

**Research into the views of GPs in Oxfordshire
on services for patients with CFS/ME
2012**

FULL report of findings

FINAL version

November 2012





Oxfordshire ME Group for Action (OMEGA)

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Oxfordshire ME Group for Action is the support group for people with ME or Chronic Fatigue Syndrome, and their carers, family and friends. Members give each other friendship and support, exchange information about treatments, and learn from each other about the management of this long-term illness.

Other work carried out by OMEGA includes evaluating local and national evidence, carrying out research in Oxfordshire, training NHS staff and campaigning.



Oxfordshire Local Involvement Network (LINK)

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The Oxfordshire LINK gives communities a stronger voice in how their health and social care services are delivered. The LINK promotes involvement and finds out what people think about the services, monitors the care provided by services and uses LINK powers to hold services to account.

The LINK is independent of the NHS and Local Authorities.

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We are very grateful to the expert advisers and GPs who gave their time to fill in the questionnaire or answer our questions over the phone or at meetings.

Our thanks also to NHS Oxfordshire and the LINK for their help in distributing the survey.

1 Introduction and methodology

Background to the project

The Oxfordshire ME Group for Action (OMEGA) is a group which campaigns on behalf of and supports and informs patients with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis.

Around 10 years ago OMEGA carried out a survey of GP practices and found that GPs were unclear about the system for referral and treatment of CFS/ME patients and that a majority were in favour of setting up a specialist clinic (see annex 3). Findings from this survey helped Oxfordshire PCTs to secure Department of Health funding for a specialist treatment clinic the Oxfordshire Community CFS/ME Team (OCCMET) and in 2010 OMEGA helped to develop and agree a new Patient Pathway.

Recent anecdotal evidence (including from sessions with trainee GPs) however suggested that, despite this work, GPs remain unaware of the CFS/ME Patient Pathway guidelines and the treatment available in Oxfordshire.

In addition, patients with CFS/ME have reported widely varying experiences of GPs, referrals and secondary care in Oxfordshire.

As a result, at the beginning of 2012, OMEGA submitted a proposal to the Oxfordshire Local Involvement Network for a follow up research project into the views of GPs on information and services for patients with CFS/ME and appointed Margaret Melling, a specialist independent researcher, to carry out the project.

Understanding GPs views of these conditions is now even more important because:

1. There is a concern that the current major reorganisation and decentralisation of health services following the Health White Paper¹ may impact the priority given to illnesses such as CFS or ME where diagnosis and treatment is complex and time consuming.
2. The handover from the Oxfordshire Primary Care Trust to the Clinical Commissioning Groups in 2012/13 is likely to affect the continuity of service planning.

Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME)

In keeping with current NHS practice, we have used 'CFS/ME' in our correspondence with GPs in this study and have adopted it throughout this report.

The grouping of patients with Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME) under the single heading of 'CFS/ME', however, remains an area of debate.

In the UK the terms Chronic Fatigue Syndrome and Myalgic Encephalomyelitis are often used interchangeably. According to NHS Choices²:

Chronic fatigue syndrome (CFS) causes persistent fatigue (exhaustion) that affects everyday life and doesn't go away with sleep or rest. For most people, symptoms will improve over time.

¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121941

² <http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>

CFS is also known as ME, which stands for myalgic encephalomyelitis. Myalgia means muscle pain and encephalomyelitis means inflammation of the brain and spinal cord. Both CFS and ME are commonly used terms.

However Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (M.E.) are classified as separate illnesses by the World Health Organisation³.

The first use of the umbrella term CFS/ME was in the January 2002 Working Group report to the Chief Medical Officer⁴. The report noted that:

A consensus on definitions and terminology is urgently needed...

the Working Group suggests that the composite term CFS/ME is used as an umbrella term and considered as one condition or a spectrum of disease for the purposes of this report.

There was an acknowledgement in the same report, however, that this umbrella term covers different patient groups.

the Group noted that the term CFS/ME covered subgroups of patients who might have different aetiology, symptom complexes, or response to various treatments.

Despite this, the 'CFS/ME' umbrella term has continued to be used by the NHS, the National Institute of Clinical Excellence (NICE) and by the GP Notebook⁵. Searching the GP Notebook for EITHER Chronic Fatigue Syndrome OR Myalgic Encephalomyelitis brings up the same page discussing Chronic Fatigue Syndrome.

CFS/ME Services in Oxfordshire

Patients in Oxfordshire are mainly referred to the Oxford Infectious Diseases Clinic (which may take all mobile patients and has clinic sessions in Banbury) and the Oxfordshire Community CFS/ME Team (which may take all patients and is the only service to provide for the severely affected group).

TalkingSpace (Mindfulness meditation) also provides groups for people with physical illnesses including CFS/ME. Patients may be referred to other specialists.

Research methodology

We put a significant amount of effort into planning the research, consulting local and national experts, developing the questionnaire and deciding how best to encourage a good response from GPs.

Early on in the process we met the Thames Valley Primary Care Research Partnership and consulted the National Research Ethics Service and were advised that the project did not need ethical approval.

We found a large scale project on GPs view of Chronic Fatigue Syndrome had been carried out in Gloucestershire⁶ and spoke to one of the co-authors. He has helped our study by giving

³ International Classification of Diseases 10 <http://www.who.int/classifications/icd/en/>

⁴ A report of the CFS/ME Working Group, Report to the Chief Medical Officer January 2002 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4064840

⁵ www.gpnotebook.co.uk

⁶ Chronic Fatigue Syndrome: a survey of GPs' attitudes and knowledge, Bowen, Pheby et al <http://www.ncbi.nlm.nih.gov/pubmed/15805128>

views on the methodology and reviewing our questionnaire.

Conversations and meetings during this development process indicated that:

1. GPs are a “notoriously difficult group to research” and to encourage the best response we should email GPs directly.
2. Research practice has developed over recent years and GPs are often paid a fee for completing questionnaires – typically £25 per survey.

We would have liked to have been able to email GPs directly (rather than Practice Managers) and tried several alternative approaches. We spoke to the Berkshire, Buckinghamshire & Oxfordshire Local Medical Committee (which has GP contact details) but they were unable to help a project of this type. We also tried to make contact with the heads of Oxfordshire’s Clinical Commissioning Groups (OCCGs) but had no direct response.

We considered the idea of paying GPs to complete the survey but funding restricted this option. Instead we made sure that the questionnaire took less than 5 minutes to complete.

On 28th June 2012 the Head of Communications and Engagement of NHS Oxfordshire (Oxfordshire PCT) emailed GP Practice Managers on our behalf with an introduction to the project and a weblink to the online version of the survey.

In the week commencing 2nd July, the Oxfordshire Local Involvement Network (LINK) sent a reminder letter by post enclosing paper copies of the survey, a reply paid envelope and leaflets about OMEGA. 60 GPs (11% of GPs in Oxfordshire) completed the questionnaire.

Aims of the research

The aims of this follow up survey of GPs were to understand:

1. How much GPs know about the treatment available in Oxfordshire – in particular the PCT agreed Patient Pathway - and whether they are using the agreed referral criteria.
2. How GP opinion and estimated number of patients with CFS/ME has changed since the last survey.

Structure of this report

This report gives the results of the survey in three main sections:

- Chapter 2 is a short summary of the key findings;
- Chapters 3 to 11 present an analysis of the survey findings;
- Annex 1 is the marked up questionnaire giving the breakdown of responses under each question heading;
- Annex 2 is the text of our correspondence with Practice Managers;
- Annex 3 is the report on OMEGA’s previous survey of GPs.

At the start of each chapter is a summary of the data from the research. This is followed by “topic sentence” headings and charts to illustrate the findings.

Please get in touch if you have comments and/or questions about this research or about the work of the Oxfordshire ME Group for Action (see contact details on page 2).

2 Summary of findings and recommendations

Summary of findings

1 The vast majority (93%) of GP respondents in this survey recognise CFS/ME as a clinical entity. This is above the figure of 72% found in a major survey of 811 GPs carried out in Gloucestershire in 2004⁷.

2 When asked whether they were aware of the Oxfordshire Patient Pathway for patients with CFS/ME, just under half (43%) of GP respondents replied "yes". Of those that stated that they were aware of the Patient Pathway, 81% find it useful (35% of all respondents).

3 85% of GP respondents refer patients they consider may have CFS/ME and 64% of all respondents believe that the referral criteria are clear. Those GP respondents who believe the referral criteria are NOT clear include some with greater numbers of CFS/ME patients (10 or more).

4 89% of GP respondents would be in favour of a primary care (community based) single point of access to services for CFS/ME.

"Single pathway will always be better, we have hundreds of uncommon conditions & thousands of rare ones. Keep it simple."

5 GPs currently access information on CFS/ME from a wide range of sources. 74% believe that more information should be provided, in meetings and via the internet.

"Consultant/team led education sessions. Proactive/locality based."

"Clearer information on www.oxfordhealth.nhs.uk"

6 37% of respondents know someone socially with CFS/ME (very similar to the Gloucestershire finding of 36%).

7 The majority of GPs in this survey are aware of local CFS/ME services. 73% of GP respondents are aware of the Oxfordshire Community CFS/ME Team (OCCMET) and 78% are aware of the ORH Infectious Diseases Clinic. GPs referring to OCCMET are statistically less likely to refer to ORH Fatigue service / Infectious Diseases Clinic.

8 14% have referred to specialists outside Oxfordshire. This compares with 18% found in the GP survey in Oxfordshire in 2001/03.

