group the aim of the document was
- To be accessible to people living with ME/CFS
- To contain a list of services available for people with ME/CFS
- To contain contacts for relevant healthcare professionals
- To contain self referral advice

The group agreed;
- For the framework to be uploaded on to health board websites which can then be easily accessed for people living with ME or CFS and can be taken to healthcare professionals for support and advice for completing
- To draft a flow chart format which can be easy to read – Clare Ogden offered to look in to drafting a flow chart for discussion
- To ensure the framework is available for GPs who have little experience in diagnosing ME or CFS
- Gareth Jordan spoke of the rapid diagnostic pathway which is currently used by GPs in Cwm Taf were cancer is suspected; Clare Ogden agreed to look at using the pathway to fit with ME/CFS
- To include links to websites such as DEWIS and healthy partnership – NHS Wales and relevant third sector charities
- To ensure the framework works differently for each health board to reflect what services are available

The group discussed drafting sample briefings around the 'management plan' element of the draft pathway – Jan Russell agreed to do this.

Carol Ross spoke of the neurology passport which has been developed and has now been adopted by ABMU. The passport includes useful information about the patient for health professionals to be aware of such as medication, mobility needs, health professionals who have already seen and treated the patient. The passport is handed out by the GP and nurses on the ward. The passport was developed by both health professionals and patients and the group agreed would be useful for people living with ME/CFS.

**Action:** Clare Ogden to look in to developing a flow chart format for inclusion in the pathway
**Action:** Clare Ogden to adapt rapid diagnostic pathway
**Action:** Carol Ross to send link to healthy partnership – NHS Wales
**Action:** Clare Clark to send links to Dewis and info engine
**Action:** Jan Russell to draft sample information sheets under the management element of the pathway
**Action:** Carol Ross to send passport to WG Officer 8 <redaction s40(2)>, to circulate to the group

## 4. WAMES update

Jan Russell informed the group of the 'Unrest' film which now has a date to be shown at the Senedd.

## 5. AOB and date and time of next meeting

Owen advised the group that the next meeting would be for the group to discuss and agree how the framework can be fitted in to practice and asked that all actions from the meeting are completed 2 weeks ahead of the next meeting.
The group agreed for the next meeting to be arranged early in December.
Claire Rooke advised the group of the pain consultation which closed on 14 September.

**Action table:**

| **Action** | **For who** | **Complete by** |
|---|---|---|
| HB responses to Cabinet Secretary's letter to be circulated to the group and members to confirm the correct people are represented on the group. | WG Officer 7 <redaction s40(2)>, / WG Officer 8 <redaction s40(2)>, | |
| Clare Ogden to look in to developing a flow chart format | Claire Ogden | |
| Clare Ogden to adapt rapid diagnostic pathway | Claire Ogden | |
| Carol Ross to send link to healthy partnership – NHS Wales | Carol Ross | |
| Clare Clark to send links to WG Officer 8 | Clare Clark | Completed |
| Carol Ross to send passport to WG Officer 8 to circulate to the group | Carol Ross | |
| Jan Russell to draft sample information sheets under the management element of the pathway | Jan Russell | |

**Meeting – 4 December 2018**

**Attendees:**
Owen Hughes, Chair, Powys THB
Clare Clark, Powys THB
Wayne Jepson, Public Health Wales
Jan Russell, Patient Representative, WAMES
Christine Samuel, ABMU
Bethan Jones, Cardiff & Vale UHB
Ruth Crowder, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government
Gareth Jordan, Cwm Taf UHB
WG Officer 7 <redaction s40(2)>, Welsh Government

**Video/audio conference:**
Clare Ogden, Action for M.E
Sam Bromiley, Action for M.E

**Apologies:**
Christine Roach, Public Health Wales
Peter Carr, Aneurin Bevan UHB
Claire Hurlin, Hywel Dda UHB
John Palmer, Cwm Taf UHB
David Minton, Aneurin Bevan UHB
Tom Owen, Action for M.E
Christine Morrell, AMBU

**Meeting Notes:**

1. **Welcome and introductions**

The chair welcomed the group, introductions were made around the table and apologies were noted.

