Great Yarmouth and Waveney Joint Health Scrutiny Committee

Date:	**Tuesday 4 April 2017**
Time:	**10.30 am**
Venue:	**Supper Room, Town Hall** **Great Yarmouth Borough Council** **Hall Plain** **Great Yarmouth, Norfolk, NR30 2QF**

Persons attending the meeting are requested to turn off mobile phones. A car parking pass for use by Members and Officers attending the meeting is enclosed with the agenda.

Under the Council's protocol on the use of media equipment at meetings held in public, this meeting may be filmed, recorded or photographed. Anyone who wishes to do so must inform the Chairman and ensure that it is done in a manner clearly visible to anyone present. The wishes of any individual not to be recorded or filmed must be appropriately respected.

Membership –

MEMBER	**AUTHORITY**
Margaret Stone	Norfolk County Council
Alison Cackett	Waveney District Council
Michael Carttiss	Norfolk County Council
Michael Ladd	Suffolk County Council
Bert Poole	Suffolk County Council
Shirley Weymouth	Great Yarmouth Borough Council

For further details and general enquiries about this Agenda please contact the Committee Administrator:
Tim Shaw on 01603 222948
or email timothy.shaw@norfolk.gov.uk

1. Apologies for Absence and Substitutions

To note and record any apologies for absence or substitutions received.

2. Minutes (Page 5)

To confirm the minutes of the meeting of the Great Yarmouth and Waveney Joint Health Scrutiny Committee held on 20 January 2017.

3. Public Participation Session

A member of the public who is resident, or is on the Register of Electors for Norfolk or Suffolk, may speak for up to 5 minutes on a matter relating to the following agenda.

A speaker will need to give written notice of their wish to speak at the meeting by contacting Tim Shaw at the email address above by no later than 12.00noon on 29 March 2017.

Contributions from the public will be taken in the order that they were received, unless the Chairman considers there is a more appropriate place on the Agenda for them to be taken.

The public participation session will not exceed 20 minutes to enable the Joint Committee to consider its other business.

This does not preclude a member of the public from indicating a wish to speak during the meeting and the Chairman will have discretion to decide how the Committee will respond to any such request.

4. Members to Declare any Interests

If you have a Disclosable Pecuniary Interest in a matter to be considered at the meeting and that interest is on your Register of Interests you must not speak or vote on the matter.

If you have a Disclosable Pecuniary Interest in a matter to be considered at the meeting and that interest is not on your Register of Interests you must declare that interest at the meeting and not speak or vote on the matter.

In either case you may remain in the room where the meeting is taking place. If you consider that it would be inappropriate in the circumstances to remain in the room, you may leave the room while the matter is dealt with.

If you do not have a Disclosable Pecuniary Interest you may nevertheless have an Other Interest in a matter to be discussed if it affects

- your well being or financial position

- that of your family or close friends
- that of a club or society in which you have a management role
- that of another public body of which you are a member to a greater extent than others in your ward.

If that is the case then you must declare an interest but can speak and vote on the matter.

5.	**Learning disability services**	(Page 13)
	Progress with implementation of the Transforming Care Programme for people with learning disabilities and / or autism.	
6.	**Out of hospital teams**	(Page 17)
	Progress with development of out of hospital teams and towards provision of service for the Halesworth area.	
7.	**ME / CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome)**	(Page 25)
	Report on commissioning decisions.	
	Appendix 1 – Timeline and brief summaries of previous reports and information bulletins to the Joint Committee	(Page 29)
	Appendix 2 – CCGs' report	(Page 35)
	Appendix 3 – East coast Community Healthcare information	(Page 110)
	Appendix 4 – Norfolk and Suffolk ME & CFS Patient Carer Group information	(Page 147)
8.	**Information Bulletin**	(Page 162)
	To note the written information provided for the Committee	
	(a) Update on developments in primary care:- 1. Development of the Shrublands centre 2. GP services for the Woods Meadow development, Sands Lane, Oulton	(Page 163)
	(b) Delayed Transfers of Care – update on the outcomes of the learning event held on 11 January 2017	(Page 164)
	(c) Stroke information, advice and support service – Stroke Association	(Page 165)
	(d) Norfolk and Waveney STP – response to Norfolk Health Overview and Scrutiny Committee's comments	(Page 166)

9. Forward Work Programme

To consider and agree the forward work programme and dates and times of future meetings. (Page 171)

10. Urgent Business

To consider any other items of business which the Chairman considers should be considered by reason of special circumstances (to be specified in the minutes) as a matter of urgency.

Glossary of Terms and Abbreviations (Page 173)

Chris Walton
Head of Democratic Services
Norfolk County Council
County Hall
Martineau Lane
Norwich
NR1 2DH

Deborah Cadman OBE
Chief Executive
Suffolk County Council
Endeavour House
8 Russell Road
Ipswich IP1 2BX

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GREAT YARMOUTH AND WAVENEY JOINT HEALTH SCRUTINY COMMITTEE
MINUTES OF THE MEETING HELD ON 20 January 2017

Present:

Alison Cackett	Waveney District Council
Michael Ladd (Vice-Chairman and Chairman for the meeting)	Suffolk County Council
Dr Nigel Legg (Substitute)	South Norfolk District Council
Bert Poole	Suffolk County Council
Shirley Weymouth	Great Yarmouth Borough Council

Also Present:

Cath Byford	Deputy Chief Executive, NHS Great Yarmouth & Waveney CCG
Lorraine Rollo	NHS GY&W CCG
Gill Morshead	Locality Manager, Norfolk and Suffolk NHS Foundation
Alex Stewart	Chief Executive, Healthwatch Norfolk
Barbara Robinson	Member of the public (spoke on ME / CFS (Item 7(e) Information Bulletin).
Cllr Sonia Barker	Suffolk County Councillor and Waveney District Councillor
Cllr Jane Murray	Waveney District Councillor
Maureen Orr	Democratic Support and Scrutiny Team Manager, Norfolk County Council
Tim Shaw	Committee Officer, Norfolk County Council

1A The Late Mr Colin Aldred

The Chairman said that he was sad to have to report on the funeral arrangements for Mr Colin Aldred who had recently passed away. Mr Aldred had served as a Member of the Joint Committee from July 2014.

1B Apologies for Absence and Substitution

An apology for absence was received from Graham Wilde, Acting Chief Operating Officer, James Paget University Hospital NHS Foundation Trust, who due to unforeseen circumstances was unable to attend the meeting to answer questions about the services to replace Greyfriars GP practice and walk-in centre.

Dr Nigel Legg substituted for Michael Carttiss.

In the absence of Michael Carttiss, who had given his apologies, Michael Ladd, the Vice-Chairman, took the chair for the meeting.

Michael Ladd in the Chair

1C Recording of the meeting

It was pointed out that a member of the public would be taking a sound and /or picture recording on a mobile phone of part of today's proceedings. This met with Norfolk County Council's protocol on the use of media equipment at meetings held in public.

2 Minutes

The minutes of the previous meeting held on 7 October 2016 were confirmed as a correct record and signed by the Chairman.

3 Public Participation Session (Myalgic Encephomyelitis / Chronic Fatigue Syndrome)

3.1 With the permission of the Chairman, Mrs Barbara Robinson, a member of the public, spoke about ME / CFS which was Item 7(e) on the Information Bulletin. Mrs Robinson said that ME/CFS was commissioned by the 7 CCGs in Norfolk and Suffolk and provided by East Coast Community Health (ECCH). She said that in 2009 the then 3 PCT's had accepted that the change to the service from 'consultant led' to 'therapy led' that had taken place in 2005 had resulted in significant inequalities of care. The NHS had accepted the recommendations of this Joint Committee in 2009 to develop the service to address these inequalities of care. The consultant led review carried out in autumn 2016 had accepted that there were significant inequalities of care, especially for the severely affected. Mrs Robinson estimated that there were 8,000 potential patients who would benefit from a consultant led service.

