



Healthwatch Gloucestershire Focus Group Report

Access to services in Gloucestershire for patients with Fibromyalgia and ME



Date: October 2014



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1. Introduction

Healthwatch Gloucestershire (HWG) was established in April 2013 as part of the Health and Social Care Act 2012 and is the local consumer champion for health and social care in Gloucestershire, giving children, young people and adults a powerful voice in helping to challenge and influence the way health and social care services are planned and delivered locally. One of the primary functions of Healthwatch is to gather local people's views and experiences of health and social care. These are passed on to those who plan and deliver services in Gloucestershire and to Healthwatch England, to help them identify national trends.

In 2011, Gloucestershire Local Involvement Network (LINK), held a focus group and produced a report on 'Access to services in Gloucestershire for people with Fibromyalgia'. This report, which included conclusions and recommendations (See Appendix 1), was sent to the Commissioners and Providers of the services. Responses to the report can be found in Appendix 2

Local Healthwatch (funded by the Department of Health through the Local Authority) replaced LINKs (Local Involvement Networks) on April 1st 2013 and carries forward the LINKs' work whilst taking on the additional functions of signposting and Independent Health Complaints Advocacy. As Healthwatch began, comments continued to be gathered on the experiences of fibromyalgia and Myalgic Encephalomyelitis (ME), many echoing those made during the 2011 focus group. The HWG Board, in planning its work priorities for 2014/15, agreed to include provision for a piece of work to follow the LINK report of 2011. ME was included in this study because:

- both conditions are not well-understood
- they could have a variety of causes (e.g. viral infection, trauma)
- there is no known cure
- they share some symptoms

A description of some of the symptoms of these conditions can be found at references 1 and 2.

The HWG focus group took the form of a survey and a focus group workshop for people living with fibromyalgia and ME, assessing whether recommendations made in the 2011 report had been implemented and if access to services and information with respect to Fibromyalgia and ME had improved since June 2011.



2. Process

2.1 Research

Research was carried out to determine if access to services and information for patients with fibromyalgia/ME had improved compared to 2011 and if the commissioners and providers had responded practically to the recommendations of the 2011 report. The work showed that there had been developments:

Gloucestershire Hospitals NHS Foundation Trust (GHNHSFT)

The GHNHSFT website has a page dedicated to fibromyalgia. GHNHSFT does not specifically deal with Chronic Fatigue Syndrome but had a regional service based at Frenchay Hospital and a small satellite service run in Gloucestershire Royal Hospital. Although not stated on the website it is understood that this service is now provided at Southmead Hospital in Bristol where there is a Local Multi-Disciplinary Team providing advice and support to other health professionals in the clinical management of fibromyalgia/ME.

The page includes links to:

- The Institute for Chronic Pain - 'What is Fibromyalgia Syndrome?' (reference 3)
- The British Pain Society and Map of Medicine care pathway for 'Chronic Widespread Pain, including Fibromyalgia' published in March 2014 (reference 4)
- The Arthritis Care Information page on Fibromyalgia (reference 1)
- The American College of Rheumatology patient information page (this link was not working at the time of going to print) however information can be accessed via the American College of Rheumatology website as detailed in reference 5
- Arthritis Research UK information page and downloadable booklet (see reference 1)
- Fibromyalgia Association UK (reference 6)

2gether NHS Foundation Trust

The 2gether Trust has piloted a 5 week course in Cheltenham, under the 'Let's Talk' programme, 'Managing Fibromyalgia and Chronic Fatigue' with a view to extending the course to the rest of Gloucestershire. The 'Let's Talk' Service is for people with mild to moderate depression and/or anxiety. When interest in the course is registered, the client's GP is notified unless specifically requested otherwise.

Gloucestershire Care Services

Gloucestershire Care Services runs an Expert Patient Programme, teaching patients with long term health conditions self-management skills to improve the quality of their lives. Patients can self-refer to this programme (reference 8).

Physiotherapy

Self-referral for physiotherapy services can be made to GHNHSFT for musculoskeletal conditions where an assessment may lead to a variety of treatments including hydrotherapy (see reference 7).



Self-referrals can also be made to Gloucestershire Care Services NHS Trust via Physio Direct or via the GP for musculoskeletal physiotherapy services.

Social Prescribing

Social prescribing is the linking of people to activities in the community that they might benefit from, i.e. connecting people to non-medical sources of support e.g. art classes. Social prescribing is currently being piloted in the Cotswolds and Stroud.

Complementary therapies

Complementary therapies are not offered from Gloucestershire Pain Clinics with the exception of acupuncture, though it is not generally used in fibromyalgia and similar pain conditions as its effects, if any, are found to be 'very short lived' (reference 9). Funding may be considered on an individual basis where the GP or clinician believes there are exceptional clinical circumstances (Individual Funding Request - IFR) see reference 10.

Referrals

Arrangements are in place for referrals to be made to the Royal National Hospital for Rheumatic Diseases in Bath (also known as the Royal Mineral Water Hospital) which has specialist Fibromyalgia and ME clinics, or Southmead Hospital, Bristol, which has an ME/Chronic Fatigue clinic

Information sheets

These are available on-line to patients and GPs with trusted, validated information. (see references 1 and 2)

National and local support organisations

A variety of national and local support organisations give information on their websites about symptoms and treatments for fibromyalgia/ME and provide opportunities for socialising and networking. See Appendix 3

2.2 Survey by Questionnaire

A questionnaire (included at Appendix 4) was developed which mirrored the questions used in the survey for the 2011 report. It was sent out via email in April 2014 to members of HWG who had registered an interest in either fibromyalgia or ME and also to members of local support groups. The survey enabled those who could not attend the workshop to share their opinions and experience and possibly inform the agenda for the Focus Group.

31 questionnaires were completed of which 7 (23%) related to fibromyalgia/ME sufferers diagnosed from 2012 to the present day.

The main findings of the survey are shown below:

GP Understanding

GPs would benefit from a greater understanding of fibromyalgia and Chronic Fatigue Conditions. Better training would help to improve their attitude towards these conditions.



“Throughout the process I cannot fault my GP practice. I have been treated with respect and none of the doctors I saw made me feel like I was making it up and all took my concerns seriously”

“More training for GPs and consultants and official recognition that fibromyalgia is a serious condition”

Specialist Consultation

63% of the respondents were referred for a specialist consultation, although this was not always instigated by the GP but at the request of the patient. A significant majority of respondents gave positive reviews of these consultations.

“Excellent - two consultants (infectious diseases and neurology) with good experience of this illness”

The majority of referrals were to rheumatology at Cheltenham General Hospital and the Royal National Hospital for Rheumatic Diseases in Bath. Other referrals were made to Frenchay Hospital in Bristol, the Nuffield in Cheltenham, the Winfield in Gloucester, Southmead in Bristol and the Royal Free Hospital in London.

Waiting Times

Waiting times for specialist consultations were also an issue with some patients waiting over 6 months.

Care Pathways

None of the respondents had ever had a fibromyalgia/ME care pathway explained to them

Effects of fibromyalgia/ME

A variety of detailed and moving testimonials were given in response to the question, “What has been your personal experience of the effects of Fibromyalgia?” - making it clear that the chronic fatigue and constant pain severely restricts not only the ability to carry out daily activities but all aspects of work and personal relationships

“Debilitating, affecting all areas of my life, loss of job, loss of income, the stress of this alone makes the fibro worse”

“It is not the medical profession that don’t recognise the condition, it is family and friends who are disbelieving. At the mention of fibro they look ‘skyward’ and I get a feeling they think I’m malingering and quickly change the subject”



Survey Recommendations

The survey produced a series of recommendations resulting from the experiences of the fibromyalgia/ME sufferers:

- Single, multi-disciplinary point of access in Gloucestershire for care, support and education

“Have one point of contact eg fibromyalgia clinic for support and appointments with a Consultant and Nurse Specialist instead of seeing all different doctors in different specialities”

“Provide dedicated FM nurses like those provided for diabetic patients”

“Assistance with other key aspects of management such as benefits, education, employment etc”

- Better training for the medical profession, especially GPs

“communication is needed so doctors can advise patients of what is available to them... give doctors more information about treatments available”

“the most important thing is for doctors to accept that Fibromyalgia does exist and not try to make you think it is all in your mind”

“need GPs to have better training so can identify conditions and refer to appropriate specialist sooner”

- Fibromyalgia/ME not to be treated as a mental illness

“These illnesses are not all in the mind and should not be treated as if they are. Treatment approaches should be multidisciplinary and not focus on CBT”

- Use of Alternative Therapies

“We need support. We need alternative therapies to enable us to cope. We are not all mental health”



- Work with support groups

“Tell patients about support groups.....NHS should work with support groups”

Other recommendations included:

- Support for families and carers
- Create a list of GPs, both private and NHS, who specialise in fibromyalgia/ME
- Regular blood tests, particularly Vitamin D

2.3 Focus Group Workshop

The focus group took place in Gloucester on 8th May 2014 and was led by a volunteer member of HWG, Eileen Morrison, and supported by three HWG staff. The group consisted mainly of fibromyalgia patients although a few participants had ME. The 20 participants were split into 2 discussion groups, each with 2 facilitators. The group discussed 6 questions which are outlined below, together with the responses. A fuller account is given in Appendix 5.