9 GPs are significantly less satisfied with services for younger patients and the majority (68%) would be in favour of a multidisciplinary team for children with CFS/ME.

10 From information provided in this survey it is estimated that GPs across Oxfordshire see 2,400 patients with CFS/ME in total (equivalent to 3.9 per 1,000 population) including 310 children with CFS/ME (equivalent to 2.6 per 1,000 population). This is close to the prevalence of 4 per 1,000 advised in the report to the Chief Medical Officer (January 2002) and is above the estimate of 1.88 per 1,000 from the last OMEGA GP study in 2001/2003.

⁷ Bowen, Pheby et al, see footnote 6 on page 5 of this report

Recommendations

Recommendation 1: **Review and improve guidance to GPs**

Specific issues highlighted by GP respondents in this research were:

- **A need for more information** on CFS/ME.
- **A need to clarify and improve the guidance to GPs (Patient Pathway and the referral criteria) and to improve awareness of CFS/ME services** especially in the north of the county.

Recommendation 2: **Set up a single (Primary Care) point of access for services**

There is strong support for a single primary care (community based) point of access to services for CFS/ME in Oxfordshire (89% of GP respondents).

More work is needed to understand why GPs refer outside Oxfordshire.

Recommendation 3: **Set up a service for children with CFS/ME**

There would be support for a multidisciplinary team for children with CFS/ME (68% of GP respondents).

Recommendation 4: **Review and improve support provided to research into the views of GPs in the future**

We encountered significant challenges in conducting this research and needed much more time than originally planned. The response rate was much lower than the previous survey and is likely to have been affected by our inability to pay GPs to participate in research.

It is of wider relevance and concern that this type of (non-commercially sponsored) research into health services in Oxfordshire is now much more difficult than 10 years ago.

3 Who responded to the survey

- ❖ 60 GPs responded, 11% of the total in Oxfordshire.
- ❖ 52% used the online survey, the remainder returned the paper questionnaire.
- ❖ 68% are female (compared with 58% female GPs in Oxfordshire PCT).
- ❖ 65% have been in practice for 10 years or more.
- ❖ 37% know someone socially with CFS/ME.

A total of 60 GPs responded to our 2012 survey on CFS/ME.

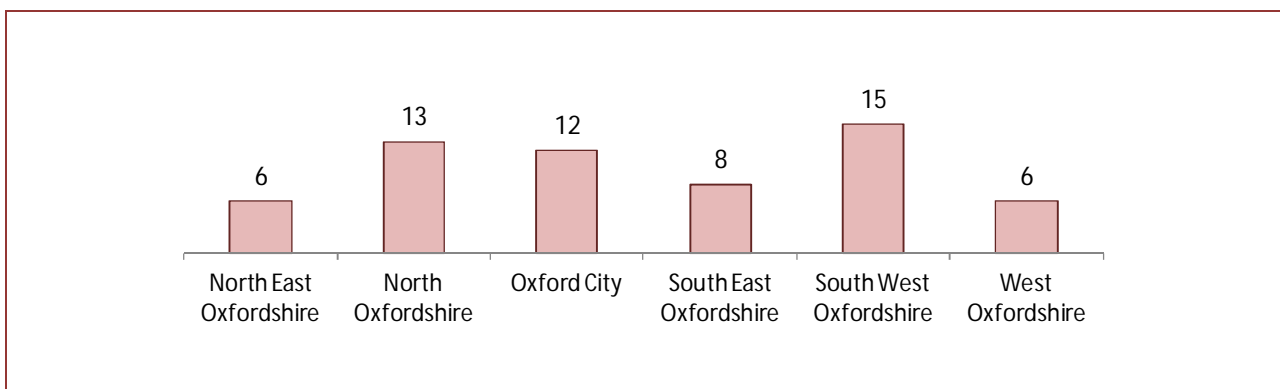
- This represents 11% of the total number of GPs registered in Oxfordshire (543⁸) and is below that achieved in OMEGA's previous survey of 2002/03 when 33% of doctors (136) responded.

It is possible that we would have achieved a higher response rate had we paid GPs to complete the survey.

- We understand from other researchers that it is now common practice for GPs to be paid for completing surveys. We did not have funding to pay the typical rate of £25 per questionnaire and this may have influenced the number of respondents.

Despite this, we have had a good distribution of responses across Oxfordshire's six Clinical Commissioning Groups with all localities having at least 6 responses.

Figure 1 Number of GP respondents by Clinical Commissioning Group



Just over half (52%) replied using the online version of the survey and the remainder responded via the paper questionnaire.

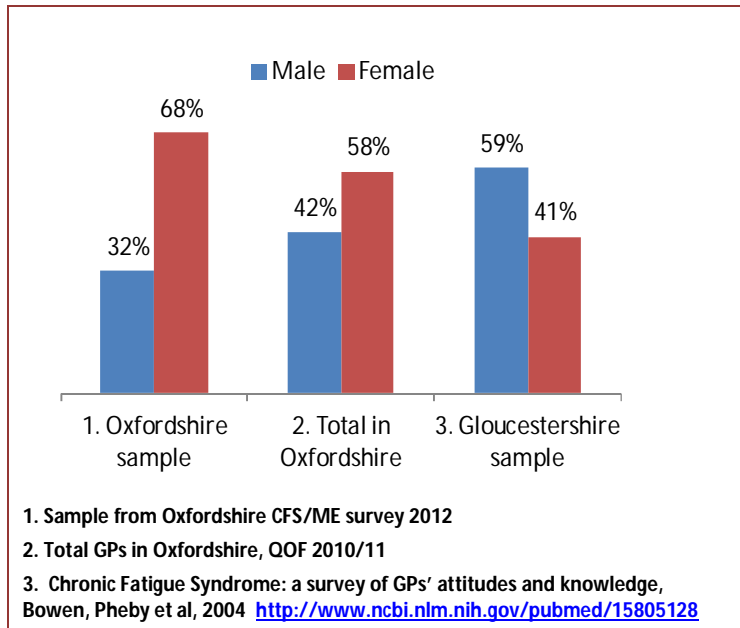
- Analysis of method of response – paper vs online questionnaire – showed no particular association with length of GP experience, gender or Clinical Commissioning Group locality.

⁸ QOF Oxfordshire PCT 2010/11

68% of GPs in our 2012 survey sample are female.

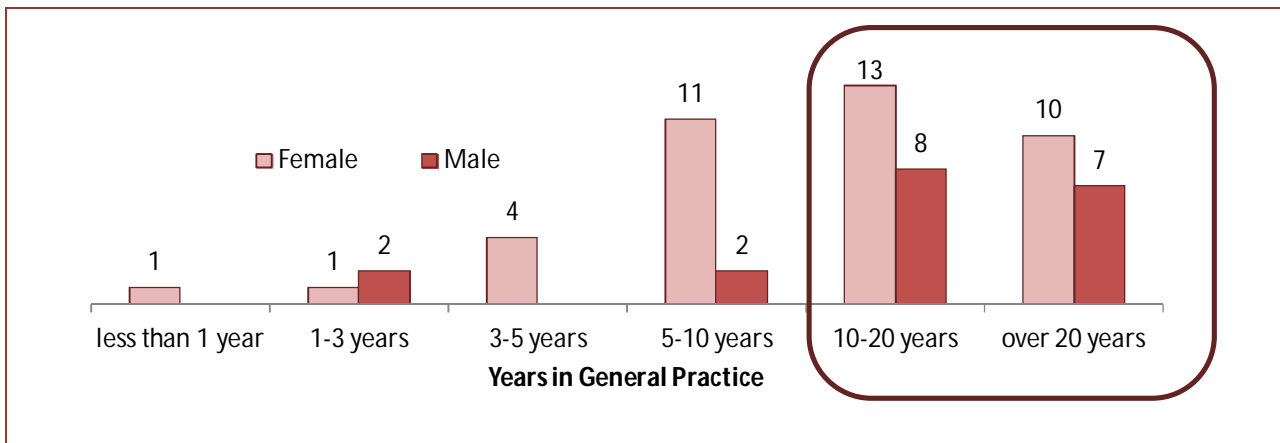
This is above the proportion of female GPs in Oxfordshire PCT (58%) and above that in the large scale Gloucestershire CFS/ME research project of 2004 (41%).

Figure 2 Comparison of GP respondents by gender with Oxfordshire PCT total and a similar Gloucestershire GP research project



We received the highest number of responses from GPs who had been in practice for at least 10 years (65%).