3.2 Mrs Robinson said that following the completion of the consultant led review an opportunity had occurred to deliver a cost neutral, consultant led service. However, HealthEast, as one of the commissioners of the service, was now reluctant to agree to the change but had given no reasons for its decision. The consultant who had expressed an interest in leading the service had waited for over 14 months to receive an answer and could not be expected to wait much longer. Without the clinical leadership that the consultant was able to provide it would not be possible to implement the proposed changes in the service. Mrs Robinson said she wanted to know if HealthEast, had undertaken an equality impact assessment before a decision not to proceed with a consultant led service was reached. Mrs Robinson also spoke about why it was very important for ME/CFS to be considered as part of the work stream of the STP Board.

3.3 This subject was discussed further as part of the Forward Work Programme (see minute 8).

4 Declarations of Interest

There were no declarations of interest.

5 Services to replace Greyfriars GP practice and walk-in centre

5.1 The Joint Committee received a suggested approach from the Democratic Support and Scrutiny Team Manager at Norfolk County Council to an update report from NHS Great Yarmouth and Waveney CCG and the East of England Ambulance Service NHS Trust on the impact of the closure of the Greyfriars GP practice and walk-in Centre and the progress of replacement services.

5.2 The Committee received evidence from Cath Byford**,** Deputy Chief Executive, NHS Great Yarmouth & Waveney CCG.

5.3 In the course of discussion the following key points were noted:

- The latest data (included in graphs 1 and 2 of the report) showed the closure of the walk-in centre to have had no significant impact on the East of England Ambulance Service NHS Trust.
- The data showed the closure of the walk-in centre to have also had no detrimental impact on A&E services at the JPUH.
- The data covered GYW patients only. It was not intended to be used for comparative purposes with data on A&E attendances at the JPUH for patients from outside as well as inside the GY&W area.
- The walk-in centre had closed at the end of the summer holiday season. This meant that the latest data for the period that immediately followed the closure did not cover a time of year when there were high numbers of tourists in the town.
- Cath Byford said that the managed patient dispersal process that followed the closure of the walk –in centre had led to a coordinated and smooth transfer of patients to GP practices elsewhere in the GY&W area and to an improved service.
- Additional GP capacity had been provided at the GP practices to which patients had been dispersed following the closure of the walk –in centre.
- The new arrangements meant that patients attending A&E at the JPUH were clinically triaged on arrival and could be streamed to out of hours primary care.
- Streaming had a positive impact on A&E by diverting patients with a primary care need to an out of hours GP, thereby reducing A&E attendances.
- By reducing the number of patients requiring A&E support, streaming had created additional A&E capacity, and helped to ensure patients were seen and treated by the most appropriate clinician.
- The A&E Delivery Board at the JPUH was due to re-examine its arrangements for streaming of patients so as to include weekend evenings and Monday evenings and provide for seasonal variations. Further details about the streaming arrangements could be made available to members at a future meeting.
- The Joint Committee noted that a review was planned into the current homeless service and also the future requirements of homeless patients

throughout the GY&W area to ensure an equitable service. Cath Byford said that she would provide Members of the Committee with the timeframe for when this review would be completed.

- The Joint Committee was informed that the vulnerable children safeguarding issues that were formerly handled by a specialist nurse at the walk-in centre were now handled by the GP practices to which patients had been transferred. A named GP was in place to support the practices in relation to safeguarding issues and making referrals to Children's Services.

5.4 **The Joint Committee agreed to:**

(a) Receive an update on the effects of the Greyfriars walk-in centre closure on JPUH A&E after the summer period (i.e. at the October 2017 meeting). The data to include analysis of visitor attendance at A&E as well as resident attendance. (*See Forward Work Programme below for further details).*

(b) Receive details of the timeframe for provision of a new service for homeless people in Great Yarmouth & Waveney.

6 Norfolk and Suffolk NHS Foundation Trust – update on mental health services in Great Yarmouth and Waveney

6.1 The Joint Committee received a suggested approach from the Scrutiny Officer at Norfolk County Council to a report from the Norfolk and Suffolk NHS Foundation Trust (NSFT) on the outcomes and impacts for mental health services in Great Yarmouth and Waveney arising from the latest Care Quality Commission inspection of the NSFT.

6.2 The Committee received evidence from Gill Morshead, Locality Manager, Norfolk and Suffolk NHS Foundation Trust who spoke about the local action that was being taken in respect of the Trust-wide action plan. The Committee also heard from Cllr Sonia Baker, a Suffolk County Councillor and Waveney District Councillor, who spoke about the Dragonfly Unit at Carlton Court, Lowestoft that was within her division.

6.3 In the course of discussion the following key points were noted:

- Gill Morshead explained the action that the NSFT was taking in response to the latest CQC's inspection report, specifically as it affected the Great Yarmouth and Waveney locality.
- It was noted that the Care Quality Commission (CQC) currently rated the NSFT as 'requires improvement' overall as NHS Improvement had taken the Trust out of special measures.
- The NSFT was still rated 'inadequate' for safety. The safety concerns included: unsafe environments that did not promote the dignity of patients; insufficient staffing levels to safely meet patients' needs; inadequate arrangements for medication management; concerns regarding seclusion and restraint practice.
- It was noted that so far as the Great Yarmouth and Waveney locality was concerned many of the outstanding issues on safety related to the property estate. A comprehensive work plan had been put in place to tackle these

issues.

- In reply to questions, Gill Morshead said that the issues in the CQC report related to service lines rather than specifically identified localities in most cases and that the safety issues had been addressed in all localities across NSFT, including the Great Yarmouth and Waveney area. A follow up inspection by the CQC was expected in summer 2017.In response to the CQC report, the NSFT had reorganised its governance processes and begun to use an updated action plan to inform performance monitoring at monthly meetings of the Board.
- The Board had raised their visibility through a programme of executive and non-executive visits to Nottinghamshire Mental Health Foundation Trust (who had supported the NSFT be acting as a "buddy trust") and by visiting a trust in East London that was considered to be outstanding.
- Managers were currently establishing the ability of staff to use the new computer system called Lorenzo. Clinical leads were being contacted to organise any additional or bespoke training that might be required on Lorenzo.
- Cllr Sonia Barker spoke about the12 in-patient beds at the Dragonfly Unit at Carlton Court in Lowestoft that had been created to replace the out –of-date Airey Close Unit at Lothingland Hospital. The Dragonfly Unit was the only unit of its kind providing mental health beds specifically for children in Norfolk and Suffolk. NHS England had commissioned 7 of the in-patient beds at Carlton Court but continued to provide for children to be placed out of area even when excellent facilities remained to be filled at the Dragonfly Unit.
- Further investment in the Dragonfly Unit would make a huge difference to young people and their families in Norfolk and Suffolk with complex mental health needs.

6.4 The Joint Committee agreed to:-

(a) Write to NHS England to welcome their commissioning of 7 in-patient beds for children at the Dragonfly Unit, Carlton Court, and to support the commissioning of five more beds so that the facility was used to full capacity.
(b) Encourage co-working between NSFT and the new school for pupils with social, emotional and mental health needs at Carlton Colville, which was sponsored by Catch 22. Gill Morshead to put Cllr Sonia Barker in touch with Rob Mack, Compass schools service manager at NSFT.
(c) Arrange a Member visit to the Dragonfly Unit within the next 2 to 3 months.