At the end of the session participants were invited to send any further thoughts on the questions by email during the following week (see 2.5)

Question 1

"Have the key recommendations from the 2011 report been addressed?"

Recommendation 1:

"In Gloucestershire, Fibromyalgia should be recognised as a chronic and disabling physical illness that can have a significant effect on mental health and well-being of the individual. Information about its diagnosis and treatment should be made available to all GPs and patients, to avoid the present inconsistencies of service provision."

It is clear that there are still inconsistencies in service provision and that some GPs are not well informed about these illnesses. Participants who were diagnosed within the last 2 years were generally more positive about their experience with the GP.

"GPs are not trained in recognising Fibro/ME so people are misdiagnosed"

"My GP is thoughtful, he listens and is interested in fibromyalgia. Makes suggestions"

Concerns were raised that the conditions were still viewed as a mental illness.



“Still not recognised as chronic and disabling physical illness - too much emphasis on mental health”

Evidence also suggests that there is a lack of information about the illness and complementary treatments such as hydrotherapy.

“Would be helpful if given leaflet with information about other services available. It’s all about information”

“Hydrotherapy - fibro patients only get hydrotherapy if they have an injury, not for fibro. There is a paying service but it is only in Gloucester

Recommendation 2:

“A jointly commissioned care pathway should be developed and published that addresses both health and social care needs. This should be done in consultation with patients and their carers. Consideration should be given to a multi-disciplinary approach to diagnosis and service provision.”

None of the participants were aware that a British Pain Society and Map of Medicine care pathway for “Chronic Widespread Pain, including Fibromyalgia” has been published and is available to download on the GHNHSFT website. None of the participants were able to provide evidence of a multi-disciplinary approach to diagnosis and service provision.

“If a fibro patient has other symptoms these are either not diagnosed or misdiagnosed. Many clinicians do not look deeper than a fibro diagnosis”

Recommendation 3:

“The clinical criteria required for referral to a specialist clinic such as in Bath or Dudley should be easily available both to patients and clinicians. This would avoid some of the protracted discussions with NHS Gloucestershire.”

The Map of Medicine care pathway for, ‘Chronic Widespread Pain, including Fibromyalgia’ is now available to both patients and clinicians and provides clinical criteria required for specialist referral.



There was some evidence that the number of referrals has increased, particularly to Bath, but this was very dependent on the GP.

"I nagged my doctor until he referred me to Bath. From January to June I had 19 appointments, it is a totally different level of care"

"I was treated for 10 years in Dudley, I had brain scans, regular bloods, acupuncture and other treatments. Since moving to Gloucestershire (from 2006) I have had no tests/monitoring"

Recommendation 4:

"Patients with fibromyalgia should be able to access counselling services to enable them to cope better with this debilitating long term condition."

There were mixed responses on this item. There did seem to be some experience of counselling but it was not considered high quality. Some people welcomed the fact that 2gether NHS Trust is running a pilot course on coping strategies. Others considered that the course assumed that participants were mentally ill and perpetuated the idea, allegedly believed by some GPs, that fibromyalgia is not a physical illness

The main cause for concern was the need for participants to complete forms GAD-7 (for the diagnosis and assessment of General Anxiety Disorder) and Form PHQ-9 (for assessing the severity of clinical depression).

"I refused to complete the assessment forms and rang the 2gether Trust, after a conversation I was told I had been assessed as being mildly depressed, I did not know I was being assessed!"

Recommendation 5:

"Financial support should be available for the development of a support organisation and community group for patients with fibromyalgia, building on existing forums such as "Fibro babes"

This recommendation was not specifically mentioned in discussions.

Question 2

"Have you experience of the fibromyalgia care pathway?"

No one had experience of the Map of Medicine care pathway or that their GPs had used it for diagnosis of either fibromyalgia or ME.



Question 3

"Have there been any other improvements?"

- More referrals to Bristol or Bath for specialist clinics. Generally people who had experience of specialist referrals were very satisfied with these services and their multidisciplinary approach. The Frenchay course for ME was considered very helpful by one participant
- A couple of more recently diagnosed patients considered that their GPs had been helpful and listened, but some longer term patients had more examples of dismissive GPs

Question 4

"Do you have any examples of good practice to share?"

- Looking further into symptoms to find out if there were other co-existing conditions eg checking thyroid function, vitamin deficiency
- Referral to a neurologist
- GP is open to suggestions/listens/refers to specialist
- Pain management or mindfulness course
- Coping skills courses eg at Bath or Bristol

Question 5

"What needs to change?"

- GP education including:
 - recognising these conditions as physical illnesses
 - knowing where to refer for specialist services, including private consultants
 - testing for other conditions and not labelling all symptoms as due to fibromyalgia/ME
 - informing patients about support groups
- More information about which GPs in Gloucestershire have a special interest and knowledge of the conditions
- Specialist centre in Gloucestershire and/or specialist nurse which is separate to the pain management clinic
- Multidisciplinary approach available in Gloucestershire
- Easier access to hydrotherapy in Gloucestershire
- Easier access to one-to-one counselling, especially when newly diagnosed
- Better support for families and carers

Question 6

The final part of the workshop was to choose 3 "key points" to take forward. There was some overlap in the ideas chosen which are summarised below:



Key Points

- GP education including training to recognise the conditions
- Development of a list of GPs, both NHS and private, with special interest/expertise in fibromyalgia and ME
- Continuity of care and monitoring by health practitioners
- Multidisciplinary approach to these conditions so treatment can be holistic

2.4 Request for Information

A comment raised at the HWG AGM relating to difficulties in obtaining rheumatology appointments at GHNHSFT prompted a request for information to the Director of Clinical Strategy. The following is a summary of the response which was received on 29th July 2014:

- **Making appointments with the Rheumatology clinic**

The rheumatology clinic has experienced a 25% increase in referrals between 2011/12 and 2013/14. A full service review was commenced in May 2014 and is scheduled to run for 1 year. Funding has been secured for an additional specialist registrar although a suitable candidate has yet to be found

- **Follow up appointments**

There is a significant backlog of patients awaiting follow up appointments

- **Inability to leave telephone messages as mailbox full**

The Rheumatology help-line is operated by the specialist nurse team. There have been difficulties recruiting into this team but it should be fully staffed from 1st September

- **Long waiting times**

The increase in referrals to the Rheumatology Service has resulted in an increase in waiting times for a first appointment. As at 30th June the waiting time for a new appointment was between 11 - 26 weeks

- **GP advised patient that list is closed**

Due to the pressures being experienced, the Rheumatology Service was temporarily closed to new Choose & Book referrals from 16th May 2013 until 2nd June 2014. At present the service remains open to new referrals

The full response can be viewed at Appendix 6



2.5 Additional Comments

Other comments were gathered during HWG community engagement activity in 2013/14 and from email correspondence throughout the year (See Appendix 7). Themes emerging focused on:

- dissatisfaction with the proposed 2gether Trust pilot course, in particular its use of the anxiety and depression questionnaires

“This course has an emphasis on mind rather than body”

- the need to produce a patient-friendly information leaflet to be shared with family/carers

“There must be a mountain of helpful information out there that needs sifting through and reducing to a leaflet guide so newly diagnosed patients can share their problems with their loved ones, who will hopefully respond in a caring, helpful way”

- access to pain management

“Access to pain management and physio to support graded aerobic exercise (rather than just be sent off with an exercise sheet)”



3 Conclusion

Based on the findings of the survey, the focus group discussions and comments gathered through community engagement, it was concluded that some services have improved since the 2011 report, though many of the longer term patients are not satisfied with the service they are receiving.