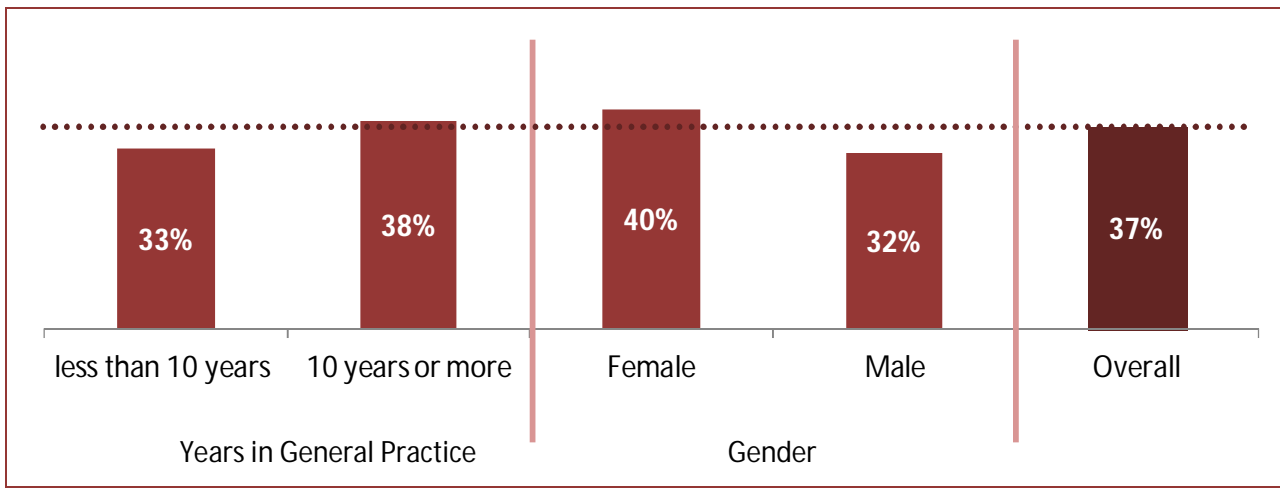
Figure 3 Number of GP respondents by gender and years in General Practice



Overall 22 out of the 60 GP respondents (37%) know someone socially with CFS/ME.

- This is very similar to the finding from the Gloucestershire study⁹ (811 GP respondents) that found 36% knew someone socially with CFS/ME. The Gloucestershire study concluded that this was one of the factors that had a statistically significant positive association with GPs' total attitudes to CFS/ME.
- Respondents with more years in General Practice or female GPs in this study are slightly more likely to know someone with CFS/ME socially (see below). However (unlike the Gloucestershire research) this difference is not statistically significant (see chapter 10).

Figure 4 Percent of respondents by type who know someone socially with CFS/ME



⁹ Bowen, Pheby et al, see footnote 6 on page 5 of this report

4 Finding information on CFS/ME

- ❖ 74% of respondents believe that more information on CFS/ME should be provided.
- ❖ GPs in Oxfordshire appear to rely on a wide range of sources to find information on CFS/ME with the majority using online resources.

74% of respondents believe that more information on CFS/ME should be provided to GPs in Oxfordshire. Suggestions from GPs on improving information on CFS/ME included:

1. Better direct support and information sharing

- *Find respected doctors to front the service to GPs as this would add credibility for those less knowledgeable.*
- *GP education meetings/practice based visits to talk about diagnosis and services*
- *Making the information readily available to GPs on the Oxfordshire clinical intranet or visiting GP surgeries to let us know what's happening and/or doing a lunchtime update at Wednesday lunchtime PGMDE meetings.*
- *Lunchtime talk at Oxfordshire Primary Care Learning*
- *Study days from clinicians.*

2. Improvements to internet resources

- *Having a 'page' on the Oxfordshire health website?*
- *Information easily available on internet eg PCT GP pages. Single portal of entry to CFS services.*
- *PCT intranet.*
- *Easy to find website with info on diagnosis, tests & referral/support - I want to be able to google CFS Oxford and have it at the top.*

GPs in Oxfordshire appear to rely on a wide range of sources to find information on CFS/ME. Most commonly mentioned were "Internet" or "Google" and medical websites such as patient.co.uk and the GP notebook.

- Respondents were asked in an open question where they look for information on CFS/ME. The majority (37 respondents of the 42 who answered this question) use online sources. Many make use of multiple sources and the most frequently cited were:
 - *"Internet" / "Google" (27)*
 - *GP notebook (8)*
 - *Clinical Intranet (6)*
 - *patient.co.uk (5)*
 - *EMIS Mentor system (4)*
 - *NICE guidance (3)*

- *ME Society (2)*
- *Books/journals (5)*
- *Local NHS/colleagues (5)*
- *OCCMET (2)*
- *Don't look (2)*
- More detailed responses to 'finding information' included:
 - *Try NICE Guideline but not very helpful.*
 - *I refer to NICE guidance primarily. The Arthritis UK organisation have also produced bulletins in the past about Fibromyalgia and I read the evidence base updates periodically in major medical journals.*
 - *"CFS - the facts" Prof Michael Sharpe*
 - *I emailed Dr Brian Angus recently.*
 - *Internet, ask experienced GP colleagues*
 - *patient.co.uk, google, resources in practice*

5 Diagnosing CFS/ME

- ❖ 93% of GPs recognise CFS/ME as a clinical entity.
- ❖ 79% distinguish between the fatigue of CFS/ME and the fatigue associated with other conditions.
- ❖ Depression is the most commonly cited condition GPs consider as differential diagnosis when seeing a CFS/ME patient.

The vast majority (93%) of GP respondents in this survey recognise CFS/ME as a clinical entity.

- This is above the figure of 72% found in a major survey of 811 GPs carried out in Gloucestershire in 2004¹⁰.
- One respondent in Oxfordshire, however, commented *“there is still reluctance for Drs to accept CFS/ME as a recognisable illness / disease.”*

The majority of respondents (79%) distinguish between the fatigue of CFS/ME and the fatigue associated with other conditions.

Depression is the most commonly cited condition that GPs consider as differential diagnosis¹¹ when seeing a CFS/ME patient. Next most commonly mentioned were thyroid, post viral fatigue, anaemia and fibromyalgia.

Table 1 Differential diagnosis when seeing a CFS/ME patient (free text coded)

Addisons	1	Manipulative behaviour	2
Anaemia	12	Malignancy	4
Arthritis	1	Myeloma	1
Autoimmune	2	Neurological disease (MS)	7
Cancer	2	Personality disorder/psychiatric	4
Coeliac disease	2	Post viral fatigue/viral	14
Depression	38	Polymyalgia rheumatic	3
Diabetes	4	Psychological issues	1
Endocrine	3	Rheumatological	5
Fibromyalgia	12	Stress/lifestyle	3
Glandular fever	2	Thyroid	17
Infection	7		

¹⁰ Bowen, Pheby et al, see footnote 6 on page 5 of this report

¹¹ Differential diagnosis is a process of systematically considering alternative conditions starting with the most common diagnosis.

6 Oxfordshire Patient Pathway and referrals

- ❖ When asked whether they were aware of the Oxfordshire Patient Pathway for patients with CFS/ME, just under half (43%) of GP respondents replied “yes”.
- ❖ Of those that stated that they were aware of the Patient Pathway, 81% find it useful (35% of all respondents).
- ❖ 85% of respondents refer patients they consider may have CFS/ME.
- ❖ 64% of all respondents believe the referral criteria are clear.
- ❖ 14% have referred to specialists outside Oxfordshire.

When asked whether they were aware of the Oxfordshire Patient Pathway for patients with CFS/ME, just under half (43%) of GP respondents replied “yes”. GPs with under 10 years experience were less likely to say they were aware of the Patient Pathway.

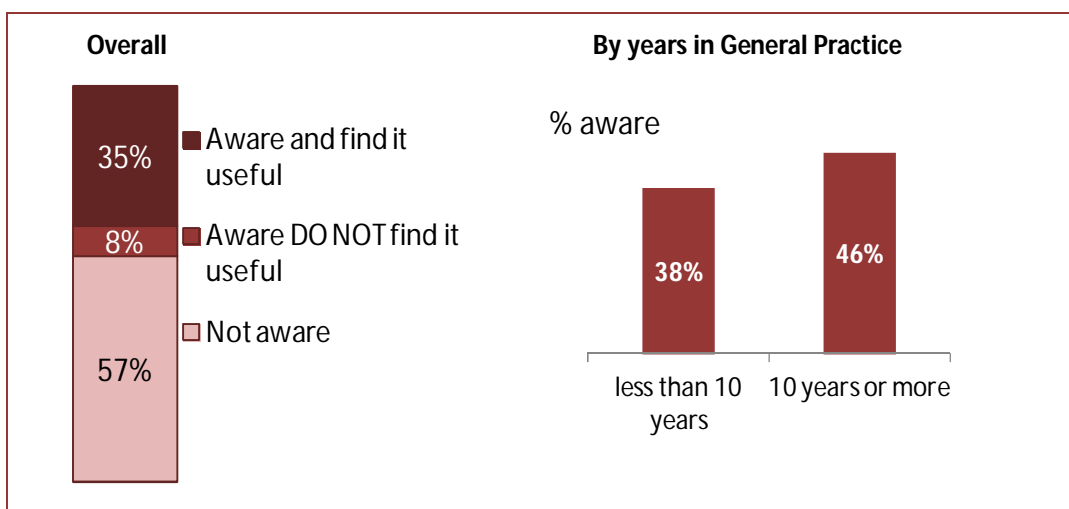
- 38% of those with less than 10 years experience in General Practice say they are aware of the CFS/ME Patient Pathway compared with 46% of those with 10 years or more. This difference is not statistically significant (see chapter 10).

It now appears, however, that we don’t know what exactly GPs had in mind when they responded to the question about the CFS/ME Patient Pathway. GPs who responded that they are aware of the CFS/ME Patient Pathway may have been thinking of a generic “pathway”.

- Our assumption at the start of this research project was that the agreed Patient Pathway - describing service options for patients with CFS/ME in Oxfordshire - had been made available to GPs. However discussions in the process of compiling this report suggest this is not the case. **Further work is needed to clarify what is already available and how best to communicate this type of guidance.**

Of those that reported that they were aware of the Patient Pathway, 81% find it useful (35% of all respondents).