2. **Minutes of last meeting**

The minutes of the last meeting were agreed as a true record and actions were discussed, all actions from the last meeting were noted as being complete.

3. **Framework development**

The chair advised the aim of the framework would be to signpost people living with M.E and CFS to services available within their local areas and would include useful resources for consideration.
There were discussions around where the framework would be made available for people to access and a number of suggestions were made such as the NHS Direct webpage, the individual health board websites and DEWIS. The group agreed a brief explanation of what the framework is for and who it is aimed at should be included along with a link to the framework on the chosen website.
The chair asked group members to look in to what resources and services are available locally.
The group suggested having two frameworks, one containing information, advice and available services/resources for patients and another for health professionals within the primary care setting.
Gareth suggested using the framework presented at the previous meeting for health professionals.
**Action:** Group to consider where the framework could be published in order to be most accessible for people living with these conditions.
**Action:** Group members to look in to what resources and services are available locally.

4. **Update from Clare Ogden on flow chart and pathway**

Clare spoke to the group about the flow chart which had been developed by Action for M.E, the main aims of the flow chart was to be patient-led, locally specific and user friendly. There were a number of suggestions on amending the flow chart, to consider aligning the document to use ‘health professional’ rather than ‘GP’, re-wording A&E at stage 6 and re-looking at stage 5 as there are currently no specialist services for these conditions in Wales.
The group discussed how GPs could facilitate conversations with people living with these conditions and Wayne spoke about ‘making choices together’ produced by 1000 lives which has 3 questions

for patients to ask a health professional once a diagnosis has been made, the questions being ‘what are my options?’, ‘what are the benefits and risks?’ and ‘what can I do to help myself?’ the group agreed this would be a good resource to include within the framework along with a link to DEWIS.
The group agreed the need for a conversation with colleagues in social care Wales who run the DEWIS webpage about where this framework would best sit.
Jan Russell agreed to update Clare Ogden with the comments from the meeting and work with Clare to update the flow chart to reflect the agreed amendments.
**ACTION:** Jan Russell to speak with Clare Ogden about updating the flow chart

## 5. Update from Jan Russell on the sample information sheet

Jan spoke to the group about the understanding ME/CFS – managing activity document she had produced. Jan advised that it was a starter template and would welcome any comments/feedback, Jan said Chris Roach had raised the possibility of devising an ME specific EPP course, which happens, could be included in the info sheets and advised the sheets are aimed at adults and a separate document would need to be produced to fit children living with these conditions.
The group agreed the draft document was useful and suggested inputting links to webpages for people living with these conditions to be aware of what services are available locally. The group also suggested having a small box with key words for people to search for further information on their conditions. Clare Clark advised that digital Wales have produced a page on websites which are safe to search for these conditions and suggested including a link with the key words.
The chair asked the group to re-look at Jan’s document for discussion at the next meeting.

## 6. Any other business

WG Officer 7 <redaction s40(2)>, spoke about the persistent pain guidance which is due to publish in March 2019 and Owen mentioned work Powys are doing on digital solutions for pain-based consultation.
Jan Russell spoke about 2 medical students who will be working with Dr Nina Muirhead to look at the role of GPs supporting people living with ME/CFS and what medical schools should be teaching medical students about M.E.
WG Office 7 <redaction s40(2)>, advised the group that due to Christine Roach’s work commitments within Public Health Wales she no longer works with the Welsh Government team undertaking a review of current services for CFS/ME and FM. She also advised the group of the Chief Medical Officer’s regular newsletter which could be used to promote the pathways once they are ready to be published.

## 7. Next meeting date

The next meeting will be held on Friday 8 March between 14.00-15.30pm at the Welsh Government building, Cathays Park, Cardiff.