7 Information Only Items

7.1 The Joint Committee **noted** information on the following subjects:

(a) **Autism services** – the situation with regard to the Autism Suffolk Family Support Worker service when the current contract (with Suffolk County Council) ended in March 2017. The CCG was unable to invest in the Autism Suffolk service and had set out action it had taken to address the likely impact on families when the Autism Suffolk service ended.

(b) **Diabetes care within primary care services** – Directors of Public Health responses to the Joint Committee's recommendation of 7 October 2016.

(c) **Out-of-hospital teams** – update regarding staffing levels and the situation in respect of Halesworth. Recruitment of physiotherapists continued to be difficult. A further update was required at the next meeting.

(d) **Delayed transfers of care** – the James Paget Hospital escalated to OPEL 4 in early January (i.e. no capacity) but was able to de-escalate quickly. The overall impression was that the planning had paid off.

(e) **ME / CFS (Myalgic Encephomyelitis / Chronic Fatigue Syndrome)** – an update on service commissioning. Also see Public Participation Session minute above for the comments made by Barbara Robinson, a member of the public.

In response to the comments that had been made in the public participation session, Cath Byford said that the CCG was unable to accept the findings of the outcome of the review because of a conflict of interest. The consultant who had led the review and the consultant whom was expected to lead the proposed new service were the same person. The review should also not be implemented because it was too limited in its scope. The review had not considered the redundancy costs and other transitional costs that would be associated with setting up a new ME/CFS service with the same high degree of resilience as the existing service. The review did not accurately reflect the concerns of existing patients and patient groups. The CCG had not undertaken an equality impact service because it had not at any time accepted the outcome of the review and it had not proposed the service outlined in the review.. The outcome of the review would be fully considered by the CCG's Clinical Executive Committee but there was currently no firm date for when this would take place. The position of the other CCGs had also not been made fully clear at this time.

(f) **Development of Shrublands centre** – aiming to submit for planning permission in spring 2017. An update would be available in the next Information Bulletin.

(g) **Norfolk and Waveney Sustainability Transformation Plan** – NHOSC met on 12 January (after agenda papers for today's meeting were published) and made some revisions to the comments before agreeing them by majority vote. The final version, as approved by NHOSC, was circulated to all Members of GY&W JHSC on 16 January 2017.

(h) **Most Capable Provider** procurement process – this subject was originally on today's agenda. The bulletin explains that the CCG did not take it forward and that the Sustainability Transformation Plan is now the vehicle for achieving greater integration of services.

(i) Briefings received from the CCG since October 2016

(1) Final two **Lowestoft hospital** services move on 5 December 2016
(2) **Westwood surgery** move

These briefings went out to Members of the Joint Committee when received in November 2016.

8 Forward Work Programme

8.1 The Joint Committee agreed the forward work programme, subject to the addition of the following items:

The Joint Committee meeting on Tuesday 4 April 2017

Agenda
- ME/CFS - to examine commissioning decisions.
- Out of Hospital Teams – progress of the teams and progress towards provision for the Halesworth area.

In the information bulletin
- Update on development of the Shrublands centre and on GP services for the Woods Meadow development, Sands Lane, Oulton.
- Update on the outcomes of the Delayed Transfer of Care learning event held on 11 January 2017
-

The Joint Committee meeting on Friday 14 July 2017
Venue to be confirmed

No additional items added

The Joint Committee meeting in October 2017

Agenda
- A&E performance at JPUH – to examine
  - the overall trend of A&E performance
  - an analysis of the effects of the Greyfriars walk-in centre closure on JPUH A&E after the summer

9 Urgent Business

9.1 There were no items of urgent business.

10 Date and Time of Next Scheduled Meeting

10.1 **It was agreed that the Joint Committee would next meet on Tuesday 4th April 2017 at 10.30am, in the Council Chamber, Great Yarmouth Town Hall.**

The meeting concluded at 13.05 pm.

CHAIRMAN

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Great Yarmouth & Waveney Joint Health Scrutiny Committee
4 April 2017
Item no 5

Learning disabilities services

Suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager

A report on progress with the implementation of the Transforming Care Programme for people with learning disabilities and / or autism in Great Yarmouth and Waveney.

1. Background

1.1 On 22 January 2016 Great Yarmouth and Waveney Joint Health Scrutiny Committee decided to add Learning Disabilies Services to its forward work programme. The CCG was and is in the process of implementing the national Transforming Care Programme for people with learning disabilities and autism, which evolved following publication of the Winterbourne View report in December 2012.

2. Purpose of today's meeting

2.1 Great Yarmouth and Waveney CCG has been invited to update the Joint Committee on progress with the Transforming Care Programme as it affects people with learning disabilities and /or autism in the Great Yarmouth and Waveney area.

The CCG's report is attached at **Appendix A** and representatives will attend to answer Members' questions.

3. Suggested approach

3.1 After the CCG representatives have presented their report, Members may wish to focus on the following areas:-

(a) How are patients and carers involved in the planning for a move from hospital to community based support?

(b) Are there enough local community placements to manage people with challenging behaviours? If not, what can be done to address the situation?

(c) Does the Programme have the necessary resources to deliver the changes expected?

(d) Is the CCG assured that there is adequate local access to inpatient assessment and treatment for patients who need them now and in the future?

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NHS
Great Yarmouth
and Waveney
Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: Transforming Care Programme

In May 2011 the BBC Panorama programme highlighted serious abuse at Winterbourne View Hospital for people with learning disabilities. Subsequent criminal investigations saw members of staff prosecuted and six received prison sentences.

This led to the Department of Health review and publication of their final report entitled **"Transforming Care: A national response to Winterbourne View Hospital"** in December 2012. This provided recommendations to health and local authority commissioners to work together to transform care and support for people with a learning disability and/or autism – who also have a mental health condition or behaviours viewed as challenging.

Some of the key actions were:

1) Review of all people in hospital placements by 1 June 2013
2) Of those who are inappropriately placed in hospital they will be moved to community based support no later than 1 June 2014
3) By April 2014 there will be joint plans in place for each area between health and social care.

October 2015 saw the publication of: **Building the Right Support – a national plan to develop community services and close inpatient facilities** (NHS England, LGA, ADASS, 2015). The expectation being that the Transforming Care Partnerships would develop plans that would see the delivery of the above over a three year period between 2016/2019.

The CCG is a partner in the Norfolk and Waveney Transforming Care Partnership with the remaining four Norfolk CCG's. This was formed in December 2015 the Transforming Care Plan was developed.

The plan describes how the transformation of learning disability services locally in Norfolk and Waveney will be implemented and it also demonstrates the implementation of the national service model including alignment to the Transforming Care principles and expectations starting with the national planning assumptions set out in **Building the Right Support.** These planning assumptions are that no area ould need more inpatient capacity than is necessary at any one time to cater to[1]:

- 10-15 inpatients in CCG-commissioned beds (such as those in assessment and treatment units) per million population
- 20-25 inpatients in NHS England-commissioned beds (such as those in low-, medium- or high-secure units) per million population

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[1] The rates per population will be based on GP registered population aged 18 and over as at 2014/15

The planning assumptions described what local commissioners need to use as we enter into a detailed process of planning. Local planning needs are both challenging and creative but are intentionally ambitious based on a strong local understanding of the needs and aspirations of people with a learning disability and/or autism, their families and carers, and on expert advice from clinicians, providers and others. In Norfolk and Waveney we are working towards a model of care that uses fewer inpatient beds both in NHS settings and those in the private care sector. We will go further still to support people in out of hospital settings above and beyond these initial planning assumptions.

There is a Transforming Care Implementation Steering Group which meets monthly to monitor and review the work plan which has been developed out of the Transforming Care Plan. Under this lies a series of work streams to ensure that the actions are delivered.