Figure 5 Awareness of the Patient Pathway for CFS/ME



85% of respondents refer patients they consider may have CFS/ME. GPs who do not refer generally have few patients.

- Of the 8 GPs who did not refer, two stated that they had no patients with CFS/ME, five had 1-2 patients and one had 3 patients.
- GPs who did refer reported a wide variation in numbers of patients, from “less than 1” to “10 or more”.

Table 2 Number of respondents by whether or not they refer and number of patients with CFS/ME

	Number of patients						TOTAL
	none	less than 1	1-2	3-4	5-10	10 or more	
I do not refer	2	1	4	1			8
I refer		3	12	13	11	5	44

No response (on both or either dimension) = 8

64% of all respondents believe the referral criteria are clear. Those GP respondents who believe the referral criteria are NOT clear, however, include some with greater numbers of CFS/ME patients (10 or more).

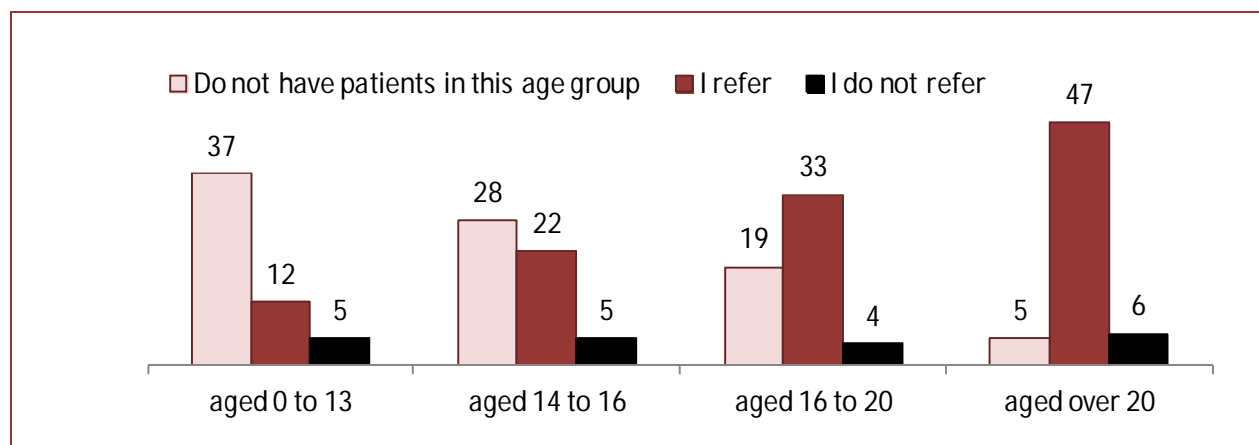
14% have referred to specialists outside Oxfordshire.

- This is below the proportion found in the GP survey in Oxfordshire in 2001/03 of 18% and may have been affected by the introduction of the new Community CFS/ME service (OCCMET). This difference, however, may be due to the profile of the two survey samples rather than a real change in referral patterns.
- We did not ask when the referral to specialists took place. It may be that the current rate of referral to outside Oxfordshire is below this.

Referral patterns vary by age of patient.

- 37 respondents (69%) do not have patients aged 0-13. This leaves 17 respondents who have patients, of which 71% (12) refer.
- 81% of respondents with patients aged 14-16, 89% of respondents with patients aged 16-20 and 89% with patients aged over 20 refer.

Figure 6 Do you refer patients you consider may have CFS/ME differently according to their age?



7 Services and support for CFS/ME patients

- ❖ The majority of GPs in this survey are aware of local CFS/ME services. 73% of GP respondents are aware of the Oxfordshire Community CFS/ME Team (OCCMET) and 78% are aware of the ORH Infectious Diseases Clinic.
- ❖ When asked how satisfied they were with local CFS/ME services for children, most GP respondents did not have an opinion.
- ❖ When asked how satisfied they were with local CFS/ME services for people aged 20 or over, 50% of GP respondents did not have an opinion and, of the remainder, the majority were satisfied.
- ❖ 68% would be in favour of a multidisciplinary service specialising in the diagnosis, treatment and management of children with CFS/ME.
- ❖ 89% would be in favour of a primary care (community based) single point of access to services for CFS/ME.
- ❖ 30% had heard of the Oxfordshire ME Group for Action (OMEGA) and, of those, 30% recommend OMEGA to patients as a source of support and information.

Patients in Oxfordshire are mainly referred to the Oxford Infectious Diseases Clinic (which may take all mobile patients and has clinic sessions in Banbury) and the Oxfordshire Community CFS/ME Team (which may take all patients and is the only service to provide for the severely affected group).

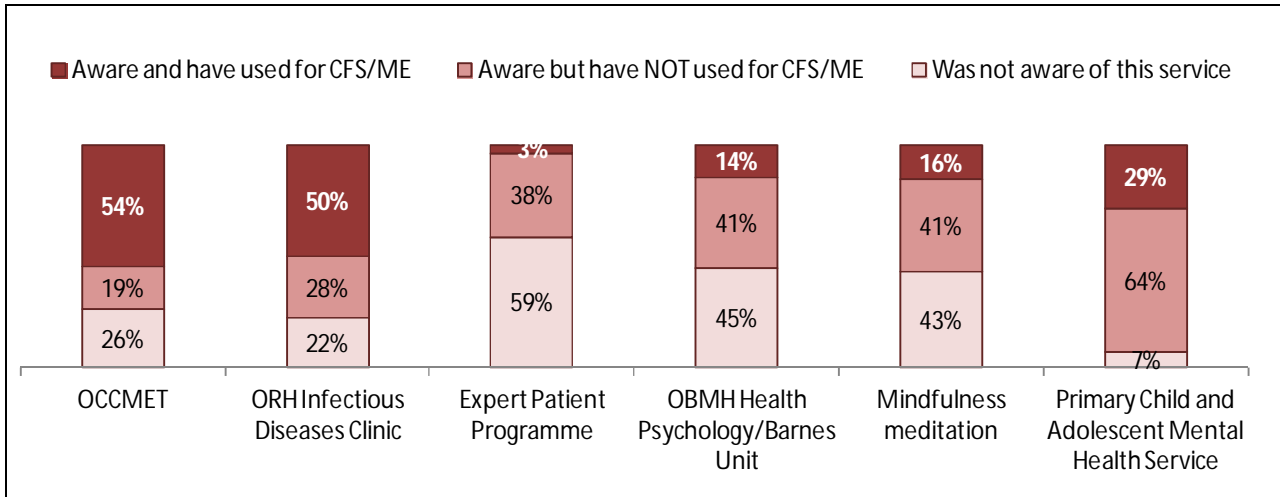
TalkingSpace (Mindfulness meditation) also provides groups for people with physical illnesses including CFS/ME. Patients may be referred to other specialists.

The majority of GPs in this survey are aware of local CFS/ME services. However around 1 in 4 GPs in this research sample were not aware of local services.

- 73% of GP respondents are aware of the Oxfordshire Community CFS/ME Team (OCCMET) and 78% are aware of the ORH Infectious Diseases Clinic.
- Other services are less commonly used by GPs for patients they consider may have CFS/ME. 29% have used the Primary Child and Adolescent Mental Health Service for CFS/ME and 16% have used Mindfulness Meditation.
- Two respondents commented that they are unable to refer to the Health Psychology/Barnes Unit.
- See figure 7 on the following page.

Statistical tests show that GPs referring to OCCMET are less likely to refer to ORH Fatigue service / Infectious Diseases Clinic (see chapter 10).

Figure 7 Have you used or are you aware of the following services for people with CFS/ME

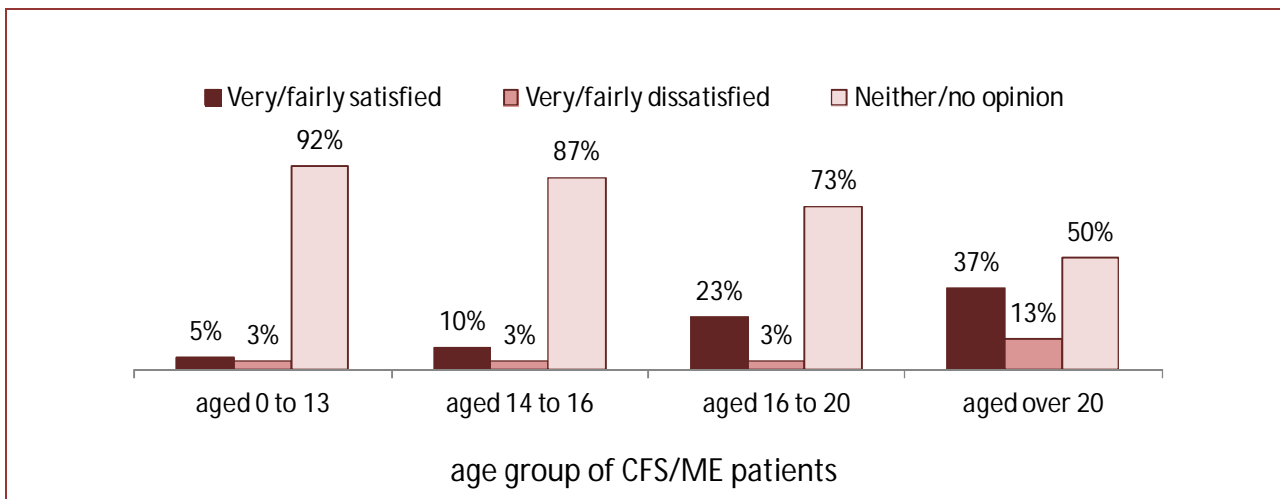


When asked how satisfied they were with local CFS/ME services for children, most GP respondents did not have an opinion. However, those who did so were significantly less satisfied with provisions for younger patients. (see figure 8 below). For many this was because they do not consider that they have younger patients with CFS/ME.