**Meeting - 8 March 2019**
**Attendees:**
Owen Hughes, Chair, Powys THB
Clare Clark, Powys THB
Gareth Jordan, GP, Cwm Taf UHB
Sam Bromiley, Action for M.E
Jo Hampson, ABMU
WG Officer 10 <redaction s40(2)>,, Welsh Government
WG Officer 8 <redaction s40(2)>,, Welsh Government

**Apologies:**
Carol Ross, Fibromyalgia

John Palmer, Cwm Taf UHB

Christine Samuel, ABMU HB

Wayne Jepson, Public Health Wales

Simon Neal, Betsi Cadwaladr UHB

David Minton, ABUHB

Claire Hurlin, Hywel Dda UHB

Debbie Owen, ABMU

Jan Russell, WAMES

Ruth Crowder, Welsh Government

**Meeting notes:**

## 1. Welcome and introductions

The chair welcomed the group and introductions were made around the table.

## 2. Minutes of the last meeting

The minutes of the last meeting were discussed with minor amendments, all actions were noted and it was agreed to re-name ‘framework’ with ‘local guidance’.

## 3. Framework development

The chair asked the group to review and comment on the draft M.E pathway produced by Action for M.E. The group reviewed and agreed:

- The pathway needed to focus on other relevant health professionals such as allied health professionals and not only GP services
- The pathway needs to be individual to each health board and include local services and resources
- Stage 5 would need to be re-looked at as there are currently no specialist services for M.E. that everyone in Wales can refer to
- To think about producing future materials in different formats so that they are as accessible as possible
- To reference the *managing activity* sheet within the pathway
- For the pathway to be easy read

- To look at how to format the stages as not all people would need to go through each stage
- Once a pathway has been developed for M.E look at using a similar format for fibromyalgia

**Action:** Members to look in to services available locally.
**Action:** Sam to make changes to the pathway with the agreed suggestions and circulate to the group ahead of the next meeting.

### 4. GP newsletter

The chair advised the group of the 2 page article on ME which is being drafted for the RCGP Wales newsletter by Jan Russell and Nina Muirhead and asked whether the group had any comments or suggestions they would like to feed in, highlighting the deadline for completion is the 22 March. The group queried whether they would see a draft of the article before being submitted to RCGP and there were discussions around how GPs can support the group's work.
WG Officer 10 <redaction s40(2)>, offered to speak with Jan about including the Welsh Government mailbox within the article as a central point for GPs to contact with their interest.

### 5. Powys Scoping Exercise

The chair updated the group of the scoping exercise currently being undertaken in Powys and suggested looking in to whether this would be suitable and useful in other health boards once an evaluation of the pilot had been completed.

### 6. Update on student project

The student scheduled to provide an update on the project being undertaken had to send apologies for the meeting.
**Action:** Secretariat to contact Nina Muirhead about attending the next meeting to provide the update.

### 7. AOB and date and time of next meeting

The next meeting has been arranged for 6 June between 14.00 – 15.30pm at the Welsh Government building, Cathays Park, Cardiff.
The agenda will include;

- Re-looking at the pathway from Action for M.E
- Outcome of Powys Scoping Exercise
- Update from Nina Muirhead on student project
- GP newsletter – discuss whether WG received any interest

**Action:** WG to write to health boards to ask for representation at meetings.

**Meeting – 6 June 2019**

**Attendees:**

Owen Hughes, Chair, Powys thb
Clare Clark, Powys thb
Jan Russell, WAMES
David Minton, Aneurin Bevan uhb
Carol Ross, Fibromyalgia UK
Bethan Jones, Velindre
Christine Samuel, Swansea Bay uhb
WG Officer 10 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

**Teleconference**

Ffion John, Hywel Dda uhb

**Apologies**

John Palmer, Cwm Taf uhb
Wayne Jepson, PHW
Clare Ogden, Action for M.E
Nick Smith, Betsi
Claire Hurlin, Hywel Dda
Christine Morrell, Swansea Bay uhb
Jo Hampson, Aneurin Bevan uhb
Ruth Crowder, WG
Peter Carr, Aneurin Bevan uhb

**Meeting Notes:**

1. **Welcome and Introductions**

The Chair welcomed the group, introductions were made around the table and apologies were noted.