NHS England has a robust process in place with regards to how the decision is made as to whether or not an individual requires a placement in an inpatient service. And for those who require inpatient services the monitoring and review continues during their period of admission.

There is reporting required by each CCG on a weekly and monthly basis. NHS England require a narrative template on each individual who forms part of the Transforming Care cohort (that is are in an inpatient bed) and their progress and plans for discharge. And NHS Improvement (previously the HSCIC) require submissions to a national data base to be added or amended on a monthly basis.

The current patient figures for NHS GYW CCG are:

CCG funded patients:
Three adults in assessment and treatment services
Three adults in private hospital

NHS England Specialised Commissioning funded patients:
Three adults in medium secure services
One adult in low secure service
One child in CAMHS LD low secure service

All of the 11 above are detained under a Section of the Mental Health Act

The CCG has also been involved with Norfolk and Suffolk Foundation Trust to redesign the Children’s and Adults Learning Disabilities service in Waveney. Over the last 18 months inpatient beds have been decommissioned at both 6 and 7 Airey Close, access to an assessment and treatment bed at Walker Close, Ipswich has also been decommissioned but extra assessment and treatment capacity funded at Astley Court on the Little Plumstead Hospital site so that individuals from Great Yarmouth and Waveney have equitable access to this service when required. Additional staff have moved into the Waveney Community Learning Disabilities teams and there is an expectation that they will provide an intensive support function to help prevent admissions and also support discharge.

Kim Arber
Head of Mental Health and Learning Disabilities

Great Yarmouth & Waveney Joint Health Scrutiny Committee
4 April 2017
Item no 6

Out of Hospital Teams

Suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager

A report on the progress of Out-of-Hospital services in Great Yarmouth and Waveney.

1. Background

1.1 On 7 October 2016 Great Yarmouth and Waveney Joint Health Scrutiny Committee (GY&W JHSC) received an update on the progress of Out-of-Hospital Teams (OHTs), which were an important part of the new service model introduced following the ‘Shape of the System’ consultation in 2015.

1.2 At that stage OHTs were established in Lowestoft and the North of the CCG area and a Community Integrated Care Team (CICT) was established in Southwold and Reydon. Discussions were continuing regarding the development and implementation of out of hospital services across the remaining areas of Great Yarmouth and Waveney including Beccles, Bungay, Kessingland and Halesworth. The CCG had given a commitment not to close Patrick Stead Hospital, Halesworth, until suitable alternative provision was available but the hospital had to close temporarily in September 2016 due to staff shortages.

1.4 The Joint Committee agreed to write to GY&W CCG to fully support the provision of an OHT for the Beccles, Bungay, Kessingland and Halesworth areas.

1.5 In January 2017 the Joint Committee received an information bulletin from the CCG which said that it was currently working with members of the Halesworth community to establish future provision of out of hospital services to the Halesworth population and planning for the build of the Castle Meadows facility.

2. Purpose of today’s meeting

2.1 The CCG has been asked to provide the Joint Committee with an update on the progress of the OHTs, including progress towards provision for the Halesworth area, including details of:-

- current vacancy rates
- patient feedback about the services
- key performance indicators (KPIs)
- effect on emergency admissions

- further development of the teams in all areas.

2.2 The CCG’s report is attached at **Appendix A** and representatives have been invited to answer Members’ questions.

3. Suggested approach

3.1 After the CCG representatives have presented their report, Members may wish to discuss the performance of the Out of Hospital services to date and the plans for implementation across the whole Great Yarmouth and Waveney area.

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NHS
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Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: Update on the Out of Hospital Teams

Description of the Services

The Out of Hospital Team (OHT) is an inter-disciplinary team of health and social care professionals. The objective of the service is to provide care at home whenever it is safe, sensible and affordable to do so. The care the team provides is organised around the patient, focusing on individual need and empowering independence. The team, in the main, provides intensive, short term care, which reduces as the patient regains health and independence. Care is holistic, co-ordinated and responsive and goal focused, using a case management approach.

The shared values and aims underpinning care delivered by the team include:

- Patient centred care; staff involve patients and their family and, or carers in the care planning approach
- Staff are sensitive to the needs of family and carers
- Care is provided in patients' usual places of residence or Beds with Care
- The team is easily accessible to patients and their families and, or carers
- The team focuses on proactive delivery of care and where a patient is in crisis reacts rapidly to keep that patient safe in their usual place of residence if it is safe and sensible to do so.

There is currently a Lowestoft OHT and North OHT provided by East Coast Community Healthcare, and a Community Integrated Care Team (CICT) in Southwold and Reydon provided by Sole Bay Health. The model in Southwold and Reydon is a locally designed model to support the needs of this population. This is in line with the CCG commitment, through the Shape of the System Public Consultation, to develop locally appropriate models of care with local stakeholders. The CICT is in the early stages and will continue to develop over the coming months.

Staffing

The OHTs are made up of key health and social care professionals supported by workers able to perform many types of basic nursing, therapeutic and personal care tasks. Teams incorporate the follow staff groups:

Senior Professionals

- Independent Nurse Prescribers
- Community Nurses
- Physiotherapists
- Occupational Therapists

- Social Workers
- Social Care Assessors

Support Staff:

- Assistant Practitioners
- Reablement Practitioners
- Generic Workers
- Home Care Workers
- Community Phlebotomists

In addition to the above the team has a combined triage team made up of both health and social care professionals including:

- Day Co-ordinators (Health)
- Duty Workers (Social)
- Allocation Co-ordinators
- Administrators

This team are responsible for:

- Receiving referrals
- Contacting various others for further information
- Triaging referrals
- Allocating assessments
- Imparting necessary information to the assessor
- Daily contact with acute and community bed providers to ascertain details of patients who will require supported discharge
- Daily contact with acute and community bed providers for updates on patients' expected dates of discharge and any changes to patients circumstances and, or care needs

The CICT consists of two part time nurses, one healthcare assistant, seven carers, a physio assistant and a support worker. GPs and the Community Matron work in partnership with the multi-disciplinary out of hospital team to ensure that where at all possible, frail and/or unstable patients are supported to stay well and independent at home.

Staffing Structures

The OHTs/CICT comprise of the following staff groups and whole time equivalents (WTE):

Lowestoft OHT Staff	Grade	WTE
Manager	7	1
Nurse	6	7
Physiotherapist	6	1.6
Occupational Therapist	6	2.8
Technical Instructor	5	1
Triage	4	3.8
Assistant Practitioner	4	6
Rehab Support Worker	4	16

North OHT Staff	Grade	WTE
Manager	7	1

Nurse	6	8.44
Physiotherapist	6	1
Social Workers	6	2.4
Occupational Therapist	7	0.8
Occupational Therapist	6	2
Pharmacy Technician	5	0.37
Triage	4	3.8
Assistant Practitioner	4	9.76
Rehab Support Worker	2	20.32

It should be noted that the above includes the Admission Prevention Service (APS) which provides support on an 8am to 8pm basis across the rest of Waveney currently. This team cannot be separated out in terms of staff as the Out of Hospital team works in a very integrated way to support both OHT and APS activity.

Sole Bay Health CICT
As described above the Sole Bay Health CICT two part time nurses, one healthcare assistant, seven carers, a physio assistant and a support worker. The carers, physio assistant and support worker are self-employed and work on an as and when basis to ensure resource can be flexed to meet demand. All members of the team are fully supervised and managed by Sole Bay Health and the appropriate screening is undertaken.

Vacancies

Below by team are the current vacancies (as of 14 March 2017) within each team:

Lowestoft OHT
1 x Band 2

North OHT
1 x Band 6 Nurse currently out to advert

Sole Bay Health CICT
There are no vacancies within the team.