When asked how satisfied they were with local CFS/ME services for people aged 20 or over, 50% of GP respondents did not have an opinion and, of the remainder, the majority were satisfied.

- 37% of all GP respondents are very or fairly satisfied with CFS/ME services for patients aged over 20 and 13% are very or fairly dissatisfied.

Figure 8 Satisfaction with CFS/ME services provided locally by age group of CFS/ME patients



Statistical tests show that overall GPs are less satisfied with provisions for younger patients (see chapter 10).

Comments from GPs highlighted issues with current services including the need to reduce waiting times.

- *"Biggest priority is to reduce waiting-list from time of referral to time of therapy. I would advocate opening GP referral to the Psychology Service and would accept referral criteria and clinical triage to ensure appropriateness of patients"*
- *"Reduce wait for adult service."*
- *"I think it's quite good but would like to see more integrated service. Would like to avoid over-medicalising and labelling these patients as have seen many with illness perpetuated by treatment approach."*
- *"More help and support. More psychological and psychotherapy."*
- *"Reduce the waiting time. Also limited contact and then discharged (OCCMET)"*
- *"Reduce time between referral and appointment."*
- *"Simplified single point of diagnosis confirmation and access to rehab support/ psychology."*
- *"Single pathway will always be better, we have hundreds of uncommon conditions & thousands of rare ones. Keep it simple."*

89% of respondents would be in favour of a primary care (community based) single point of access to services for CFS/ME.

50% of respondents would be in favour of both of these initiatives – a service for children and a single point of access.

30% of GP respondents had heard of the Oxfordshire ME Group for Action (OMEGA) and, of those that were aware of OMEGA, 30% recommend the patient group to CFS/ME patients as a source of support and information.

- There is no evidence that knowledge of someone with CFS/ME is linked to awareness of OMEGA.

The following chapter shows how these findings vary geographically.

8 Results by locality

This section shows how responses which may have had a geographical influence vary across Oxfordshire.

Note that, because there were fewer than 10 respondents in three of the six Clinical Commissioning Group localities, responses have been grouped into 3 broader areas:

North – North East Oxfordshire; North Oxfordshire; West Oxfordshire.

Oxford – Oxford City.

South – South East Oxfordshire; South West Oxfordshire.



Respondents in **Oxford city** were more likely to know someone socially with CFS/ME and more likely to be aware of the Oxfordshire Community CFS/ME team (OCCMET), the ORH Infectious Diseases Clinic and OMEGA.

Respondents in **north Oxfordshire** were more likely to have referred patients to specialists outside Oxfordshire and the least likely to be in favour of a multidisciplinary service for children with CFS/ME.

Respondents in **south Oxfordshire** were more likely to be aware of the Patient Pathway and were slightly more likely to be in favour of a single point of access to services for CFS/ME.

	North	Oxford	South	Total
Number of respondents (percent of total)	25 (42%)	12 (20%)	23 (28%)	60 (100%)
Q4: Know anyone socially with Chronic Fatigue Syndrome or ME (% YES)	36%	55%	30%	37%
Q6: Aware of Patient Pathway (% YES)	40%	42%	48%	43%
Q10: Referred patients to specialists outside Oxfordshire? (% YES)	20%	0%	13%	14%
Q12: Aware of OCCMET (% AWARE)	68%	82%	74%	76%
Q12: Aware of ORH Infectious Diseases Clinic (% AWARE)	80%	91%	68%	78%
Q12: Aware of Mindfulness Meditation (% AWARE)	52%	82%	50%	57%
Q13: Heard of OMEGA (% YES)	29%	40%	27%	30%
Q19: In favour of a multidisciplinary service for CHILDREN with CFS/ME (% YES)	56%	75%	76%	68%
Q20: In favour of a primary care (community based) single point of access to services for CFS/ME (% YES)	88%	89%	90%	89%

Percentages exclude 'no response' and 'don't know' (where 'don't know' is a question choice)

 = Highest %  = Lowest %

9 Estimating the number of CFS/ME patients

- ❖ Results from this survey indicate 2,600 patients (of all ages) with CFS/ME are registered with GPs in Oxfordshire, equivalent to 3.9 patients per 1,000 population.
- ❖ Just over half of GPs responding had no young patients with CFS/ME.
- ❖ Responses from those with young patients indicates around 340 children with CFS/ME across Oxfordshire, equivalent to 2.6 per 1,000 population.

GPs were asked in an open question to estimate the number of patients they see with CFS/ME. The responses were then coded into the most frequently used categories.

Estimate of all patients with CFS/ME

It is estimated that the GPs in this survey see around 300 patients of all ages with CFS/ME which implies a total of 2,600 CFS/ME patients registered with GPs in Oxfordshire PCT.

- This estimate of 2,600 patients is just above the top end of the estimated range of 1,847-2,462 CFS/ME patients in the Oxfordshire PCT Health Needs Assessment for Long Term Neurological conditions¹².

Using our estimate of 2,600 CFS/ME patients and the 2011 Census resident population estimate for Oxfordshire (652,800) gives an **estimated prevalence of 3.9 patients per 1,000 population.**

- This is close to the prevalence of 4 per 1,000 population advised in the report to the Chief Medical Officer of January 2002¹³.

Each Strategic Health Authority should make provision for secondary and tertiary care for people with CFS/ME, based on an estimated annual prevalence rate of approximately 4,000 cases per million population in the absence of more refined data." (p68).

Estimate of young patients with CFS/ME

GPs were also asked how many of their CFS/ME patients are children. **Just over half of GPs responding had no young patients with CFS/ME.**

Using the same method as for total patients, **it is estimated that GPs in this survey see 37 children with CFS/ME which implies a total of 340 across Oxfordshire PCT.**

With the denominator of the Oxfordshire population aged 0 to 16 (count=130,015, Census 2011) this gives an **estimated prevalence of CFS/ME in children aged 0-16 of 2.6 per 1,000.**

- A recent paper¹⁴ puts prevalence at 10 per 1,000 among secondary age children (aged 11 to 16). Previous population studies (cited in that paper) estimates between 0.1% and

¹² Health Needs Assessment for Long Term Neurological Conditions A report for Oxfordshire PCT, March 2010

¹³ CMO report on CFS/ME – see footnote 4 on page 5 of this report

¹⁴ Crawley, E, Emond, AM & Sterne, J. 'Unidentified Chronic Fatigue Syndrome (CFS/ME) is a major cause of school absence: surveillance outcomes from school based clinics', *BMJ Open*, 1, (pp. e000252-), 2011
<http://bmjopen.bmj.com/content/1/2/e000252.full>

0.5% i.e. between 1 and 5 per 1,000. The same paper states that "there may be much undiagnosed and misdiagnosed CFS/ME in children and young people".

10 Statistical analysis

The data from this survey has been independently tested by Paul Seed (Senior Lecturer in Medical Statistics, King's College London) with the following results.

Query 1: Is there more dissatisfaction about provisions for younger patients?

- GPs are less satisfied with provisions for younger patients.
p=0.036, by Wald test, following logistic regression with a random GP effect.

Query 2: How does knowledge of someone with ME affect GP attitudes?

First related question : do satisfaction rates change with knowledge of someone with ME?

- No evidence that satisfaction rates change with knowledge of someone with ME.

Second related question : does attitude to OMEGA change with knowledge of someone with ME?

- No evidence that attitude to OMEGA changes with knowledge of someone with ME.

Query 3: How does knowledge of someone with ME vary with GP groups?

- No noticeable or significant difference by GP gender.
- No noticeable or significant association on attitude to OMEGA.
- No noticeable or significant difference by GP years in practice.

Query 4: Is use of the Oxfordshire Community CFS/ME Team for referral related to lower likelihood of using other services?

- It appears that GP referring to OCCMET are less likely to refer to ORH Fatigue service / Infectious Diseases Clinic.
- The other services are used relatively rarely by these GPs.

Query 5: Pathways and years of practice

- No evidence that knowledge of patient pathway is linked to years of service.

11 Comparison with 2001-2003 survey

The following table compares the key findings from this 2012 survey of GPs and the previous survey carried out between 2001 and 2003 (questionnaires were sent to GPs in Oxford city in 2001 and to other PCTs in Oxfordshire in 2003).

	2001/2003	2012
Number of GP responses	136	60
GPs know where to refer patients with CFS/ME locally	76%	-
GPs aware of Oxfordshire Community CFS/ME Team	<i>(OCCMET did not exist at the time of this survey)</i>	76%
GPs aware of ORH Infectious Diseases Clinic		78%
GPs who are aware but <u>not</u> satisfied with services for patients with CFS/ME	31%	17% (for patients aged over 20)
GPs referring patients out of Oxfordshire	18%	14%
GPs in favour of a primary care multidisciplinary specialist clinic for CFS/ME	68%	
GPs in favour of a multidisciplinary service specialising in CFS/ME for <u>children</u>	<i>Q not included</i>	68%
GPs in favour of a primary care (community based) single point of access to CFS/ME services	<i>Q not included</i>	89%
Estimated number of patients with CFS/ME	1,270 (1.88 patients per 1,000 population)	2,400 (3.7 patients per 1,000 population)

ANNEX 1: Marked up questionnaire

This section gives the breakdown of the responses to each individual question.