3.1 GPs

The majority of fibromyalgia/ME sufferers involved in this piece of work were diagnosed prior to 2011. The evidence suggests that patients who were more recently diagnosed had more positive experiences with their GPs and were more likely to be referred to specialists.

There are inconsistencies in GP service provision around fibromyalgia and ME. This is particularly relevant in their role as gatekeepers to consultants and treatments. In particular the following issues were raised:

- There is a continuing perception by some fibromyalgia patients that GPs do not believe their condition is a physical illness
- Once diagnosed, and back under GP care, any consultation about a new symptom could be dismissed as a manifestation of fibromyalgia and ME. Other conditions, eg hypothyroidism, could be missed as the doctor is often reluctant to order tests or refer back to a consultant

There was no evidence to suggest that GPs are aware of, or refer to, the care pathways for fibromyalgia and ME in Map of Medicine when treating patients.

3.2 Specialist Referral

- The number of specialist referrals relating to fibromyalgia and ME has increased since the publication of the Gloucestershire LINK report in June 2011
- The Rheumatology Service at GHNHSFT experienced a 25% increase in referrals for all rheumatological conditions between 2011/12 and 2013/14 (not specifically related to fibromyalgia and ME)
- As a result of the increase in referrals to the Rheumatology Service there are long waiting times for appointments
- A one year, full service review is underway in the Rheumatology Department as well as recruitment of an additional Consultant
- The level of satisfaction from specialist referrals is high
- There are concerns that most specialist services are out-of-county
- Fibromyalgia/ME sufferers are not made aware of specialists in the county, both NHS and private



3.3 Multi-disciplinary Care

A consistent theme raised by the focus group was the need for a local multi-disciplinary clinic for patients with fibromyalgia/ME to provide periodic monitoring, signposting and information for patients and carers.

3.4 Care Pathway

Since the publication of the Gloucestershire LINK report on 'Access to services in Gloucestershire for patients with Fibromyalgia' in 2011 a generic Map of Medicine care pathway for "Chronic Widespread Pain, including Fibromyalgia" was published in March 2014 and a link is available on the GHNHSFT website. None of the participants in the focus group were aware of its existence. The care pathway does not include reference to social care.

There is no evidence to suggest that GHNHSFT has adopted this care pathway.

3.5 Hydrotherapy

The NHS choices website indicates that hydrotherapy is a treatment option for fibromyalgia, and it is recommended by the Fibromyalgia Association UK. Some people found that they could not easily access NHS hydrotherapy sessions at Gloucestershire Royal Hospital.

3.6 Coping Strategies Programmes

The 2gether NHS Foundation Trust ran a 5 week pilot course as part of the 'Lets Talk' programme in Cheltenham, "Managing Fibromyalgia and Chronic Fatigue", with a view to extending it to different areas of Gloucestershire. This course is for people with mild to moderate depression and/or anxiety. Concerns were raised by participants that the course approached the subject from a mental health point of view.

Gloucestershire Care Services operate an Expert Patient Programme, which teaches patients with chronic long term health conditions self-management skills to improve the quality of their lives. Patients can self-refer for this programme. Very few participants were aware of the existence of this programme.

3.7 Information

Links are provided on the GHNHSFT website to useful articles and information about fibromyalgia and ME and to the Fibromyalgia Association UK website.

Participants expressed a need for more information about GPs/consultants in Gloucestershire, both NHS and private, with a special interest and knowledge of the conditions.

Participants expressed a need for information that is tailored to the needs of the families and carers of fibromyalgia/ME sufferers.



4. Recommendations

4.1 Care Pathway

4.1.1 The generic Map of Medicine care pathway for “Chronic Widespread Pain, including Fibromyalgia” should be adapted to address both health and social care needs of patients with fibromyalgia/ME in Gloucestershire

4.1.2 The continued professional development of medical practitioners in Gloucestershire should include local management of fibromyalgia/ME in accordance with the care pathway

4.2 Multi-disciplinary clinic

Provision of a multi-disciplinary fibromyalgia/ME clinic in Gloucestershire, available to GPs and patients, manned by a nurse co-ordinator who can provide holistic care, signposting to doctors and specialists and to sources of information

4.2 Criteria for accessing services

There should be clear indications on the Gloucestershire Hospitals NHS Trust website about the criteria for accessing physiotherapy services in general, and hydrotherapy in particular, for those with fibromyalgia/ME. Consideration should be given to ways of improving access to hydrotherapy e.g. subsidised cost to patients by arrangement with private providers.

4.3 Courses/Self Management

Courses for fibromyalgia and ME patients on coping strategies, CBT or "mindfulness" and social prescribing should not have a compulsory anxiety and depression rating questionnaire for this type of patient.

Consideration should be given to developing a fibromyalgia/ME self management course in Gloucestershire not under the remit of mental health services, similar to that at the Royal National Hospital for Rheumatic Diseases in Bath. The course should include topics such as exercise and hydrotherapy, sleep management, diet, activity, pacing and medication and facilitated by specialists eg physiotherapy, occupational therapist, dietician.

4.4 Expert Patient Programme

The Expert Patient Programme should be more widely publicised, particularly by GPs and other health professionals.



Acknowledgements

HWG wishes to thank the people who completed the survey and who participated in the focus group workshop or contributed by email.

Special thanks are extended to HWG volunteer Eileen Morrison who was Chair of the focus group.



Appendices

- Appendix 1 Conclusions and Recommendations from Gloucestershire LINK report, 'Access to Services in Gloucestershire for people with Fibromyalgia' 2011
- Appendix 2 Responses to the Gloucestershire LINK report from the Commissioners and Providers
- Appendix 3 National and Local Support Organisations for fibromyalgia and ME
- Appendix 4 Questionnaire
- Appendix 5 Focus Group Workshop Digest
- Appendix 6 Response to Request for Information
- Appendix 7 Additional Comments received by email



healthwatch Gloucestershire

Appendix 1

Gloucestershire LINK

Access to services in Gloucestershire for patients with Fibromyalgia
Conclusions and Recommendations to Focus Group Workshop Report
June 2011



1. Conclusions

For the facilitators, the workshop was a very moving experience. Group members were all keen to share their experiences and did so passionately and coherently. Many of these very personal stories were very moving and distressing and told with great pain and passion. It was therefore extremely difficult to record all the issues that were raised and convey the distress that these were causing. However, some very consistent themes emerged that can be shared with confidence.

- 7.1 Fibromyalgia is a painful, disorientating, disabling and distressing chronic physical condition. It is not a mental condition, although long-term isolation, lack of support or proper treatment can cause mental issues to arise.

“I am too tired and in pain so don’t attempt much housework, but how do I explain that to Social Services when they see me walking a bit or driving?”

“There is a well-established suicide rate among people who just cannot take life under these circumstances and I was pushed to become suicidal for these reasons when I first became ill”.

- 7.2 There is a high level of dissatisfaction amongst patients about the poor service provision for Fibromyalgia in Gloucestershire.

“The memories of the last ten years: the total frustration of feeling so ill, in so much in pain, so helpless, so muddled, so exhausted; not being able to walk properly, or remember anything, and going for help to be told again and again there is nothing wrong with me. The terrible grief at losing the person I was”.

- 7.3 GPs in Gloucestershire lack appropriate information and guidance on the diagnosis and treatment of Fibromyalgia.

“The leaflet appears in different formats and giving different information. It does NOT refer to the impact of having Fibromyalgia”.

“One doctor said: ‘What’s the point in diagnosing something we can’t treat?’”

“I don’t want to be disabled, but the pure joy of having my illness defined, recognised, accepted and acknowledged has actually made me happy! It is such a relief”.

- 7.4 There is no clear integrated pathway for the diagnosis and referral for the treatment of Fibromyalgia in Gloucestershire.



“My GP has been very good and referred me, but it is the consultants themselves who do not believe in the condition, especially neurologists. How can you trust anyone who refuses to believe you?”

7.5 There is no published commissioning policy for the service provision for Fibromyalgia in Gloucestershire.

“I couldn't have any more treatment as there were too many patients being diagnosed with Fibromyalgia and I was being taken off the list, due to not getting any more money from the Government and that he was sorry”.

7.6 There is no adequate or consistent service provision for the treatment of Fibromyalgia in Gloucestershire.

“I feel let down by the system and that there is no help for people with this awful disorder in Gloucestershire”.

