

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

SUMMARY of findings

FINAL version

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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.



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.

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. 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 views on

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>

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.

This report

This report is the summary of the key findings and recommendations.

There is a full report that includes the detailed analysis, the marked up questionnaire, text of correspondence with Practice Managers and the report on OMEGA’s previous survey.

Please get in touch if you would like a copy of the full report or 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 Chronic Fatigue Syndrome: a survey of GPs' attitudes and knowledge, Bowen et al
www.ncbi.nlm.nih.gov/pubmed/15805128

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.