Locations where services are based

The OHT in Lowestoft is based within Kirkley Mill Health Centre. The OHT North team are based within the Herbert Matthes Block on the Northgate Hospital site in Great Yarmouth.

The CICT is based at Sole Bay Health Centre.

Geographic areas served

The Lowestoft OHT will accept referrals for patients registered with a General Practitioner in Lowestoft.

The North OHT will accept referrals for patients registered with a General Practitioner within the Northern locality of NHS Great Yarmouth and Waveney CCG.

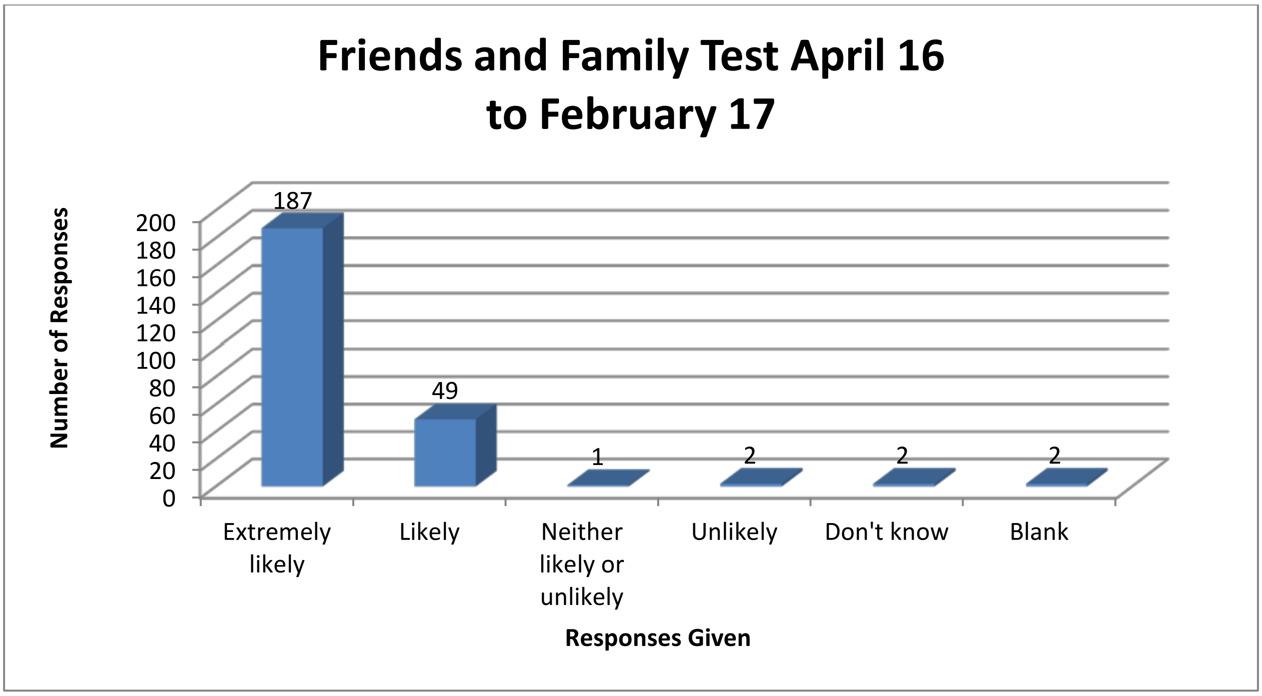
The CICT supports patients registered at Sole Bay Health Centre.

The OHTs/CICT supports patients aged 18 years and over.

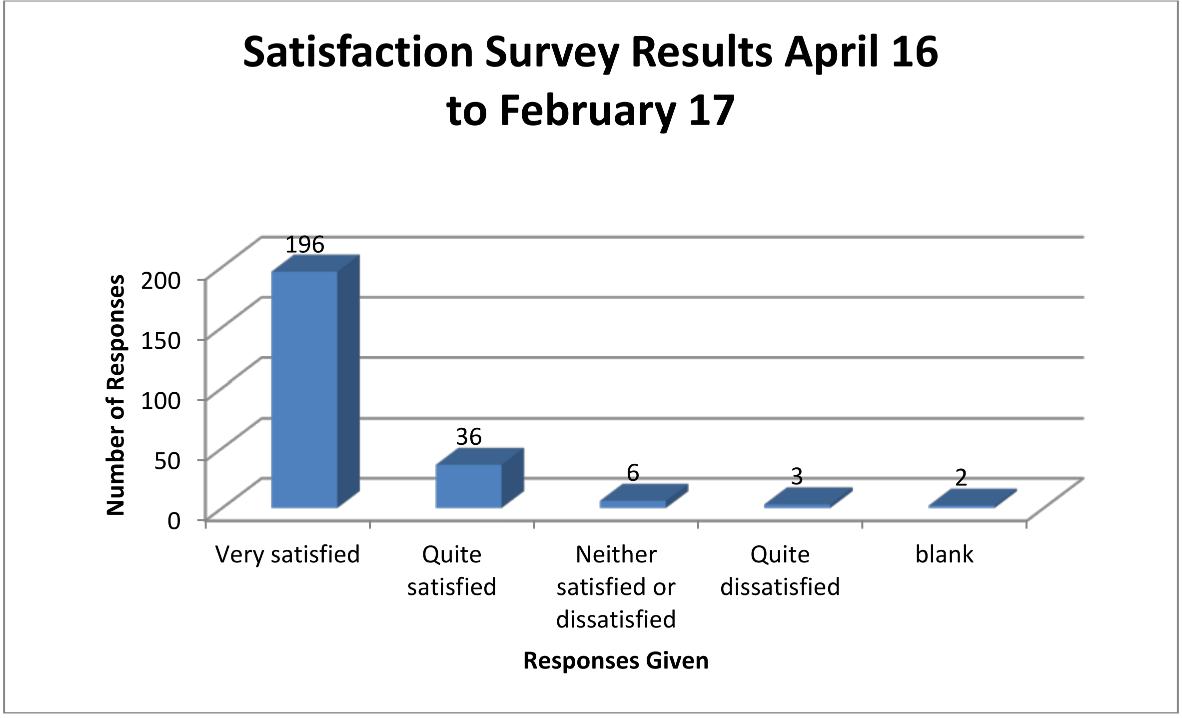
Patient Feedback

The OHTs in both Lowestoft and the North have received extremely positive patient feedback – see below.

The Friends and Family Test has been used since April 2015 and asks patients ‘How likely are you to recommend our services to your friends and family if they needed similar care or treatment?’



‘How satisfied are you with the service you have received?’ has also been routinely asked of patients seen by the service since April 2015.



Patient feedback received for the Sole Bay CICT has been extremely positive with 100% of patients and their families happy to complete the satisfaction questionnaire and comments being that the team provide an excellent service with it being highly likely to be recommended to others.

Key Performance Indicators (KPIs)

A number of KPIs are in place with providers to monitor effectiveness and compliance of out of hospital teams.

Below is the list of the main KPIs in place for the out of hospital services provided by ECCH and Sole Bay Health

1. % of Service Users referred urgently to the Out of Hospital Team assessed within two hours of referral – Threshold for compliance is 98%.

This KPI is a measure of the speed of response to a request for ‘urgent’ support. All providers are currently achieving 100% compliance.

2. % of Service Users referred non-urgently to the Out of Hospital Team assessed within one working day of referral - Threshold for compliance is 98%.

This KPI is a measure of the speed of response to a request for ‘non-urgent’ support. All providers are currently achieving 100% compliance.

3. % of all Service Users receiving a care package within 12 hours of Assessment - Threshold for compliance is 95% for the North and Lowestoft teams, and 98% for the Sole Bay team

This KPI is a measure of the speed a package of care is provided to an individual following assessment. All providers have achieved 100% compliance.