7.7 There is no up to date information for patients in Gloucestershire, either on the effects of or treatments available for Fibromyalgia.

“But because of Fibromyalgia / Chronic Fatigue no one will believe you and they put everything down to stress, anxiety or depression and it's seen as purely mental illness”.

7.8 There is no information for patients in Gloucestershire who are seeking access to specialised services for the treatment of Fibromyalgia.

“Is there anything in the policy ‘Interventions Not Normally Funded’ for Fibro patients? We do not think so”.

7.9 Where patients have accessed good services out of county - for example in Royal United Hospital, Bath or Russells Hall Hospital, Dudley – they have done so through their own initiative and effort.

“Bath talk to America, who know much more about Fibromyalgia. Bath Royal has a proper Fibromyalgia clinic”.



2. Recommendations

Having considered the report and conclusions from the focus group, the LINK would make the following recommendations to the commissioners and providers of services in Gloucestershire:

- 8.1 In Gloucestershire, Fibromyalgia should be recognised as a chronic and disabling physical illness that can have a significant effect on the mental health and well-being of the individual. Information about its diagnosis and treatment should be made available to all GPs and patients, to avoid the present inconsistencies of service provision.
- 8.2 A jointly commissioned care pathway should be developed and published that addresses both health and social care needs. This should be done in consultation with patients and their carers. Consideration should be given to a multi-disciplinary approach to diagnosis and service provision.
- 8.3 The clinical criteria required for referral to a specialist clinic (such as in Bath and Dudley) should be easily available both to patients and clinicians. This would help avoid some of the present protracted discussions with NHS Gloucestershire.
- 8.4 Patients with Fibromyalgia should be able to access counselling services to enable them to cope better with this debilitating long term condition.
- 8.5 Financial support should be available for the development of a support organisation and community group for patients with Fibromyalgia, building on existing forums such as 'Fibrobabes'.



Appendix 2

Responses to the Gloucestershire LINK report, 'Access to services in Gloucestershire for patients with Fibromyalgia' from the Commissioners and Providers of the service



healthwatch

Gloucestershire

2gether
Making life better

Foundation Trust 
For Gloucestershire

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6th September 2011

Barbara Marshall
Gloucestershire LINK
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Dear Barbara

Gloucestershire LINK Fibromyalgia Report

I am writing on behalf of Shaun Clee and 2gether NHS Foundation Trust to thank you and LINK members for the report on the review of Fibromyalgia Services within the County, which resulted from a questionnaire that was sent to LINK members and members of the public with an interest in Fibromyalgia.

The report clearly outlined peoples personal experience of having Fibromyalgia or indeed caring for somebody with this condition. As the condition is multi faceted and the presentation results in different symptoms it is clear that this has a significant impact on the variety of support and treatment that people have.

In relation to your specific recommendations the organisation would have the following response:

1a Fibromyalgia should be recognised as a chronic and disabling physical illness that can have an effect on the mental health and wellbeing of an individual.

The organisation would agree with this and believes that as part of the work on chronic disease management across the county that this condition should be integrated into that development programme.

1b Information about its diagnosis and treatment should be available to all GPs and patients to avoid present and inconsistency as a service provision.

Information is currently made available on Fibromyalgia through the NHS Choices website which many clinicians use to direct patients to, to provide validated information on conditions. There is useful information on the site including support groups.

GPs also direct patients or give out information from the website patient.co.uk which is also validated information. We would suggest that these sources are reviewed and determined which or indeed both would be a useful information site for practitioners as well as patients.



2. A jointly commissioned care pathway should be developed

We would support the development of an agreed care pathway within the County and would be happy to participate in this noting that it would need to be led by commissioners.

3. Clinical criteria required to refer to a specialist clinic should be easily available to both patients and clinicians

As this is a commissioning decision we will not comment directly on this.

4. Patients with Fibromyalgia should be able to access counselling services to enable them to cope better with this debilitating and long term condition

gether NHS Foundation Trust provides the Improving Access to Psychological Therapies service which is open to all people within Gloucestershire. So people with Fibromyalgia are able to access this service directly. This means that people with this condition would be prioritised as others in relation to their condition and the further support that they would require.

It may be more appropriate to discuss specific cognitive behaviour therapy as part of an integrated pathway for these patients which has occurred in other services across the Country.

5. Financial support should be made available for the development of a support organisation of community groups for patients with Fibromyalgia building on existing forums such as "Fibrobabes"

Nationally there are a number of support organisations available for people with Fibromyalgia. We would suggest that there is a review of these support organisations and whether there is an opportunity to work with them to develop a local support group.

We hope that these comments are useful in progressing the outcomes from your review.

Yours sincerely

TRISH JAY

Director of Quality and Performance (Nursing, Social Care and Allied Health Professionals)

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Our ref: LM/BP/B Marshall 6458

4 October 2011

Barbara Marshall
Chair
Gloucestershire LINK
Community House
15 College Green
Gloucester
GL1 2LZ

Dear Barbara

Gloucestershire LINK Fibromyalgia Report

Thank you for the hard work Gloucestershire LINK have put into exploring concerns raised about fibromyalgia services locally. The report offers an excellent overview of the concerns of sufferers and carers, together with offering some helpful recommendations. Jan Stubbings has asked me to respond on behalf of NHS Gloucestershire.

I am also grateful to you for extending the usual timescale within which it would not have been possible for me to consult and respond to your report in a meaningful way. I understand that Gloucestershire County Council are responding separately to your report.

Various colleagues within NHS Gloucestershire and service providers have had an opportunity to review the report and discuss the recommendations. I considered that the most helpful way of structuring my response was to do so largely around the specific recommendations made in the report.

At NHS Gloucestershire we understand that fibromyalgia is a disabling, painful, long-term condition. I can appreciate the level of frustration experienced by sufferers, particularly as there is no agreed approach to treatment which is universally effective. Talking with clinical colleagues, I know that the frustration experienced by patients and carers is shared by clinicians – both non-specialists such as GPs, therapists and specialists.

Response to recommendations as listed in the report:

1. In Gloucestershire fibromyalgia should be recognised as a chronic and disabling physical illness that can have a significant effect on the mental health and well-being of the individual. Information about its diagnosis and treatment should be made available to all GPs and patients to avoid the present inconsistencies of service provision.
 - o Fibromyalgia is recognised locally and nationally as a chronic and disabling illness. NHS Gloucestershire is committed to ensuring equity of access to services for all Gloucestershire residents based on clinical need. Where individuals, their families or professionals are aware of



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inconsistencies and problems with service provision we welcome communication about this and will address it.

- o Regarding information about diagnosis and treatment; there is a wealth of information readily available on the internet from a range of organisations. The following are useful summaries aimed at health professionals and the public:

NHS Evidence/ Patient.co.uk

[http://www.patient.co.uk/doctor/Fibromyalgia-\(Fibrositis\).htm](http://www.patient.co.uk/doctor/Fibromyalgia-(Fibrositis).htm)

NHS Choices / NHS Direct

<http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Introduction.aspx>

2. A jointly commissioned care pathway should be developed and published that addresses both health and social care needs. This should be done in consultation with patient and carers. Consideration should be given to a multi-disciplinary approach to diagnosis and service provision.
 - o Currently here is no pathway available locally or nationally for the diagnosis and treatment of fibromyalgia;
 - o The British Pain Society (BPS) is working with Map of Medicine on a Patient Pain Pathways Mapping (PPPM) project and have developed a draft Chronic Widespread Pain Pathway <http://www.paincommunitycentre.org/sites/default/files/files/Chronic%20Widespread%20Pain.pdf> . This is currently out to consultation. Once this pathway is finalised it could be adapted for local application;
 - o It is anticipated that any adopted pathway will be multi-disciplinary in its approach to both diagnosis and management;
 - o In developing local care pathways, NHS Gloucestershire is committed to wide consultation and stakeholder involvement particularly involving patient advocacy groups, the third sector and carer representation.
3. The clinical criteria required for a referral to a specialist clinic (such as in Bath and Dudley) should be easily available both to patients and clinicians. This would help avoid some of the present protracted discussions with NHS Gloucestershire.
 - o Services available in Gloucestershire for fibromyalgia are found within broader pain management and Improving Access to Psychological Therapies (IAPT) services;
 - o As there is as yet no care pathway for fibromyalgia, there are no clinical criteria for access to specialist clinics in Bath or Dudley. These services themselves do not set referral criteria and NHS Gloucestershire does not have criteria. Depending on how the referral arises, the Primary Care Trust (PCT) may use its Interventions Not Normally Funded (INNF) process. The INNF panel will not decline funding on the basis of access criteria as these do not exist. The INNF process should allow for decisions to be made and communicated within two months as the First Stage Panel meets monthly. Individuals who wish to challenge the decision of the First Stage Panel can appeal to a Second Stage Panel. NHS Gloucestershire is committed to ensuring that decisions regarding funding are made through a fair, transparent and timely process;