How completing the questionnaire

	Count	Percent
Paper	29	48%
Online (surveymonkey)	31	52%
Total	60	100%

Q1: In which Clinical Commissioning Group is your practice based?

	Count	Percent
North East Oxfordshire	6	10%
North Oxfordshire	13	22%
Oxford City	12	20%
South East Oxfordshire	8	13%
South West Oxfordshire	15	25%
West Oxfordshire	6	10%
Total	60	100%

Q2: Approximately how many years have you been in General Practice?

	Count	Percent
less than 1 year	1	2%
1-3 years	3	5%
3-5 years	4	7%
5-10 years	13	22%
10-20 years	22	37%
over 20 years	17	28%
Total	60	100%

Q3: Are you..

	Count	Percent
Male	40	68%
Female	19	32%
Total	59	100%
No response	1	

Q4: Do you know anyone socially with Chronic Fatigue Syndrome or ME?

	Count	Percent
No	37	63%
Yes	22	37%
Total	59	100%
No response	1	

Q5: If you need information about CFS/ME where do you look?

Comment = 42 responses

- ?Oxfordshire PCT intranet, google, GP notebook
- At our intranet where referral forms are kept
- "CFS - the facts" Prof Michael Sharpe
- Clinical intranet, books and medical websites
- Contact Oxford Health NHS Foundation Trust
- Don't look
- Emis mentor system
- Google
- google, me society
- GP notebook
- GP Notebook I emailed Dr Brian Angus recently
- GP notebook, CKS, Gp handbook, internet.
- GP Notebook, Google
- GP notebook. NHS clinical website
- Gp notebook
- I refer to NICE guidance primarily. The Arthritis UK organisation have also produced bulletins in the past about Fibromyalgia and I read the evidence base updates periodically in major medical journals
- Internet
- Internet Churchill
- Internet Patient.co.uk
- Internet and textbooks
- Internet patient.co.uk
- Internet, ask experienced GP colleagues
- internet, GP notebook
- internet, NICE
- Intranet, patient.co.uk
- ME website
- Mentor
- mentor.
- Mentor. Web
- Not occurred
- Not sure. Try NICE Guideline but not very helpful.
- OCCMET
- OCCMET; online; google
- on line
- On line, our intranet, <http://www.oxfordhealth.nhs.uk>
- online / google
- Oxfordshire NHS website
- patient.co.uk
- patient.co.uk, google, resources in practice
- Proactive intranet and internet
- Web - CK5, GP notebook
- Yes. RCGP/RCPsch document or web.

Coded..

Internet/Google	27
GP notebook	8
Clinical Intranet	6
patient.co.uk	5
Books/journals	5
Local NHS/colleagues	5
EMIS Mentor system	4
NICE guidance	3
ME Society	2
OCCMET	2
Don't look	2

NB: many respondents mentioned more than one source

Q6: Are you aware of the Oxfordshire Patient Pathway for CFS/ME?

	Count	Percent
No	34	57%
Yes	26	43%
Total	60	100%

Q7: If you are aware of the Patient Pathway, do you find it useful?

note - filtered on respondents replying "yes" to previous question

	Count	Percent
No	5	19%
Yes	21	81%
Total	26	100%

Q8: Do you refer patients you consider may have CFS/ME?

	Count	Percent
No	8	15%
Yes	47	85%
Total	55	100%
No response	5	

Q9: Are the referral criteria clear?

	Count	Percent
No	16	36%
Yes	28	64%
Total	60	100%
No response	16	

Q10: Have you referred patients you consider may have CFS/ME to specialists outside Oxfordshire?

	Count	Percent
No	50	86%
Yes	8	14%
Total	60	100%
No response	2	

Q11: Do you refer patients you consider may have CFS/ME differently according to their age?

	for patients aged 0 to 13	for patients aged 14 to 16	for patients aged 16 to 20	for patients aged over 20
Do not have patients in this age group	37	28	19	5
	69%	51%	34%	9%
Do not refer	5	5	4	6
	9%	9%	7%	10%
I refer	12	22	33	47
	22%	40%	59%	81%
Total	54	55	56	58
	100%	100%	100%	100%
No response	6	5	4	2

Q12: Have you used or are you aware of the following services for people with CFS/ME?

	OCCMET	ORH Infectious Diseases Clinic	Expert Patient Programme	OBMH Health Psychology_ Barnes Unit	Mindfulness meditation	Primary Child and Adolescent Mental Health Service
Aware and have used for CFS/ME	31	29	2	8	9	16
	54%	50%	3%	14%	16%	29%
Aware but have NOT used for CFS/ME	11	16	22	23	24	36
	19%	28%	38%	41%	41%	64%
Was not aware of this service	15	13	34	25	25	4
	26%	22%	59%	45%	43%	7%
Total	57	58	58	56	58	56
	100%	100%	100%	100%	100%	100%
No response	3	2	2	4	2	4

Q13: Have you heard of Oxfordshire ME Group for Action (OMEGA)?

	Count	Percent
No	39	70%
Yes	17	30%
Total	56	100%
No response	4	

Q14: If YES do you recommend OMEGA to patients as a source of support and information?

note - filtered on respondents replying "yes" to previous question

	Count	Percent	Percent of total respondents
No	11	69%	18%
Yes	5	31%	8%
Total	17	100%	28%
No response	1		

Q15: How satisfied or dissatisfied are you with CFS/ME services provided locally?

COUNT	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Dis-satisfied	Very dis-satisfied	Don't know / no opinion	No response
for patients aged 0 to 13	0	3	18	1	1	24	13
for patients aged 14 to 16	0	6	21	1	1	18	13
for patients aged 16 to 20	0	14	20	1	1	15	9
for patients aged over 20	3	19	16	6	2	9	5

Q16: Do you consider that CFS/ME is a recognisable clinical entity?

	Count	Percent
No	4	7%
Yes	51	93%
Total	55	100%
No response	5	

Q17: Which conditions would you consider as differential diagnosis when seeing a CFS/ME patient?**Comment = 49 responses***Comments coded and grouped..*

Addisons	1	Manipulative behaviour	2
Anaemia	12	Malignancy	4
Arthritis	1	Myeloma	1
Autoimmune	2	Neurological disease (MS)	7
Cancer	2	Personality disorder/psychiatric	4
Coeliac disease	2	Post viral fatigue/viral	14
Depression	38	Polymyalgia rheumatica	3
Diabetes	4	Psychological issues	1
Endocrine	3	Rheumatological	5
Fibromyalgia	12	Stress/lifestyle	3
Glandular fever	2	Thyroid	17
Infection	7		

Q18: Do you distinguish between the fatigue of CFS/ME and the fatigue associated with other medical conditions?

	Count	Percent
No	12	21%
Yes	46	79%
Total	58	100%
No response	2	

Q19: Would you be in favour of a multidisciplinary service specialising in the diagnosis, treatment and management of CHILDREN with CFS/ME?

	Count	Percent
No	15	32%
Yes	32	68%
Total	60	100%
Don't know/No response	13	

Comment (note that only the online survey – i.e. not the paper version - included a comment box with this question)

- Anecdotally this sounds like an awfully costly exercise for relatively little gain when the current systems appear to function reasonably
- As a branch of a single ME service
- done between paed and PCAHMS
- have not seen any children
- I do not encounter this much and would refer to a Paeds team for exclusion of other causes first
- It depends on the cost and which services I would have to decommission to pay for it
- Need to incorporate with child psych but give them more resources

- this would be useful and I would use it
- though not aware of how frequent this condition arises in under 14

Q20: Would you be in favour of a primary care (community based) single point of access to services for CFS/ME?

	Count	Percent
No	6	11%
Yes	48	89%
Total	54	100%
No response	6	

Comment (note that the paper survey did not include a comment box with this question)

- Don't mind as long as it is well publicised.
- not sure

Q21: Do you think that more information on CFS/ME should be provided to GPs in Oxfordshire?

	Count	Percent
No	15	26%
Yes	42	74%
Total	57	100%
No response	3	

Q22: How do you think that services or information on CFS/ME might be improved?