Effect on Emergency Admissions

When comparing data between calendar years for 2015 and 2016 the CCG has seen a 4.1% increase in emergency admissions for patients aged over 75 being admitted to the James Paget University Hospital for a medical speciality. This is for North and Lowestoft practices which have an out of hospital team. From 4071 patients in 2015, to 4236 in 2016.

This increase is in line with the national picture where there have been increases in A&E attendances and emergency admissions. It is also worth noting that during 2016 Beccles Hospital operated at a reduced capacity level for part of the year, and also inpatient activity at Patrick Hospital was temporarily suspended due to safe staffing levels.

As the Sole Bay CICT model has been implemented part way through the year comparable data is not yet available.

Developing out of hospital teams across the CCG Area

As described in the CCGs Shape of the System consultation, the CCG wants a community model provided across Great Yarmouth and Waveney which helps our more older people and people with long term health conditions to remain independent in their own homes and avoid going into hospital or ending up in long term care.

The CCG is currently planning a review of the different models in place in the North, Lowestoft and Southwold to inform future out of hospital services for the population of Great Yarmouh and Waveney. This will ensure the CCG understands demand for services including reasons for intervention, peak periods, any gaps in delivery and also the differing issues facing rural and urban areas.

Beccles Intermediate Care

As part of the Shape of the System consultation the CCG Governing Body agreed in November 2015 to change the use of the GP community hospital beds at Beccles Hospital to provide an intermediate care facility for the whole of Great Yarmouth and Waveney.

Since that decision a £1.65 million development has been completed on the Minsmere ward at Beccles Hospital to provide the Intermediate care facility. This work was completed by the developers in February 2017.

The facility is now open and includes 20 beds including the following:

- Eight single rooms with ensuite toilets and washing facilities
- Three four bed bay areas with separate toilet and washing facilities
- Piped oxygen to all beds
- Dedicated therapy area and resource room
- Space for four chair intravenous therapy area
- Patient lounge and dining area

Additional resource has been commissioned with ECCH to ensure that patients can receive intense rehabilitation and therapy to enable patients' function to be optimised and suitable for discharge. This includes both therapy, nursing and assistant practitioner roles. Additional social work capacity has also been commissioned to ensure that there are as few patients as possible that have delayed discharges and that patients will transition quickly and efficiently from the hospital back to the community.

Recruitment is currently taking place for the additional staff and the new model of care will be fully operational over the coming months.

Cath Byford
Director of Commissioning and Quality

Great Yarmouth & Waveney Joint Health Scrutiny Committee
4 April 2017
Item no 7

ME/CFS (Myalgic Encephalomyelitis / Chronic Fatigue Syndrome)

Suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager

A report on the commissioners' decision-making processes in respect of a proposed consultant-led ME/CFS service for Norfolk and Suffolk.

1. Background

1.1 Over the years since 2008 Great Yarmouth and Waveney Joint Health Scrutiny Committee (the Joint Committee) has received numerous reports and information bulletins about concerns in relation to ME/CFS services in Norfolk and Suffolk and plans for their redesign. A time-line and brief summaries of these reports and bulletins are attached at **Appendix 1**.

1.2 There has been significant reorganisation within the NHS since 2008. At the time of the first report to the Joint Committee the service was provided by NHS Great Yarmouth and Waveney Primary Care Trust's provider arm, Great Yarmouth and Waveney Community Health Services, which was the predecessor of the current provider, East Coast Community Healthcare (ECCH) community interest company. The service was commissioned separately by the three Primary Care Trusts (PCTs) in Norfolk and Suffolk:-

NHS Norfolk PCT
NHS Suffolk PCT
NHS Great Yarmouth and Waveney PCT (GY&W PCT).

The three PCTs were ultimately replaced by the seven Clinical Commissioning Groups (CCGs) that exist today:-

NHS Great Yarmouth and Waveney CCG
NHS Ipswich and East Suffolk CCG
NHS West Suffolk CCG
NHS North Norfolk CCG
NHS South Norfolk CCG
NHS Norwich CCG
NHS West Norfolk CCG

The seven CCGs currently work in partnership to commission the service under a single contract covering Norfolk and Suffolk. Ipswich and East Suffolk CCG is the lead commissioner for the contract.

1.3 The following link will take you to the March 2012 Needs Assessment for ME/CFS in Norfolk and Suffolk on the Norfolk Insight website.

http://www.norfolkinsight.org.uk/resource/view?resourceId=895

This is the most recent full needs assessment for the service. However, the ‘Feasibility assessment of the Implementation of a ME & CFS Consultant-led Service for Norfolk and Suffolk’ presented at Appendix A to Appendix 2 of this paper uses updated data and provides a range of estimates of the potential numbers of ME/CFS cases in Norfolk and Suffolk. The middle estimate is 6,780, with one third of these severe enough to warrant clinical input. .

2. Purpose of today’s meeting

2.1 The summaries of previous reports and bulletins at Appendix 1 show how the previous PCTs and more recently the current CCGs appeared to be moving towards implementing a new service specification for ME/CFS which included consultant input.

2.2 On 20 January 2017 it was made clear to the Joint Committee that officers of GY&W CCG had serious reservations about the proposed consultant-led service which the other six CCG appeared to be considering. None of the seven CCGs had taken any formal decisions about whether or not to commission the proposed service, but in light of GY&W CCG’s reservations it was unclear to the Joint Committee how the commissioning of a Norfolk and Suffolk-wide service was to proceed.

2.3 The Joint Committee agreed to invite CCG representatives to today’s meeting to examine their decision-making processes in relation to the proposed consultant-led ME/CFS service. The CCGs were asked to provide a report, which is attached at **Appendix 2**. This includes (at Appendix A) the review completed by a specialist ME/CFS consultant on the options to develop a consultant-led service. The appendices to the review have not been reproduced, but are available on request from the Democratic Services and Scrutiny Team Manager, Norfolk County Council.

East Coast Community Healthcare (ECCH), the provider, was also asked to provide information about the current service, which is attached at **Appendix 3**

Representatives of GY&W CCG and Ipswich and East Suffolk CCG will be in attendance to answer Members’ questions.

2.4 The Chief Executives of Healthwatch Norfolk and Healthwatch Suffolk were approached for any information that they wished to provide for today’s report. Their joint comment was that the Healthwatches were not aware of any complaints about ME/CFS service provision, except for one complaint made by a representative of the patient/carer group.

The Chief Executive of Healthwatch Suffolk has previously advised the CCG and ECCH to consider a stringent consultation and then basing a decision on future provision around this.

2.5 The Norfolk and Suffolk ME & CFS Patient Carer Group provided the information at **Appendix 4** and one of their members will address the Joint Committee during the Public Participation session.

2.6 Although ME/CFS service is for patients across Norfolk and Suffolk, the GY&W Joint Health Scrutiny Committee is considered to be the appropriate health scrutiny committee to examine the commissioning process at this stage. This is because only the GY&W CCG was known to have reservations about the proposed way forward. Should the seven CCGs choose different paths in relation to this service, then Norfolk and / or Suffolk Health Scrutiny Committees may wish to be involved.

3. Suggested approach

3.1 After the CCG representatives have presented their information, the Joint Committee may wish to discuss the following areas with them:-

(a) The CCGs' report (Appendix 2) sets out a number of criteria regarding cost and suitability of a potential consultant-led service. The next steps that the 7 CCGs agreed on 13 March 2017 were to:-

- Carry out a market test process to explore whether or not there would be a provider for a consultant-led service meeting the agreed criteria
- Develop a formal Quality and Equality impact assessment around any new proposed service
- Meet again to discuss the outcome of the above before each CCG makes a decision on the future of the service.