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- The Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath run 'The Bath Out Patient Fibromyalgia Coping Skills (FCS) Programme' which is lead by specialist rheumatology therapists supported by the rheumatology medical team. The programme is designed to support people to implement health behaviour change and lifestyle changes. One-to-one therapy input or referral is also available as an alternative to this group-based approach;
 - The Dudley Group of Hospital NHS Foundation Trust run a pain management service at Russell's Hall Hospital. Although this is not a dedicated fibromyalgia service, it is suitable for some fibromyalgia sufferers and may be funded by NHS Gloucestershire.
4. Patients with fibromyalgia should be able to access counselling services to enable them to cope better with this debilitating long term condition.
- Psychological therapies including Cognitive Behavioural Therapy (CBT) are utilised within several services including Pain Management and Improving Access to Psychological Therapies (IAPT). These services, including some counselling services, are also available to patients via their GP or together NHS Foundation Trust;
 - Looking at the dedicated fibromyalgia services available throughout the country, many aspects of the services they offer are available in Gloucestershire but are accessed as part of broader pain management and IAPT services.
5. Financial support should be available for the development of a support organisation and community group for patients with fibromyalgia, building on existing forums such as 'Fibrobabes'.
- Currently no financial support is available to support the development of support organisations / community groups for any condition. Primary Care Trusts such as NHS Gloucestershire have no powers to financially support such organisations. However, third-sector organisations (such as charities) can hold NHS contracts for services with PCTs.

Within the report, issues were raised relating to hydrotherapy – both availability of this and patient safety. Colleagues at Gloucester Hospitals NHS Foundation Trust have clarified the position for me. Any clinician (GP, specialist, therapist) can refer to hydrotherapy and patients may also self-refer. All patients have an initial assessment by one of the physiotherapists to determine whether hydrotherapy is appropriate for them.

Following a supervised course of hydrotherapy, patients are offered attendance at the self-help group at Gloucestershire Royal Hospital if exercise in water has been helpful to them. There is a member of staff on duty throughout the self-help group sessions for patient safety. Risk assessments are carried out on an annual basis. Patients can also continue to practice the exercises learned during the supervised course of hydrotherapy in their local pool if they wish to do so.

I can appreciate that the landscape of services and support available to fibromyalgia is complex, with a plethora of services dispersed through community services, primary care, secondary care and tertiary care. Because of the lack of any evidence-



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based consensus on the best treatments for fibromyalgia none of these are specifically signposted for fibromyalgia. However, this can allow a tailored approach, where treatments and management strategies can be varied between patients; particularly suitable where the symptoms experienced by individuals are so widely variable. This complex landscape is difficult for sufferers, carers and GPs to navigate. Perhaps one of the roles of the support organisations and community groups might be to provide advice and support in accessing the right services. NHS Gloucestershire has a Patient Advice and Liaison Service (PALS), which is also able to support, assist and advise patients, GPs and carers in accessing appropriate services. Gloucestershire's Expert Patient Programme (EPP) works with patients to enhance their knowledge about their condition and how to manage it; including the skills needed to access appropriate services for themselves.

In conclusion, I am grateful to you for completing such a thorough review and report into services available for Gloucestershire residents with fibromyalgia. I hope that this response demonstrates that NHS Gloucestershire takes the problems and challenges faced by individuals affected by fibromyalgia very seriously. In the absence of national consensus on patient care pathways based on evidence, I hope I have demonstrated that we offer a range of services for fibromyalgia and are ready to improve on these when recommendations on best practice become clearer. I hope that you will be available for consultation when any improvements to patient pathways and treatments are planned.

Kind regards.

Yours sincerely

Dr Elizabeth A Mearns FRCGP
Medical Director, NHS Gloucestershire and NHS Swindon

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Gloucestershire
COUNTY COUNCIL

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Community & Adult Care Directorate

Margaret Willcox
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Our Ref: MW/JS/CW/FJ

Your Ref:

Date: 06 October 2011

Dear Barbara,

Thank you for sending me the LINK Focus Group Workshop's report on "Access to services in Gloucestershire for patients with Fibromyalgia". To read first hand feedback on experiences of accessing social care services was very powerful. I am writing to respond to the report's recommendation 8.2 that relates specifically to social care.

The current long term conditions pathway that we use in Gloucestershire is a generic approach. It supports prevention and wellbeing, diagnosis, access to appropriate therapies and reablement, if appropriate. It promotes self care and peer support in order to encourage community participation and quality of life rather than reliance on medical models of care. The County Council also recognises the importance of the needs of carers and works closely with the NHS to ensure that carers are able to contribute to the development of appropriate support. I have asked that your report be included in the body of evidence being used in our "call for evidence" that is contributing to redesigning what we are calling "the customer journey".

I understand that NHS Gloucestershire is also considering your report in detail and will be responding separately in due course. I have therefore asked Helen Bown in her role as Joint Commissioner to liaise with NHS Gloucestershire when they have completed their consideration of your recommendations and in particular that "a jointly commissioned pathway should be developed and published that addresses both health and social care needs". It is appropriate for social care to collaborate with health at that point so that we have a joint response to meeting the needs of people with fibromyalgia. I have asked Fiona Jones to report progress back to the LINK Partners meeting.

.../Continued





- 2 -

Yours sincerely,

Margaret Willcox
Director of Commissioning: Adults & DASS

CC: Helen Bown, Lead Commissioner: Long Term Conditions
Fiona Jones, Strategic Planning & Policy Manager,



Appendix 3

National and local support organisations for fibromyalgia and ME

Fibromyalgia

- **National Support Organisations:**

Fibromyalgia Association (FMAUK) www.fmauk.org

UK Fibromyalgia www.ukfibromyalgia.com

FibroAction www.fibroaction.org

Fibromyalgia Online Support Group - MD Action www.mdjunction.com

- **Local Support Groups**

Fibro Guys & Gals - www.yourewelcome.to/group/fibro-guys-gals

Fibro ME/CFS Babes and Guys - www.fibrobabes.co.uk

South Gloucestershire Fibromyalgia Support Group - www.southglosfibro.btik.com

ME

- **National Support Organisations**

ME Association. <http://www.meassociation.org.uk/>

Action for ME <http://www.ukfibromyalgia.com>

Mechat Extra. <http://www.mechat.co.uk/>

- **Local Support Groups**

Gloucester ME and You Group - Kerry-Anne Goss, Tel: 01452 530492,
Email: kerryannegoss@yahoo.com

Fibro, ME/CFS Babes and Guys - www.fibrobabes.co.uk

Nailsworth ME/CFS Support Group - Richard Easthope, Tel: 07814
223567, sue_easthope@yahoo.co.uk



Appendix 4

Fibromyalgia Workshop Questionnaire

1. When were you diagnosed with Fibro/ME/CFS?

2. What has your experience been with your GP and support?

3. Did your GP refer you for a specialist consultation?

YES / NO

If yes, where were you referred to?

4. What was your experience of these consultations?



5. What could be improved?

6. Have you ever had a Fibromyalgia Care Pathway for Gloucestershire shown or explained to you? YES / NO

If so, when and by whom?

7. Have you been given any policy documents to check whether you may be eligible for specialist treatment? YES / NO

If yes, when and by whom



8. Has the Individual Funding Request (IFR) (formerly Interventions Not Normally Funded) process ever been explained to you?

YES / NO

If yes, when and by whom?

**9. What has been your personal experience of the effects of Fibromyalgia/ME/CFS?
(200 words max)**

10. What are three key points you would like us to recommend to NHS Gloucestershire?



Appendix 5

Fibromyalgia Focus Group Digest

1. Have the key issues from the Gloucestershire LINK report 'Access to services in Gloucestershire for patients with Fibromyalgia' been addressed?