2. **Minutes of the last meeting**

The minutes of the last meeting were agreed as a true record and actions were discussed.

3. **Welsh Government update**

Due to technically difficulties the update on the student project was delayed. WG Officer 10 <redaction s40(2)> provided an update of work being undertaken by the Welsh Government which considered a wide range of long term conditions. This included:

i) Guidance relating to persistent pain was published in May 2019. Easy read guidance is currently under development
ii) An implementation group is being established to consider the implementation of the guidance and wider issues
iii) Guidance for NHS staff is being developed for Arthritis and associated conditions. This is due for consultation later in 2019
iv) A paediatric guidance document shall also be developed
v) Welsh Government wants to improve the evidence base regarding long term conditions. Currently viewing which management stats are available
vi) Welsh Government is liaising with HEIW to understand training and education of NHS staff in relation to long term conditions
vii) Welsh Government are reviewing how these conditions can have stronger inclusion in health board integrated medium term plans

viii) Welsh Government are looking to compare approaches with other countries and consider best practice.
ix) Welsh Government are investigating a funding stream for a self-management fund which could help pilots for self-management techniques.
x) For future consideration, Welsh Government are considering an overarching long term condition approach.

### 4. Update on student project

Nina Muirhead dialled in to the meeting to provide an update on the student project currently being undertaken at Cardiff University and supported by WAMES.
Nina spoke about the two part audit which will look in to the current ME/CFS services through a questionnaire/survey which will be completed by patient volunteers, the volunteers will also be asked to be interviewed face to face or by telephone. All volunteers will be from Wales. Nina agreed to send the questionnaire to the group for information and asked if anyone had anything they would like to feed in.

Owen thanked Nina for the update and suggested Nina and WG Officer 8 <redaction s40(2)> attend a future meeting to update the group on the outcome of the audit.

### 5. Pathway development

The group spoke about the pathway which has been updated by Sam at Action for M.E. Owen suggested discussing the pathway at the next meeting when Sam is available to attend.

Jan spoke about the information sheets she had updated ahead of the meeting and asked the group for comments and feedback on the format, length and content of the documents.

Owen suggested for group members to work virtually and provide comments on the information sheets so they can be updated and discussed in detail at the next meeting.

**Action:** Group to send WG Officer 8 <redaction s40(2)> comments on Jan's information sheets and WG Officer 8 will collate to send back to Jan for action.

### 6. GP newsletter

Jan advised she had drafted a newsletter for the Royal College of GPs. She was currently in the process of redrafting to align with their wishes. Jan advised she will update the group as to the status of this newsletter going forward.

### 7. Powys Scoping exercise

Owen provided an update on the scoping exercise currently being undertaken at Powys tHB. Owen advised Cwm Taf uhb are working with Powys and looking for support to pilot the model in their health board.
Owen agreed to provide a full update of the outcome at the next meeting.

### 8. AOB and date and time of next meeting

The Chair reiterated the importance of group members bringing agenda items to future meetings to ensure the meetings are purposeful. The Secretariat and the Chair agreed to discuss the approaches to the meeting.

The next meeting was arranged for 12 September, group members advised this is on the same day as a pain event in which many members would be attending, therefore, the next meeting has been arranged for Friday 13 September between 10-11.30am at the Welsh Government building, Merthyr Tydfil.

Welsh Government will contact the health boards for representation at all future meetings and to check the meeting venue to ensure technical capabilities are working.