How long do the CCGs expect these three steps to take?

(b) In the meantime, are the CCGs content with the current service or would they wish to make changes?

(c) When the time comes for the CCGs to make decisions on a potential consultant-led service, will these decisions be taken by the Governing Bodies in public?

(d) What are the implications of one or more of the CCGs deciding to take a different direction from the rest in commissioning the ME/CFS service?

(e) The former PCTs' assurance that they would deliver a consultant-led service was not met because they were unable to find a consultant. How do the CCGs balance the priority of securing a consultant against the priority of meeting the criteria they agreed on 13 March 2017?

(f) What is the CCGs' response to Healthwatch Suffolk's suggestion that there should be thorough consultation on the proposed new service before any decisions are made?

4. Action

4.1 The CCGs’ report makes it clear that there is work to be done before the seven CCGs will be in a position to take decisions in relation to commissioning a potential consultant-led service. The Joint Committee may wish to ask the CCGs to keep it up-to-date with developments.

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Time-line and brief details of previous reports and information bulletins to Great Yarmouth and Waveney Joint Health Scrutiny Committee regarding ME/CFS

13 Mar 2008	Suffolk Health Scrutiny Committee referred concerns of the East Anglian ME Patient Partnership to the Joint Committee. The concerns were about the level and nature of ME/CFS service provision. One of the Patient Groups concerns was that the Health Overview and Scrutiny Committee had not been consulted about a substantial variation to the service in 2005.
12 Aug 2008 Report	GY&W PCT reported to the Joint Committee that it did not consider the service model agreed in 2005 constituted a substantial variation to the service. In 2008 GY&W PCT was leading for the three PCTs (Norfolk, Suffolk and Great Yarmouth and Waveney) on a service redesign. A Service Design Project Group (SDPG) had been established, including patient representatives, to produce a new service specification in line with National Institute of Health and Clinical Excellence (NICE) guidance. The intention was to formally consult when a proposed service specification was ready. The Joint Committee focused on the process of redesigning the service specification.
22 Oct 2008 Report	The Joint Committee received a progress report on the drafting of the new specification. A consensus view on the ‘Treatment and Management’ section of the specification had not been reached as there was disagreement about the appropriateness of NICE guidance in this area. The Joint Committee asked Norfolk Local Involvement Network (LINk) to meet with the PCT to ascertain progress.
16 Jan 2009 Report	The Joint Committee received a further progress report, including an update from Norfolk LINk. At this stage the PCT was preparing to formally establish its Provider Arm (Great Yarmouth and Waveney Community Health Services) as an Arm’s Length Trading Organisation by 1 April 2009, and was preparing to tender all the services provided by the Provider Arm, including ME/CFS. The PCT gave assurance that the tender document would include the current ME/CFS service specification and that it would continue to work with the other commissioners and patient representatives through the SPDG to develop a robust service specification.
12 May 2009 Report	The Joint Committee heard that a draft service model had been agreed in principle. The intention was that a full public consultation would start around May / June 2009. Norfolk LINk had offered to organise a consultation reference group, including the Patient and Public Involvement leads from the three PCTs, patient representatives from the three areas and Suffolk and Norfolk LINks.

30 Jul 2009 Report	The Joint Committee heard that NHS Norfolk PCT was leading the development of the ME/CFS consultation document at this stage and that consultation was scheduled to begin in September 2009. The Joint Committee received the 'Pre Consultation Preparatory Document for the Proposed Service Model for a Specialist ME/CFS Service, May 2009'.
12 Nov 2009 Report	The consultation had not begun and the Joint Committee was concerned about the delay. GY&W PCT assured the Joint Committee that if it were determined that a formal consultation about the proposed consultant led service was not necessary, the three PCTs working together could provide consultant led services within the next 3 months. The Joint Committee recognised that as the views and patient and carer groups were already known and a consultation process would delay further the implementation of services and recommended:- 'NHS Suffolk, NHS Norfolk and NHS Great Yarmouth and Waveney set up an acceptable consultant led service as soon as possible'. It also recommended that Norfolk and Suffolk LINks and patient representatives should be involved and that the Joint Committee be kept informed of progress, with any concerns being referred to the appropriate health scrutiny committee.
10 Mar 2010 Report	The Joint Committee heard that NHS Norfolk PCT was taking the lead to commission a new consultant led service to meet the needs of patients with more severe and complex ME/CFS. The PCTs were also continuing to commission a specialist ME/CFS service from Great Yarmouth and Waveney Community Health Services. NHS Norfolk PCT was looking to identify and contract with a consultant or consultants to provide support for patients on an outreach basis. It was intended that this part of the service would start in April – June 2010. There was also an intention to expand the existing service to two additional sites in Suffolk and two in Norfolk, starting in April – June 2010 The report from the three PCTs also said that educational material and guidelines for GPs were to be refreshed once the details of the consultant component of the service were in place and additional locations for service provision were finalised. There was also to be a full needs assessment by an NHS Norfolk Public Health Consultant and a review of the service to establish a development plan for the next few years.

27 Jul 2010 Report	The Joint Committee received an update from the three PCTs and from Norfolk and Suffolk LINk outlining concerns about lack of progress. The PCTs acknowledged that progress had not been as quick as they hoped. They noted the lack of ME/CFS consultant services nationally but re-stated that they were committed to commissioning consultant support for the service. At this stage two members of the Joint Committee started to attend meetings between the commissioners and the patient/carer representatives and reported back verbally to subsequent meeting of the Joint Committee.
13 May 2011 Info bulletin	The Joint Committee received a written information bulletin from NHS Great Yarmouth and Waveney PCT. At that stage it had committed to continuing to commission the existing service from its provider arm for three years when it moved into a proposed social enterprise organisation (East Coast Community Healthcare). In addition to four sites in Great Yarmouth and Waveney, a service was also running at Norwich Community Hospital. NHS Norfolk PCT was continuing to lead the service development work and the three PCTs were working on it together.
During 2011-12 the three PCTs formed into two PCT clusters in advance of reorganisation under the Health and Social Care Act 2012.	
31 Jan 2012 Info bulletin	In an information bulletin the Norfolk and Waveney and Suffolk PCT Clusters informed the Joint Committee that they were still committed to commissioning consultant input to support the ME/CFS service but were struggling to find a provider. There was not a consultant speciality for ME/CFS and there were very few consultants anywhere in the NHS with an interest in ME/CFS. The PCT Clusters continued to meet with stakeholders, including Norfolk and Suffolk LINks, on a regular basis. The service provider, East Coast Community Healthcare (ECCH), was about to open a further clinic in Suffolk, and the NHS Norfolk Public Health Consultant had completed an ME/CFS needs assessment for Norfolk and Suffolk. Work on developing a service specification based on the needs assessment was starting, led by NHS Norfolk PCT.
16 Oct 2012 Public participation	The Joint Committee received an update from Mrs Barbara Robinson, a member of the public, during the public participation session. Mrs Robinson informed the Joint Committee that staffing changes at NHS Norfolk and Waveney PCT cluster had caused a delay but that Norfolk's Clinical Commissioning Groups had recently agreed the service specification in principle and all concerned wanted to prevent any unnecessary delays in the implementation of the new service. Mrs Robinson confirmed that