'Yellow' group discussion

- No, nothing has changed
- Service is variable between GPs
- GPs are no more knowledgeable now than they were 3 years ago
- No-one in group referred to pain clinic recently
- No recent experience in group of referral for therapies
- Referrals to a neurologist are unusual in Gloucestershire
- Referrals to 2gether Trust for therapy are rarely offered

'Red' group discussion

- Still inconsistencies - not getting the help needed
- From report nothing has been addressed (GPs still lack understanding)
- Counselling - can access but not high quality - EPP useful
- Referrals to rheumatology sometimes
- Still being seen as mental illness - not recognised as a chronic and disabling physical illness
- Self- help groups all based on depression
-

2. Have you got experience of the fibromyalgia care pathway?

'Yellow' group discussion

- Lack of awareness of care pathway and that it is publicly available on the internet (no-one in group had experience of the care pathway)

'Red' group discussion

- No experience of care pathway - referrals have been made to Bath, some have gone privately
- Can get referrals to Bath but GPs/surgeries vary in their approach

3. Have there been any other improvements?

'Yellow' group discussion

- More people are being referred to Bath
- Some GPs are sympathetic and 'listen'

'Red' group discussion

- Can only seem to get CBT



- Referral to Frenchay course for ME - excellent and very helpful
- Depends on GP practice - some GPs listen but there is “no magic pill”

Other comments

- There is a lack of monitoring once diagnosis has taken place
- Vitamin D tests not carried out
- If fibro patient has other symptoms these are either not diagnosed or misdiagnosed. Many clinicians do not look deeper than a fibro diagnosis
- Hydrotherapy - fibro patients only get hydrotherapy if they have an injury, not for fibro. There is a paying service but it is only in Gloucester
- It is difficult to see the same doctor twice so there is no continuity

Do you have any examples of good practice to share?

‘Yellow’ group discussion

- Doing thyroid test
- GP referring to neurologist
- GP open to suggestions/listens/refers
- Pain management - mindfulness course

‘Red’ group discussion

- Frenchay hospital (ME) coping skills CBT
- Bath - coping skills programme

What needs to change?

‘Yellow’ group discussion

- Support for families/carers
- Fibro nurse - hospital based
- Hydrotherapy - easier access
- GP education - more awareness
- Fibro/ME clinic - separate to pain management clinic
- 1 - 1 counselling
- Better access to pain clinic and all options available (multi-disciplinary)

‘Red’ group discussion

- GPs need to test for other conditions - people have to ask for themselves eg Vitamin D B12
- Need for specialist centre in Glos and/or specialist nurse (clinic)
- Greater understanding by GPs that there is a specialist unit and to refer there (should not be specialist funding for this; should automatically refer)
- List of GPs with special interest in Glos (perhaps target those and provide info/training)



- Offering generalised help, not specific eg pain management- (any condition, GPs need to refer to support groups - provide information)
- To be seen as physical condition, not mental health

3 Key Points

‘Yellow’ group discussion

- GP education (leaflet) including a comprehensive list of consultants (NHS & private)
- Continuity of care and monitoring
- Holistic approach (multi-disciplinary)

‘Red’ group discussion

- List of GPs in county with specialism in fibro/ME
- GP education and training to recognise
- Holistic approach

Comments gathered at Fibromyalgia Focus Group

‘Yellow’ Group Notes

‘I was treated for 10 years in Dudley, I had brain scans, regular bloods, acupuncture and other treatments. Since being in Gloucestershire (2006) I have had no tests/monitoring’

‘My doctor listens to me’

‘The doctor wouldn’t send me to Frenchay as he said I was ‘too far down the line’

Lady was sent to Frenchay and they said to her, ‘You’ve got fibro, we only treat ME here’

‘GP said there was no-one to help me on the NHS so we had to pay’

‘I am in debt as I had to pay to go out of county to a specialist’

‘I have paid to see pain specialists, they don’t look at whole illness, just the bit you present with’

‘my specialist was good’

‘blood tests aren’t done as they are too expensive’

‘I was diagnosed with fibro this year, I have to wait 6 weeks to see the one GP who listens. He did blood tests (Vitamin B12) and collectively looked at the symptoms’

‘If you have multiple conditions, who do you see? There is a danger things are overlooked’

‘I nagged my doctor until he referred me to Bath. From January to June I had 19 appointments, it is a totally different level of care’



'I was told by my doctor 'you are in a minority now and can't expect special treatment'

'GPs are not trained in recognising Fibro/ME so people are misdiagnosed'

'Fibro is GP managed, you only see a specialist once and then sent back to GP'

'the 2gether course is not the answer, it attempts to meet people's needs but it is a good way of meeting other people'

'social care assessments are very slow'

'What support is there for carers?'

'I wish there was more information for those who don't understand about the illness'

'Red' Group notes

'Papers are all about 'care' services - we're not getting any 'care''

'depends on surgery you're with - one GP dismissed as getting older - another sent me to rheumatology'

'There are six GPs in practice - they don't understand fibro/ME or CFS'

'Still not recognised as chronic and disabling physical illness - too much emphasis on mental health'

'Sleep problems - GP wanted to prescribe anti-depressants - tried and now feel 'stuck''

'GP says "No magic pill" we know that, but is still feels like having door slammed in your face'

'GPs are general practitioners and don't have time to look at every condition in depth'

'I have lived outside Gloucestershire (Birmingham). There is better awareness of fibro here than there'

'Frenchay course excellent'

'I go to Holt Health Centre - GP is thoughtful - listens and interested in fibromyalgia. Makes suggestions'

'Dr Shepherd could give talks to GP surgeries'

'Would be helpful if given leaflet with information about other services available. It's all about information'



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Appendix 6

Gloucestershire Hospitals 
NHS Foundation Trust

Clinical Strategy
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29th July 2014

Claire Feehily
Chair
Healthwatch Gloucestershire
Community House
15 College Green
Gloucester. GL1 2LZ

Dear Claire

Re: Rheumatology Appointments for Fibromyalgia Patients

Thank you for your letter of 9 July requesting information in relation to our rheumatology services. Although the header of your letter was specific to patients with Fibromyalgia, the response below relates to all patient groups accessing our rheumatology clinics.

- **Making appointments with the clinic**

There are significant capacity issues within the service which mean that the service is struggling to cope with the demand. The Rheumatology service has seen a 25% (720 referrals) increase in referrals between 2011/12 and 2013/14, this has impacted on our ability to make timely follow-up appointments.

We are taking steps to improve the service and our recovery plan includes undertaking a full service review, which started in May 2014 and is scheduled to run for 1 year. The review includes 5 individual work streams which are:

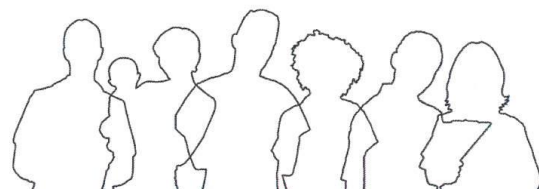
- (i) Referrals & Diagnostics
- (ii) Acute Service Efficiency
- (iii) Long Term Management
- (iv) Overdue Pending List
- (v) Patient Experience

We have already identified the need for additional staffing to keep pace with the increasing referral rate. We have secured funding for an additional specialist registrar but to date have not been able to recruit and we have advertised for a Locum Consultant. Unfortunately there were no suitable applicants and this is due to be re-advertised shortly.

Continued

Chair: Professor Clair Chilvers DSc
Chief Executive: Dr Frank Harsent PhD, MBA

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In the longer term there may be a need for further expansion of the Rheumatology team, however, the need for this will be identified as a result of the service review.

- **Follow up appointments**

There is currently a significant backlog of patients within the service who are overdue their follow up appointment. As at May 2014, the number of patients was 2556. Since this date the number has reduced to approximately 2000. The reduction is a result of both additional clinic capacity and clinical validation of those patients requiring follow up.

- **Inability to leave telephone message as mailbox full**

I assume that this refers to the Rheumatology help-line that is operated by the Specialist Nurse team. There have been significant staffing shortages within the Specialist Nurse Team due to a combination of sickness and difficulties recruiting into the team following retirement. The team will be fully recruited with effect from 1st September 2014.

- **Long waiting times**

The 25% increase in referrals to the Rheumatology Service between 2011/12 and 2013/14 has resulted in an increase in waiting times for patients being referred for a first appointment.

As at the 30th June, the waiting time for a new appointment was between 11 – 26 weeks. The length of time varies between both clinician and site. Those patients that cannot be accommodated within 11 weeks are booked into the next available appointment with the clinician or sub-specialty service they require.