## Meeting – 13 September 2019

Owen Hughes, Chair, Powys
Simon Neal, Betsi Cadwaladr UHB
Bethan Jones, Velindre NHS
Jo Hampson, Velindre NHS
Sam Bromiley, Action for M.E
Carol Ross, Fibromyalgia Wales
Sanam Kia, Swansea Bay UHB
Gareth Jordan, Cwm Taf Morgannwg UHB
Jan Russell, WAMES
Ruth Crowder, Welsh Government
WG Officer 10 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government

**Videoconference;**
Ffion John, Hywel Dda UHB

**Apologies;**
Wayne Jepson, Public Health Wales
Clare Clark, Powys THB
David Minton, Aneurin Bevan UHB
Peter Carr, Aneurin Bevan UHB
Christine Morrell, Swansea Bay UHB
Christine Samuel, Swansea Bay UHB

**Meeting Notes:**

### 1. Welcome and apologies

The chair welcomed the group, introductions were made around the table and apologies were noted. The chair advised Nina Muirhead had given her apologies and therefore the agenda item would be discussed at a future meeting.

### 2. Minutes of the last meeting

The minutes of the last meeting were agreed as a true record with changes to the attendee list and actions were discussed, Jan advised that WAMES will look to publish the information sheets on their webpage with support from the group if required.
Jan mentioned that the RCGP Wales had accepted a news item inviting feedback from GPs to the group, however, Jan didn't receive a copy of the newsletter from them.

### 3. Welsh Government update and presentation

WG Officer 10 provided an update on the IMTP process and informed the group that Pain, arthritis and ME/CFS and FM would be included in the next round of health board IMTPs for 2020/21. WG Officer 10 also spoke about the Arthritis guidance which will be out for consultation later this year.
WG Officer 10 <redaction s40(2)> gave a presentation on the proposal of 'A Strategy for Long Term Pain & Musculoskeletal conditions'. The proposed strategy would look to merge the Persistent Pain, Arthritis and Musculoskeletal and ME/CFS and FM groups together to create an overarching group looking at common solutions to related conditions where appropriate whilst considering the individual requirements of each condition. Some of the aims of the strategy would be to;

- Focus the approach within Welsh Government and NHS
- Improved utilisation of resources
- Achieve better care for patients
- Optimise NHS staff roles and job satisfaction
- Heighten awareness of conditions and their importance
- Alignment with the approach Wales is heading e.g. the National Clinical Plan, Primary Care Plan, a Healthier Wales, etc.

The group agreed the strategy would be a positive step for ME/CFS and FM conditions. Some concerns were raised around the name of the strategy as it does not include ME and the potential of certain conditions losing their voice. WG Officer 10 <redaction s40(2)> asked for any suggestions around the naming to be sent to him and agreed for the presentation to be circulated for further thoughts.
**Action:** Group to provide feedback and any suggestions/comments or queries from the presentation to WG Officer 10 <redaction s40(2)>.

### 4. Digital Services Scoping exercise update

The Chair provided an update report to the group ahead of the meeting. The Chair advised that the exercise resulted in a positive outcome and has confirmed services can be undertaken digitally beyond boundaries, however, funding would need to be considered before being adopted by all health boards.
The Chair asked if any of the group members would like to discuss the exercise further to contact him. Gareth Jordan advised this would be something Cwm Taf Morgannwg would be interested in discussing further.
WG Officer 10 <redaction s40(2)> spoke about the self-management fund currently being discussed within Welsh Government and advised the proposal is for a sum of money to be shared equally between the health boards and the health boards would then need to propose how they will use the funding to support the programme. The Welsh Government strongly encourages cross health board collaboration to utilise the funding as best as it can.

### 5. Action for M.E – survey findings

Sam provided an overview on the survey findings from the 2016 review undertaken by Action for M.E the review received over 4,000 respondents from across the UK, of these, 4.7% of the respondents were from Wales. The survey questions were based on the NICE guidelines. Some of the findings were;

- 24.7% of people in Wales wait over 6 years for a diagnosis
- 45% of people did not feel confident that their GP understands ME/CFS
- 57.76% of people had not been seen by a ME/CFS specialist
- 84% of carers/family members received no support

Sam offered to work on regional specific work for Wales if the group would find it useful.

