



Healthwatch Gloucestershire Focus Group Report

Access to services in Gloucestershire for patients with Fibromyalgia and ME



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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 [full document available upon request]

- 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



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

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