- **GP advised patient that list is closed**

Due to the pressures being experienced the Rheumatology Service temporarily closed to new C&B referrals on 16th May 2013 until 2nd June 2014. At present the service remains open to new referrals.

I hope this response addresses your queries. If you require any further information, please do not hesitate to contact me.

Yours sincerely

Dr Sally Pearson
Director of Clinical Strategy

Cc Caroline Pennels, Head of Legal Services, GHNHSFT
Heather Beer, Head of Patient Experience, GHNHSFT
Justine Willoughby, General Manager, Rheumatology Services, GHNHSFT



Appendix 7

Additional Comments gathered at public events and via email

13/09/2013 I suffer from Fibromyalgia and I would like doctors to make sufferers aware that there is help out there, in particular, support groups. They should recommend heat pads and pacing your activities. Counselling should be recommended immediately and please send patients immediately to Bath hospital

13/09/2013 I have been affected by ME for 9 years. Many sufferers are abandoned by their employers, their doctors (who often don't understand), even friends and relatives think they are being lazy. They then spend any savings they have built up, living on them. Many feel threatened that their little money will be cut off if they do not seek jobs/prove beyond doubt that they cannot work. They are treated as wastrels by the very system that is supposed to help them

13/09/2013 Stress is the biggest threat to a Chronic Fatigue Syndrome/ME sufferer. Please understand and help them

13/09/2013 ME sufferer. After 3 years with this illness, where professionals had no sense of the impact of the condition, my daughter was given an appointment at Frenchay. Prior to the appointment she was asked to complete a form which indicated their awareness of the effects of the condition and of how this might impact the appointment. This made a huge difference to her ability to attend and participate in the appointment

13/09/2013 Chronic Fatigue Syndrome/ME. Prompt and correct diagnosis is essential, many people with CFS have other things wrong with them which can be treatable

13/09/2013 Chronic Fatigue Syndrome/ME. There are treatment centres in Bristol. These should be available in Gloucester. If research in another country eg USA, have had positive results, why not make these treatments available in UK?

13/09/2013 Chronic Fatigue Syndrome/ME. Neurologists should know that ME is a neurological problem and treat it as such

13/09/2013 Chronic Fatigue Syndrome/ME. Heart specialists should arrange for tests on ME patients to be done standing up

13/09/2013 Chronic Fatigue Syndrome/ME. GPs should prescribe medications recommended by private specialists, if they are unfamiliar with these they should inform themselves. GPs and specialists should keep up with new findings and research. I have sent my GP lots of information but she said she doesn't have time to read it



13/09/2013 Chronic Fatigue Syndrome/ME. GPs should keep abreast of the requirements needed for people to obtain benefits, as they do not follow a realistic interpretation of people's illnesses, especially something like ME which is a 'fluctuating' illness

13/09/2013 We need a co-ordinated approach to ME, as it affects so many different parts of the body. Specialists need proper training on ME and have someone overseeing each patient's treatments, to co-ordinate it

20/09/2013 When Fibro patients ask the Pain Management Clinic staff if there are any self-help groups in the area (eg Fibrobabes) they say 'No there isn't and they would not do anything for you' . She has just found Fibrobabes and wished she had found them years ago

01/10/2013 Please notify CCG Commissioners regarding the lack of understanding amongst GPs in the county about fatigue conditions. I don't want to make a complaint for fear of being blacklisted

06/11/2013 Have been diagnosed with ME eventually and have been given an appointment at Frenchay Hospital in February 2014 - 5 months time!

17/12/2013 I attend St Luke's Medical Centre in Stroud and recently discovered that their Dr Mike Gould runs an ME clinic (in Leicester); however they are considering starting one up in this area. Dr Gould said something about a private clinic, so I told him that many of us had to stop work before we could collect our pensions, so most of us are quite hard up.

03/03/2014 Fibro patient was issued with crutches in St Pauls Cheltenham - causing her pains in her arms! She has just attended Bath who advised that she has the wrong size crutches and only needs medium not large. It is going to take some time for her arms to recover as they now stick out!

13/03/2014 ME patients in Glos feel isolated and cannot get out

10/06/2014 St Catherine's Surgery . My GP said he doubted the validity of fibromyalgia, all my pain is due to stress (even though some of it is due to injury). At first I couldn't do Fibro course as I was awaiting P7 (which took 8 months until I kicked up fuss). No signposting after being told all of 'Let's Talk' therapies had been done. Never been told that there's physio for MH patients who also have physical problems.

17/06/2014 RE: Glos. Course for Fibromyalgia & ME - this is under 2gether - ie. Mental Health. The questionnaire produced and repeated each week is not relevant to patients with a neurological condition, even though it might lead to anxiety. We understand funding is only available if the course is under "Mental Health". Please can we have a tailor-made relevant course, like the one produced by Bath?



8/5/14 These patients need to have access to a specialist/rheumatology assessment if required, especially if diagnosis uncertain (without expectation of long-term follow-up however) Access to pain management and physio to support graded aerobic exercise (rather than just be sent off with an exercise sheet) Where disease not being managed well or difficult to manage - referral to tertiary centre such as Mineral Hospital or Bristol (health care professional)

9/5/14 The FM course scheduled to run in Cheltenham this summer is being provided by the 2gether Trust and will therefore approach the subject from a mental health point of view. Most disturbing of all, I have learned since yesterday, that before starting the course participants are required to fill in Form GAD-7 (for the diagnosis and assessment of General Anxiety Disorder) and Form PHQ -9 (for assessing the severity of clinical depression). They will also be asked to complete the forms at each of the weekly course sessions. Though some sufferers of FM do develop mental health disorders not all do so. They do however all suffer from pain, fatigue and sleep problems. These symptoms must be addressed, if patients are to live well with the condition. The Gloucestershire Commissioners and Providers would do well to study the Care Pathway and The FM Coping Skills course provided by Bath Mineral Hospital. I have been fortunate enough to attend the above course. Sessions cover exercise and hydrotherapy, to reverse the physical deconditioning experienced by FM patients, sleep management, diet, activity pacing and medication. It is run by specialist physiotherapists, an occupational therapist and a dietician. Interestingly, patients with mental health problems are not eligible for the course as it is felt they would not be able to undertake the lifestyle changes required. It is extremely unfortunate that when the NHS is suffering such funding difficulties, that Gloucestershire is targeting its only intervention for FM on an outdated, mental health approach, run by staff who are not specialists in the condition. Some sufferers may require talking therapies like CBT and all can benefit from techniques like meditation and relaxation. These alone however, most definitely do not constitute a comprehensive treatment programme for FM. Not only will this course not gain the best value for money, but it risks worsening the condition of patients by not addressing their physical problems and demoralising them by suggesting that FM is a mental health problem. Patients are tired of their illness being dismissed in this way. I have already spoken to two people who have been upset by the questions about suicide and self-harm in the GAD and PHQ forms. They will however attend the course because, like most people with FM, they are determined to take anything offered, in their determination to improve their health as much as possible so as to live the best life possible with this illness.

12/5/14 As a matter of urgency we need a list of doctors who have some real experience of ME and Fibro, and who are prepared to give us some proper treatment. We need proper tests to establish what our various medical problems are, (eg thyroid, muscle weakness, sleep issues) and need to have doctors who are prepared to prescribe things that could help alleviate



at least some of our symptoms, so that our quality of life may be improved. Eventually, we should have a clinic in the area, as many people find it impossible to get to Bath, and even those who do manage to get there can remain in agony for days afterwards due to the stresses of the journey. We're rather tired of being offered "coping" techniques, as many of us have already been coping with our problems for decades! Although a few people may have developed mental health issues because of their condition, it is infuriating that even those of us who do not have such problems are only offered CBT, etc. If we were given proper treatment for at least some of our symptoms, then we wouldn't need to learn how to "cope" with them! Lack of funding always seems to be quoted as being an issue with the NHS, however I find it most unfair that they will spend millions of pounds on people with self inflicted problems (drugs, alcohol, etc) and even on dubiously necessary treatments (such as breast enhancement operations) yet it's very difficult to get prescriptions for even the cheapest meds that can help us, eg vitamin B12 injections.

12/5/14 A lot of people are unhappy about the course that is being run by the 2gether Trust. They are saying that it is clearly a mental health course and that the log that they are being asked to keep includes such questions as - are you feeling suicidal today?