Comment = 35 responses

- advertising it better - I have been in the area for 7 years and not aware of its existence
- Better communication with GP and education for GP
- Biggest priority is to reduce waiting-list from time of referral to time of therapy. I would advocate opening GP referral to the Psychology Service and would accept referral criteria and clinical triage to ensure appropriateness of patients
- Central coordination of news
- Children's service. Reduce wait for adult service. Phased progressive exercise group therapy and individual according to preference
- clear choices and information on clinics
- Clear referral pathway/form with criteria
- Clearer access. Timely
- Clearer information on <http://www.oxfordhealth.nhs.uk>
- Consultant/team led educational sessions. Proactive / locality based
- Don't see enough of patients with symptoms fitting criteria to have much of an opinion
- easier access to private as well as nhs one stop clinic

- Easier to access specialist to give initial diagnosis
- Email
- Find respected doctors to front the service to GPs as this would add credibility for those less knowledgeable.
- GP education meetings/practice based visits to talk about diagnosis and services
- having a 'page' on the Oxfordshire health website?
- I have only been practising in Oxfordshire for 2 months, so cannot comment more fully.
- I think it's quite good but would like to see more integrated service. Would like to avoid over-medicalising and labelling these patients as have seen many with illness perpetuated by treatment approach
- Information easily available on internet eg PCT gp pages. single portal of entry to CFS services. At present, you refer to ID service for diagnosis but this does not provide any treatment, so you then have to refer to OCCMET. Would be better if you could
- Is there any evidence-based treatment?
- It would be useful to be aware of whats on offer for our patients
- Link via PCT intranet
- Making the information readily available to GPs on the Oxfordshire clinical intranet or visiting GP surgeries to let us know what's happening and/or doing a lunchtime update at Wednesday lunchtime PGMDE meetings. Could contact pru-watson@dph.ox.ac.uk www
- More help and support. More psychological and psychotherapy
- more info and easier access and better info following consultations esp a plan when a pt is discharged
- PCT intranet. Lunchtime talk at Oxfordshire Primary Care Learning
- Reduce the waiting time. Also limited contact and then discharged (OCCMET)
- Reduce time between referral and appointment. Easy to find website with info on diagnosis, tests & referral/support - I want to be able to google CFS Oxford and have it at the top.
- Referral criteria and awareness of services available
- Simplified single point of diagnosis confirmation and access to rehab support/ psychology
- Single pathway will always be better, we have hundreds of uncommon conditions & thousands of rare ones. Keep it simple
- Study days from clinicians. Info on internet.
- Unified service with single point of access
- We seem to be doing ok as it is.

Q23: On average how many patients do you estimate you see each year with CFS/ME?

Comment = 56 free text responses *Responses have been coded.*

Number of patients with CFS/ME

	Count	Percent
none	2	4%
less than 1	4	7%
1-2	16	30%
3-4	16	30%
5-10	11	20%
10 or more	5	9%
Total	54	100%
don't know	2	
no response	4	

Number of children with CFS/ME

	Count	Percent
none	29	52%
less than 1	8	14%
1	12	21%
2-4	7	13%
Total	56	100%
no response	4	

Q24: Any other comments

Comment

- I am very part time and the numbers I see are small. The adult patients I see rapidly exhaust and seem to exasperate the service that is supposed to be providing for these challenging patients.
- I did see one pt who recognised the symptoms and asked to be referred privately to a specialist he knew in London. I didn't know that there were services and may have treated him locally.
- I think children need to see a paediatrician first to be sure nothing being missed.
- I would prefer to see a joined up service on NHS rather than see people after they have received dodgy private treatment.
- I'm fairly new in this region which may be why I was unaware of the service.
- Thank you for helping these people. Thank you for helping clinicians who are trying to support them!
- The same patients keep coming back. There are many other conditions getting fewer resources than those going towards ME sufferers.
- There is still reluctance for Drs to accept CFS/ME as a recognizable illness / disease.
- We need better support. OCCMET not helped my serious patients.
- We see lots of patients who think they have or have self diagnosed ME.

ANNEX 2: Correspondence with Practice Managers

The following is the text of the email sent to Practice Managers in Oxfordshire by Sarah Adair, Head of Communications and Engagement, NHS Buckinghamshire & Oxfordshire Cluster on 28th June 2012.

EMAIL SUBJECT: **Help us to improve services for patients with CFS/ME in Oxfordshire**

Dear Practice Manager

Could you please help us by forwarding this email to GPs in your practice?

Best wishes

Sarah Adair | Head of Communications and Engagement | NHS Buckinghamshire & Oxfordshire Cluster

Dear GP

Ten years ago the Oxfordshire ME Group for Action (OMEGA) carried out a survey of GPs in Oxfordshire and found that just over half of doctors either did not know about or were not satisfied with existing dedicated services for patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME).

Since that time a new dedicated community service, the Oxfordshire Community CFS/ME Team (OCCMET) has been set up and a Patient Pathway has been agreed.

We would like your views on this and whether there is a need for additional support in the treatment of CFS/ME for children and adults.

Can you help us by completing our short survey?

The survey can be accessed by clicking this link www.surveymonkey.com/s/CFS_ME_in_Oxfordshire (you may need to copy and paste it into your browser). It should take no more than 5 minutes of your time to complete and your response will remain anonymous.

The results will be shared widely and, we hope, will lead to improvements in the information and support in the diagnosis and treatment of CFS/ME in Oxfordshire - saving your time and improving the lives of patients.

Thank you for your help,

Margaret Melling,

Independent Researcher, on behalf of the Oxfordshire Local Involvement Network,

LINK is an independent body with the aim of giving communities and patients a stronger voice in how health and social care services are delivered.

The following is the text of the reminder letter sent to Practice Managers in the week commencing Monday 2nd July 2012 by the Local Involvement Network.

Enclosed with the letter were 5 copies of the questionnaire, 5 freepost envelopes plus OMEGA leaflets.

Dear Practice Manager

Help us to save GP time and improve the lives of patients

The Oxfordshire Local Involvement Network with the Oxfordshire ME Group for Action (OMEGA) is carrying out a survey to understand GPs views on whether there is a need for additional support in the treatment of CFS/ME.

You may have received an email from the Communications and Engagement team of the Oxfordshire PCT with a link to the survey, however, we are aware that some may prefer to complete the survey on paper and have enclosed 5 copies of the questionnaire.

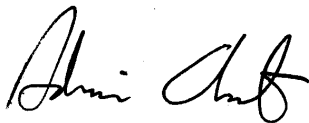
Could you please let your GPs know of this work and distribute the paper copies on our behalf?

Also enclosed is an OMEGA leaflet which we hope you will find useful.

For ease of return, we have also enclosed a FREEPOST envelope that we hope you will make use of.

If you have any questions about this project, or would like a copy of the report, please contact our independent researcher Margaret Melling by email on Margaret@mmconsulting.org.uk or by phone 07958 239857.

With thanks for your help,



Adrian Chant

Oxfordshire Local Involvement Network

ANNEX 3: Previous survey of GPs in Oxfordshire

Oxfordshire ME Group for Action

Chronic Fatigue Syndrome/ME: Summary of Survey of GPs in Oxfordshire Primary Care Trusts, Nov. 2003*

Main findings:

- Doctors from 66% of GP Practices replied.
- 54% of doctors who responded either did not know about or were not satisfied with existing dedicated services for patients with Chronic Fatigue Syndrome (CFS/ME)
- Average number of patients gives an estimated prevalence of 1.9 per 1000.
- 18% of GPs had referred patients out of Oxfordshire
- 68% of doctors were in favour of a primary care multidisciplinary specialist clinic for the diagnosis, treatment and management of CFS/ME patients

Introduction

Oxfordshire ME Group for Action (OMEGA) is the patient group for people with CFS/ME in Oxfordshire¹⁵. Surveys of patients have shown that there is a huge unmet need for early diagnosis, treatment and help to manage the illness. See References (1) and (2). In 2002 the Report of the Chief Medical Officer's Working Group on CFS/ME (the CMO Report) stated that the illness is *a relatively common clinical condition, which can cause profound, often prolonged illness and disability [see(3)]*.

Survey of Doctors and Response Rate

In July 2001 a brief questionnaire was sent to all GPs in Oxford City PCT (See Reference (4)) and in August 2003 the survey was extended to the other PCTs in Oxfordshire¹⁶. The questionnaire was written with the advice of Karen Rhodes-Byneo, then Head of Training and Clinical Governance at Oxford City PCT. In total 413 GPs in 88 practices were surveyed. Replies were received from 136 doctors (33%) in 58 practices (66%). This

* Last update 3 Feb. 2004

¹⁵ Oxfordshire ME Group for Action (OMEGA) has worked with CFS/ME patients and carers over 14 years and has an annual paid-up membership of about 120. It is affiliated to the largest national CFS/ME charity, Action for ME. Activities include regular meetings for those well enough to attend, a Newsletter and Telephone Listening Ear service. In conjunction with Oxford City Primary Care Trust it held a Training Event for Health Practitioners in 2001, and a further training event will take place on 19 March 2004. **In January 2003, OMEGA and Oxfordshire PCTs received news that their Bid for a specialist CFS/ME local multidisciplinary team is to be funded by the DoH. This CFS/ME Team ("OCMT") will be set up c. November 2004.**

¹⁶ We wrote to each Practice Manager, enclosing enough survey forms for each GP in the practice.

compares with a response rate of 37% of GP practices in a survey in Gloucestershire. See Reference (5).

Results

A summary of the results is given in the Table (and Notes to Table). Doctors' comments are given in full in Annex A.

Number of People with CFS/ME in Oxfordshire

1. We first asked: *How many patients with CFS/ME do you have on your list?*

The total number of patients identified by the 136 responding doctors was 484. We were very cautious in recording and interpreting this information. (Full details of frequencies are shown in the results for each PCT, obtainable from OMEGA.) In any ambiguity we took the lower number given. Based on the figures given by these GPs we have estimated the total number of patients in the five Oxon PCTs to be 1270. See Notes b. and c. to Table. The Oxon PCTs include a population of 675,000, so we estimate a prevalence of at least 1.88 patients per 1000 population. The CMO Report gives a prevalence of 4 per 1000.