### 6. Update on ME project from Nina Muirhead

Nina provided apologies for this meeting, therefore, the update will be provided at a future meeting.

### 7. Plan for next meeting

WG Officer 10 <redaction s40(2)>, advised he would be presenting the proposal of A Strategy for Long Term Pain & Musculoskeletal conditions to the Persistent Pain and Arthritis steering groups within the next couple of months and agreed to advise the group on the outcome and feedback following the meetings.
The next meeting will be arranged for the beginning of December and the date will be circulated shortly.

**Meeting – 12 December 2019**

**Attendees:**
Owen Hughes, Chair, Powys THB
WG Officer 10 <redaction s40(2)>, Welsh Government
WG Officer 8 <redaction s40(2)>, Welsh Government
Gareth Jordan, Cwm Taf Morgannwg UHB
Ffion John, Hywel Dda UHB
Christine Samuel, Swansea Bay UHB
Carol Ross, Fibromyalgia in Wales
Simon Neal, Betsi Cadwaladr UHB
Clare Clark, Powys THB

**Teleconference:**
Sam Bromiley, Action for M.E

**Apologies:**
Jan Russell, WAMES
Jo Hampson, Velindre
Bethan Jones, Velindre
John Palmer, Cwm Taf Morgannwg UHB
Wayne Jepson, Public Health Wales
Ruth Crowder, Welsh Government
Sanam Kia, Swansea Bay UHB
<redaction s40(2)>, Patient Representative

**Meeting Notes:**

1. **Welcome and introductions**

The Chair welcomed the group, introductions were made around the table and apologies were noted.

2. **Minutes of the last meeting**

The minutes of the last meeting were agreed as a true record and actions were discussed. SB advised the group that Action for M.E are working through the regional figures for Wales.

3. **Reflection of advisory group merger proposal**

KF advised the proposal of merging the three groups (Persistent Pain, Arthritis and ME/CFS and FM) had now been presented to all groups. The groups have all agreed the proposal with positive feedback, however, concerns were raised regarding individual conditions becoming overlooked. It was advised that when individual conditions require consideration of topics, these issues will still be considered via the Welsh Government and relevant stakeholders.

Concerns were also raised that currently there were no deliverables from the current ME/CFS and FM steering group. The group all agreed that these are complex conditions which need a good services provided.

KF suggested the proposal for the new group would be for each meeting to result in reports to be presented to the CMO which covered all commonalities between conditions, as well as bespoke issues relating to specific conditions when appropriate. KF also advised he has spoken with HEIW who will be at attendance on the new group and will feed in to workforce development.

Queries were raised around when the new group will be in place. KF advised that Persistent Pain and Arthritis have one more meeting early in 2020 and the hope is for the new group to be established by April 2020.

SN advised being a member of this group has led to an invite to meet with the Medical Director to discuss ME/CFS. KF suggested membership of the new format will raise the profile of these conditions also.

4. **Research and development grants and funds**

KF advised a complaint often received is the lack of research for ME/CFS and fibromyalgia. KF met with the Welsh Government research and development team who confirmed funding is available for research projects, but bids for this funding for these conditions were few and often not comprehensive enough. KF asked group members to consider how we can utilise research money of this nature and who would look to undertake this research project. If anyone had suggestions, please contact WG Officer 10 <redaction s40(2)>.
KF suggested research and development is likely to be one of the main issues for the new network to consider.

### 5. Services in North Wales

SN provided an overview of the ME/CFS services within North Wales and advised it is currently the only standalone service for these conditions in Wales. SN has been the clinical lead for 18 years and has over 20 years of service.