12/5/14 A chap (with Fibro) is doing a course in Worcester under the Expert Patient Programme, if only we had something like it in our area! I actually went on their (web) page and they say they have nothing in our area.

12/5/14 It appears to me that in Gloucestershire the medical profession do not understand how to deal with a patient with Osteo - Arthritis in most joints and upper/lower spine plus my symptoms of Fibromyalgia. This is no criticism of my GP who understands my problems but he is just one health advisor and my total problems are outside of his ambit.

13/5/14 Today is Fibromyalgia Awareness Day & I'm not sure if any events going on locally, which is disappointing, but maybe we could trigger the NHS into looking at any reports of sufferers' problems as it is such an invisible condition? There must be a mountain of helpful information out there that needs sifting through & reducing to a leaflet guide so newly diagnosed patients can share their problems with their loved ones, who will hopefully respond in a caring, helpful way.

22/5/14 Last year, I had to go through a pain assessment, 3 pain clinics & the pain specialist, all he did was to confirm I had fibro. & to state that the pain management was not what I needed! He could only suggest a choice of 2 tablets. No referral or signposting to further help. My Dr even said he doubted the validity of Fibromyalgia!

11/6/14 We have got the impression that HWG is keen to promote Fibro as a mental health condition. Whilst it's good to have recognition of this side of things, and have appropriate training, etc, we fear that this will mean it's more difficult to be taken seriously



by health professionals and the physical aspect (99% of fibro) won't be properly addressed. We don't want CBT to be the only thing on offer (MH being only 1% of the condition) but fear that this may turn out to be the case. There is already evidence that GPs are stopping prescribing medication they used to provide, eg her GP won't prescribe Omega 3 which she has always found helpful and cannot afford to buy on benefits.

16/6/14 We do have constant, chronic pain, but there are many other symptoms & side effects of treatment not of a physical nature. FM is frequently a result of a severe injury or trauma, but research also shows that imbalance of vital vitamins can affect the symptoms. Personally, I don't believe my main physical problem is due to FM, but I do have muscular/joint problems because the pain never goes away. Knowing this contributes to the mental side of the problem, which added to the possible side effects of regular strong medications, can cause stress, depression & anxiety. The forms mentioned are part of learning about this connection & building a bigger picture of what's going on generally.

16/6/14 I attended the 2gether Trust course and was very impressed by a young lady who told us at last Friday's initial meeting that she had piloted the current course & found it had changed her life. I have had a lot of help from LINK/Healthwatch/2gether & feel that the current course will gradually help me & maybe I'll try new approaches to all my physical & mental problems, some of which are nothing to do with FM.

17/6/14 This course has an emphasis on mind rather than body.

17/6/14 I refused to complete the assessment forms and rang the 2gether Trust, after a conversation I was told I had been assessed as being mildly depressed. I did not know I was being assessed.

18/6/14 The first topic covered at the Fibro CFS Lets Talk in Chelt last Friday was suicide, and that thoughts of suicide are normal, it's the preparations that are made for the actual attempt that make it important to seek help. Firstly you need to speak to family/friend/GPs, then Samaritans, and then if desperate the A&E dept of hospital. That was actually rather overwhelming, given that I am not depressed, I have Fibro/ME ! However if I was depressed I would rather be sent on another course that covered that particular subject. Fibro is neurological, not mental health! (I appreciate some people will be depressed/mourning the loss of their pre-fibro body etc, and they may need CBT, which would presumably be covered by mental health). Personally, I want physical and practical help and information, not an emotional self-help group. I left the first session feeling exhausted and overwhelmed with no answer to my questions " Is it right that with Fibro gentle exercise is helpful, with ME it isn't, is that right? What is recommended?", and "Does the menopause exacerbate the Fibro/ME symptoms?" "How do we learn to control the exhaustion?" was answered with the handing out of a daily diary sheet, so we can work out for ourselves what we do, how long we take to do it and how we feel physically afterwards, which will be



helpful. I am worrying that the travelling into Cheltenham a 2hour course and travelling home is too much for me at the moment, I have taken 3days to get over the last meeting. There were approx 30+ people at that meeting. It is exhausting. I hope the other four sessions are based more on physical/practical help and less emotional/mental issues. I am also concerned that my GP will now class me as being "helped" because I will have done this CBT Course, and not refer me to Bath where the course sizes are 10 people and Physio based.

1/7/14 Caller last saw the Rheumatologist last August and was due to have a follow on appointment six months later, which was February 2014. She has not heard anything and has not been offered an appointment. She tried phoning the Rheumatologist Secretary, but could not get through and could not leave a message as her mailbox was full. She then phoned the booking office for Rheumatology who told her they could not take booking appointments but said phone the secretary but she could not get through so the Booking office gave her another secretary who took a message. Now waiting for a phone call. She saw her GP today who asked her to phone Rheumatology. She has heard on the grapevine that patients are having to wait nine months to get an appointment and told the GP this. The GP said she had heard on the grapevine that the list was closed.

7/7/14 Homeopathic medicine - the GCCG are stopping patients receiving Homeopathic medicine - Caller is receiving treatment at South Bristol Community Hospital and has been informed that Gloucestershire will no longer fund her (due to their policy on homeopathic medicine). People like caller cannot take conventional medicine other than Paracetamol because she has severe drug reactions - she says her lifeline is the Homeopathy medicine. One good point is that someone said that she and patients like her qualify for NEPTS - she applied and got it.



References/Bibliography

1. Symptoms of Fibromyalgia and treatment options can be found on the following websites:

Arthritis Care (recommended by Gloucestershire Hospitals Foundations NHS Trust website)
<http://www.arthritiscare.org.uk/AboutArthritis/Conditions/Fibromyalgia>

NHS Choices - <http://www.nhs.uk/conditions/Fibromyalgia/Pages/Introduction.aspx>

Patient UK - <http://www.patient.co.uk>

Arthritis Research UK - <http://www.arthritisresearchuk.org>

2. Symptoms of ME and treatment options can be found at the following websites:

North Bristol NHS Trust - (specialist referrals from Gloucestershire are made to the service at Southmead Hospital, Bristol) <http://www.nbt.nhs.uk/our-services/a-z-services/chronic-fatigue-syndrome-me/chronic-fatigue-syndromeme-service>

NHS Choices - <http://www.nhs.uk/conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>

Patient UK - <http://www.patient.co.uk/health/chronic-fatigue-syndromeme>

3. Link to Institute for Chronic Pain from GHNHSFT website at:

<http://www.gloshospitals.nhs.uk/en/Wards-and-Departments/Departments/Pain-Management/Different-Pains/Muscle-Pain/Fibromyalgia/> or direct to website at:
<http://www.instituteforchronicpain.org/common-conditions/fibromyalgia>

4. British Pain Society and Map of Medicine - link to site and map of medicine from GHNHSFT website (see ref 3 above) or can be accessed direct at:

http://bps.mapofmedicine.com/evidence/bps/chronic_widespread_pain_including_fibromyalgia1.html

5. American College of Rheumatology - link to site from GHNHSFT not working at time of going to print but can be accessed at following website:

http://www.rheumatology.org/Practice/Clinical/Patients/Diseases_And_Conditions/Fibromyalgia/

6. The Fibromyalgia Association UK website is at <http://www.fmauk.org>



7. Physiotherapy - self-referral and services including hydrotherapy information can be found at GHNHSFT website at: <http://www.gloshospitals.nhs.uk/en/Wards-and-Departments/Departments/Physiotherapy/Musculoskeletal-Physiotherapy/> includes multi-disciplinary pain management and chronic fatigue syndrome

8. Expert Patient Programme - details can be found on website of Gloucestershire Care Services at: <http://www.glos-care.nhs.uk/our-services/rehabilitation/expert-patient-programme>

9. Acupuncture at GHNHSFT and pain management services:
<http://www.gloshospitals.nhs.uk/en/Wards-and-Departments/Departments/Pain-Management/What-can-we-do/Stimulation-produced-analgesia/Acupuncture/>

10. Individual Funding Request - information can be found at the Gloucestershire Clinical Commissioning Group website at: <http://www.gloucestershireccg.nhs.uk/about-us/funding-treatment/interventions-not-normally-funded/>



Glossary

FG	Focus Group
FMAUK	Fibromyalgia Association UK
GHNHSFT	Gloucestershire Hospitals NHS Foundation Trust
HWG	Healthwatch Gloucestershire
LINK	Local Involvement Network
ME	Myalgic Encephalomyelitis