Satisfaction with current services

2. The second question we asked in the initial survey in Oxford City PCT was: *Are you satisfied with services provided locally for CFS/ME patients to whom you can refer them?*

Many doctors in the initial survey wrote that they did not know about any such services, so when we surveyed the other PCTs in Oxon, we asked:

2a. *Do you know where to refer them locally?*

2b. As a supplement we asked: *Are you satisfied with services provided locally for CFS/ME?*

Thirty-two of the responding doctors (24%) said they did not know where to refer patients locally. Of those who did know where to refer patients 42 (31% of the total) were not satisfied with the service. So more than half of the GPs in Oxfordshire (54%) were either not satisfied or did not know of existing services. Many doctors knew of no clear system for referral and treatment for patients with ME/CFS. (This was confirmed by the doctors attending the Oxford City PCT/OMEGA Training Session in September 2001.)

2c. And then we asked: *If no, why not?*

All responses are set out in full in the Annex. Many refer to waiting times, or to lack of support and treatment. Some acknowledge the usefulness of diagnosis, although one says *'some specialist help with diagnoses would be nice'*. Several comment *'poor support and follow up'* or *'never seems to help'* or *'often does not meet the needs of the patients'*. One acknowledges a *'very complex chronic condition, which typically is under-resourced in NHS.'*

Referrals outside Oxfordshire

3. The third question we asked was: *Have you referred patients to specialists outside Oxfordshire Health Authority?*

Then we asked: *If so please state where.*

Twenty five doctors (18%) said they had referred patients outside the area. (Full details of these referrals are in the Annex). Some are to private treatment but the funding currently spent on NHS referrals could be used to support better services locally.

Support for a primary care multidisciplinary clinic

4. We asked: *Would you be in favour of a primary care multidisciplinary clinic specialising in the diagnosis, treatment and management of patients with CFS/ME?*

Two thirds of the doctors (68%) surveyed were in favour of such a clinic. Some added comments like, *'Yes, very much so – patients need an early diagnosis and plan of action.'*

Conclusions

The survey showed that one quarter of the doctors in General Practice in Oxfordshire are unclear about the present system for the referral and treatment of CFS/ME patients. More than half of the doctors surveyed either did not know about or were dissatisfied with the services provided. The majority were in favour of establishing a primary care multidisciplinary specialist clinic to treat patients with CFS/ME.

References:

1. CFS/ME: Towards more Equitable Treatment in Oxfordshire, OMEGA (Oxfordshire M.E. Group for Action) June 2001
2. *Second Survey of ME/CFS Patients in Oxfordshire.* OMEGA November 2002
3. *The Chief Medical Officer's Working Group Report on CFS/ME. January 2002.* Dept of Health. London.
4. *Survey of General Practitioners in Oxford City Primary Care Trust.* OMEGA December 2001
5. *GP Attitudes about Services for Chronic Fatigue Syndrome/ME in Gloucestershire,* Westcare July 1999

PCT:	Oxford City	Cherwell Vale	NE Oxon	SW Oxon	SE Oxon	County Total or Average
Number of practices [a]	30	16	10	22	10	88 Practices
Practices replying to Survey (response rate; practices)	14 (47%)	15 (94%)	5 (50%)	16 (73%)	8 (80%)	58 practices out of 88 (66%)
Number of GPs in PCT [a]	129	65	42	125	52	413 GPs
GPs replying to Survey (response rate; GPs)	33 (20%)	30 (46%)	12 (29%)	41 (32%)	20 (38%)	136 replies from 413 GPs (33%)
Number of CFS/ME patients reported [b]	110	133	31	168	42	Total patients reported is 484
Average no. of patients with CFS/ME per GP	2.4	3.8	2.6	3.9	2.2	Average of 3.1 patients per GP
Estimated total no. of CFS/ME patients [c]	311	247	109	488	114	1270 patients in whole County
Population in PCT (all ages) [d]	195,000	128,000	74,000	197,000	81,000	675,000 population for whole County
Patients with CFS/ME per 1000 population	1.6	1.9	1.5	2.5	1.4	average of 1.88 patients per 1000
GPs unaware of local services	3	7	5	11	6	32 out of 165 GPs replying (24%)
GPs who are aware of, but not satisfied with dedicated services in Oxfordshire	12	7	2	14	7	42 out of 136 GPs replying (31%)
GPs who referred patients outside Oxfordshire	5	7	0	9	4	25 out of 136 GPs replying (18%)
GPs in favour of primary care multidisciplinary clinic	21 (64%)	18 (60%)	11 (92%)	30 (73%)	13 (68%)	93 out of 136 GPs replying (68%)

Notes to Table

[a] Details of the names of practices and numbers of GPs have been taken from the web-sites of individual PCTs or from "Local services search" at www.nhs.uk.

[b] This is the number of patients identified by replying GPs; a few gave the number for the whole practice. Knowing the number of GPs in each practice allows us to estimate the average number of patients per GP, given in the next row of the Table.

[c] This is calculated by multiplying the average number of patients per GP by the total number of GPs in the PCT.

[d] Population numbers are total GP list sizes as at 1 October 2001, given in the "Vital statistics" document issued by each PCT.

Annex A - Summary of Comments from GPs

1) Answered NO to the question: *Do you know where CFS/ME patients may be referred locally for treatment?*

"I'm never quite sure who to refer them to"
 "not aware of specific services for CFS"
 "not aware of any dedicated services for this"
 "not aware of them"
 "not aware of any services"
 "not aware of any"
 "what would clinic service provide?"
 "little support"
 "Oxfordshire has no service as far as I am aware (no holistic approach), fragmented"
 "not really as don't know where to refer patients .."
 "unaware of services I'm afraid"
 "no service"
 "burden on GP"
 "who do we send to?"
 "don't know of any services"
 "not aware of them"
 "unaware of where and who is available, NHS (if anyone)"
 "unsure where to send people and evidence it works"
 "who has an interest?"
 "if there is someone to refer to they have not made their presence known"

2) Answered YES to above question, and YES or NO to the question: *Are you satisfied with the services provided for CFS/ME patients?*

Positive comments:

"on a level with other NHS, good in parts, deficient in others"
 "Yes, patients who had cognitive behavioural therapy found it helpful in most cases"
 "Yes, but can be patchy"
 "good for diagnosis and initial advice, but little ongoing help & support. Also, quite long wait to be seen"
 "fairly satisfied, but resources are very limited so ongoing support & treatment limited"

Negative comments:

"No, waiting lists too long"
 "No, there isn't a coordinated approach to treating these patients who tend to remain off work/ill for long periods"

"No, lack of access to CBT (cognitive behavioural therapy), general collusion with dysfunctional behaviour"
 "need for more counselling services"
 "very few (consultants or specialists) take referrals. After assessment they send them back without any clear or helpful plan for ongoing support or treatment"
 "extremely long wait and not very helpful - patients have become entrenched in symptoms by the time of seeing"
 "disjointed, but care is expensive"
 "diagnosis, but then little in the way of treatment"
 "assessment is diagnostic and treatment not really offered - comes back to Primary Care for support"
 "no long term support"
 "poor support and follow up"
 "too long a wait for psychological intervention"
 "shorter waiting times preferred"
 "not sufficient psychological support, help with social services, etc."
 "very complex chronic condition which typically is under-resourced in NHS"
 "tertiary referrals are too long or non-existent; no support service either in hospital or in the community"
 "often does not meet the needs of the patients"
 "CBT not really available"
 "never seems to help"
 "we need a specialist service"
 "would like a referral with more psycho/cognitive treatments"
 "insufficient, excess waiting"
 "more psychology input and a specific graded exercise programme needed"
 "long waits – completely unsatisfactory for CBT, and NO graded exercise programme available"
 "no specialist interest team & very long wait to access psychology - may be better now we are switching to Oxon Mental Health team"
 "no GP access to psychology/psychiatry"
 "would like to have CBT available from someone who understands CFS. Some specialist help with diagnoses would be nice"
 "inadequate, delays"
 "uncoordinated"

3) Answered the question *Have you referred patients to specialists outside Oxfordshire Health Authority, YES or NO, and If so please state where.*

"Yes, to homeopathic physician"
 "Yes, no funding available"
 "Yes, Dr Shepherd"
 "Yes, London and Cheshire"
 "Yes, ECR, St. John's Wood - did not help"
 "Yes, once - cannot recall"
 "Yes, Northhamptonshire CMHT"
 "Yes, St Mary's, London"
 "Yes, Bath"
 "Yes, at patient's request"
 "Yes, informally to Dove Clinic, Twyford"
 "Yes, Royal Free"
 "Yes, London, homeopathy"
 "Yes, ME Centre, Romford"
 "Yes, London"
 "Yes, but patients generally find their own way, private on the whole; sometimes refer to London (Charing Cross)"
 "Yes, can't remember"
 "Yes, as CMO for Lloyds TSB, multiple centres"
 "Yes, private referral to Benenden Hospital, Cranbrook, Kent"
 "Yes, private homeopathy"
 "Yes, medical herbalist"
 "No, but have patients who attend private London clinics"

"Yes, Reading, Windsor"
"Yes, privately to Manchester"
"Yes, Mandsley"
"Yes, Reading"
"No, the PCT will not support outside area NHS referrals"

4) Comments on the question *Would you be in favour of a primary care multidisciplinary clinic specialising in the diagnosis, treatment and management of patients with CFS/ME?*

"no need"
"Yes, only if good access and evidence-based"
"Yes, would be helpful. I imagine however the PCT would say there is not enough evidence for it to be cost effective"
"Yes, very much so - patients need an early diagnosis and plan of action"
"Yes, if financial priorities allow"
"No, an extension of the clinic in Oxford"
"Possibly, with experience of only one patient I can't comment"
"Probably, if secondary or tertiary care, e.g. dietician, exercise physiologist, psychologist ..."

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