- The service was developed against best practice evidence at the time. It is a community and was given funding for audit and research at first. The service was first set up with a physiotherapist, GP, Dietitian, Clinical Psychologist and administrative support however the GP withdrew and the centre were unable to recruit to the GP post and money has now disappeared in cost savings.
- The service receive referrals from primary and secondary care. The GP will write to the service if they feel a patient has CFS and often asks for confirmation of this, although guidelines suggest that this is the GP’s task. Each person seen in the centre receives a uni-disciplinary assessment from Psychologist or Physiotherapist a change from when there was a GP in the team when multi-disciplinary assessment was the norm.
- The mainstay of intervention is a group based self-management programme centred on Acceptance and Commitment Therapy, and also includes, mindfulness, pacing, sleep hygiene, and dietary advice.
- 1,453 people have been seen in the centre over the last 18 years and the group receives high satisfaction rates.
- There is currently no domiciliary work undertaken, no access to medical records, poor mental health support and as it’s a small service there is no room to educate.

SN advised he would wish to see ring-fenced national funding provided to ME/CFS services in Wales to ensure the service is sustainable.

### 6. Nordic walking and fibromyalgia / areas of social prescribing and support for primary care

KF advised he had spoken with CRoss following the last meeting to consider Nordic walking for younger age groups. Following this discussion, KF instigated discussions with WG colleagues within the public health team and within Public Health Wales. The appetite to date regarding progress has been variable from the different parties involved.
CRoss advised she is currently a Nordic walking instructor for people living with chronic conditions and is looking at integrating the work within the NERS programme. CRoss advised she is working with Christine Roach to look at the current exercise referral programme for Fibromyalgia. CRoss agreed they would look in to the referral programme for ME/CFS once the fibromyalgia pilot is complete. CRoss advised they have developed a survey to look at what is being offered from the current self-management programme.
CRoss agreed to share the outcomes with the group and KF suggested self-management programmes will be one of the fundamental topics considered by the new group.

### 7. Self-management fund update

KF provided an update on the self-management fund advising the bidding process has now closed and WG are currently reviewing the applications. KF informed that applications had been received from every health board on a wide range of topics and to a high standard. KF advised the hope is for the fund to continue for next year and will be extended to the third sector.

## 8. Patient representatives and support groups feedback

KF advised he had met with the Cardiff & Vale fibrofighters and MESIG and is happy to meet with other groups/third sector organisations to discuss the work they are undertaking to support people living with these conditions and further understand the perspective of those living with conditions.

KF advised since meeting with MESIG they have formed a group to provide a business case as to how they view services within Wales should be developed. This paper shall be shared with relevant stakeholders when received.

KF asked group members to send him contact details of any groups they feel would be beneficial for him to meet.

## 9. Pain guidance – further implementation and alignment

KF advised the pain guidance was published in May and WG gave health boards a six month period to embed the actions and recommendations within. The Welsh Government have now requested updates from the health boards regarding their current services and future plans.

KF advised a poster has been drafted to be on display within GP surgeries, libraries and other community areas to promote the guidance and will look to issue this nationally within the New Year.

KF spoke about the Chronic Pain Coalition event which was held at the Senedd on 3rd December, viewed as a success.

SN advised there is an early intervention musculoskeletal service in North Wales and agreed to write to KF with an overview.

## 10. Action for M.E survey – next steps

SB advised Action for M.E are undertaking a breakdown of the survey results for Wales. SB agreed to look at any areas suggested from the group.

KF asked whether the findings will be presented to the Welsh Government for consideration, to which SB advised he would consider.

## 11. AOB and future approach

KF asked for thoughts on writing to health boards for updates on the 2014 strategy and what health boards have achieved since its publication. The group agreed it would be beneficial as the original objective of the group was to raise the profile of ME/CFS and FM and would be useful to see what health boards have achieved to date.

KF spoke about the updated NICE guidelines which will be published later in 2020 and suggested they will be on the agenda of the new group.

It was agreed that this group would not form another meeting at this point as we look to align with the new approach. KF did caveat that the new group was subject to review and if it was found to be not working, then the opportunity to revisit how discussions for ME/CFS and fibromyalgia would take place.