	the main outstanding difficulty was finding a suitable consultant for the new service.
29 Jan 2013 Info bulletin & Public participation	A final update on behalf of Norfolk and Waveney PCT Cluster in January 2013 NHS Norfolk & Waveney Commissioning Support Unit advised the Joint Committee that a revised service specification had been agreed with the majority of service users in in November 2012 to a point where it felt it could start to have discussions around procurement and mobilisation of a revised service. Subject to CCG approval, it was expected that a new service would be in operation from the third quarter of 2013 at earliest, or the first quarter of 2014 if a full procurement exercise was undertaken. Christine Harrison, a member of the public, said that as a result of collaborative working the Great Yarmouth and Waveney area had the opportunity to have the first biomedical ME/CFS service in the country led by a specialist in ME/CFS at consultant level and that it was important that the Needs Assessment (2012) and Service Specification (2012) were fully implemented and adhered to.
In 2012-13 seven Clinical Commissioning Groups were formed in Norfolk and Suffolk and took over commissioning responsibility from the two PCT clusters on 1 April 2013. The Health and Social Care Act 2012 also established local Healthwatch organisations in place of Local Involvement Networks.	
23 Jul 2014 Info bulletin	The Joint Committee received an information bulletin update from the Deputy Chief Contracts Officer, Ipswich and West Suffolk CCGs. This had been circulated to members in advance of the cancelled meeting of 16 May 2014. Dated 16 April 2014, the update covered the period since 29 January 2013. As of April 2014 the Suffolk CCGs had taken the lead for the ME/CFS contract from the Norfolk CCGS. The contract remained with ECCH and commissioners were working with them to scope a change programme to work towards the new specification. The fundamental differences between the existing service and new service specification were:- • Specialist consultant input into the service • Significant increases in domiciliary (home visits) care • Additional re-referral costs Consultation with existing providers in the wider health economy on the specification had taken place and little interest was shown other than from the existing provider (ECCH). Initial cost of change estimates had been received from ECCH. Based on their analysis of the specification they anticipated and increase in cost of 79% on the existing price.

	In summary, the information bulletin also said that:- - The CCGs had not been able to find a consultant with the necessary skills or experience for the service. - In the meantime patients requiring specialist ME or CFS care were being considered by Individual Funding Request Panels on a case by case basis. - The commissioners had begun to work with ECCH to scope a change programme to move the service towards new specification by initially making changes that could be made for no extra cost. - In order to achieve more fundamental changes the seven Clinical Commissioning Groups would need to ask their Governing Bodies to approve additional funding. - It was anticipated that by June 2014 a costed draft plan would be available for each CCG's consideration. - Subject to each CCG's agreement, a preliminary market engagement exercise was to be undertaken by December 2014 to ascertain if there was a market for the service other than with the incumbent provider. - If the outcome suggested there would be benefit in tendering the service, this was to be done in 2015.
13 Nov 2015 Info bulletin	Ipswich and East Suffolk CCG was the current lead commissioner working in partnership with the other 6 CCGs in Norfolk and Suffolk and the ME &CFS User and Patient Group to support the development of the service. ECCH were still providing services against the 'old' service specification and the commissioners were working with the ME & CFS User and Patient Group and ECCH to agree a plan to implement the requirements of the new service specification. A draft transition plan had been developed to support the move to the new specification. The Joint Committee was informed that in the summer of 2015 the commissioners had agreed to change the skill mix of the team and recruit a consultant to lead the service and support complex patients. An Expression of Interest advertisement had been published which closed at the end of October. The CCGs had also agreed to implement a number of other changes detailed in the new specification. Decisions on some of the other new requirements were dependent on having the consultant in place and would be reviewed by in due course (pending successful recruitment). The commissioners confirmed their intention to continue to work with ECCH and the User and Patient Group, supporting the implementation of the new service specification.
20 Jan 2017 Info bulletin	GY&W CCG informed the Joint Committee that six of the seven CCGs in Norfolk and Suffolk had commissioned a review in the

& Public participation	summer of 2015 to be completed by a specialist ME/CFS consultant to review the options to develop a consultant led service for this group of patients across Norfolk and Suffolk. GY&W CCG had not been involved in commissioning this review but in December 2016 the other six CCGs had shared it with them, ME/CFS patient groups and ECCH. ECCH had been asked to provide a commentary on the operational implications of the consultant's report, and its report was awaited. On receipt, ECCH's report was to be considered by GY&W CCG's Clinical Executive Committee and similar committees across the other six CCGs to enable a decision to be made on future commissioning arrangements. Mrs Barbara Robinson, a member of the public, addressed the Joint Committee during the Public Participation Session and expressed concern that an opportunity to deliver a cost neutral consultant led service would slip away due the GY&W CCG's reluctance to agree to the change. The Joint Committee also heard from Cath Byford, Deputy Chief Executive, GY&W CCG, who said that the CCG was unable to accept the findings of the outcome of the consultant's review because of:- • A conflict of interest. The consultant who had led the review and the consultant who was expected to lead the proposed new service were the same person. • The review was too limited in its scope. It had not considered the redundancy costs and other transitional costs that would be associated with setting up a new ME/CFS service with the same high degree of resilience as the existing service. • The review did not accurately reflect the concerns of existing patients and patient groups.

NHS
Great Yarmouth
and Waveney
Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: ME/CFS Update

Background

The Myalgic Encephalomyelitis and Chronic Fatigue Service (ME & CFS) is commissioned by the seven CCGs in Norfolk and Suffolk and is provided by East Coast Community Healthcare (ECCH). Ipswich and East Suffolk CCG is currently the lead commissioner for the service on behalf of West Suffolk CCG and the NHS Great Yarmouth and Waveney CCG leading for the four Norfolk CCGs have a separate contractual arrangement for the service. Ipswich and East Suffolk CCG is also responsible for working in partnership with the other CCGs in Norfolk and Suffolk and the ME & CFS User and Patient Group to support the development of the service.

ECCH provide a multi-disciplinary specialist service to assess, diagnose and advise on the clinical management of ME/CFS to adult and paediatric patients across Norfolk and Suffolk. There are approximately 1400 active patients undergoing treatment. The team consists of general practitioners with specialist interest in ME/CFS (GPwSI), occupational therapists and physiotherapists. The initial assessment of patients to confirm diagnosis is carried out by therapists or, in more complex cases, the GPwSI. As per other services in Essex, Peterborough and Cambridgeshire, the service is a non-prescribing outpatient service with therapy-led treatments: there is no consultant leading the service.

In the summer of 2015, six CCGs in Norfolk and Suffolk commissioned a review to be completed by a specialist ME/CFS consultant to review the options to develop a consultant led service for this group of patients across Norfolk and Suffolk. This report was completed and shared with the CCGs including Great Yarmouth and Waveney CCG in December 2016. The review is attached at **Appendix A.**

The CCGs have also shared the report with ME/CFS patient groups and with the current provider of ME/CFS services, ECCH. ECCH have since provided a commentary on the operational implications of this report on current service.

Next steps

On Monday 13 March 2017 all of the Norfolk and Suffolk CCGs met to agree next steps.

It was agreed that the commitment to deliver a consultant led service had been made by the CCG’s predecessors, NHS Norfolk and NHS Suffolk ,and that the CCGs would like to explore this option further.

A number of criteria for a new service were agreed:

- Within the current cost envelope
- A viable model
- A resilient model
- The change to a new service would not result in patients currently receiving a service losing access to a service completely
- Any new service model cannot deliver improvements for one group of patients and disadvantage another.

Suffolk CCG have agreed to carry out a market test process to explore whether or not there would be a provider for a consultant-led service which would be delivered to the criteria above.

It was agreed that there should be formal Quality and Equality impact assessment developed around any proposed new service to ensure that everyone was aware of the potential impact before making decisions about the future of the service.

Once that exercise is completed the CCGs will meet again to discuss the outcome before each CCG makes a decision on the future provision of the service.

Performance of the current service

A number of documents have been attached to show the performance of the current service:

- Patient change audit comparison of responses 2012 – 2016 (Appendix B)
- Patient change audit January 2016 (Appendix C)
- Children and young people’s survey (Appendix D)

Rebecca Driver
Director of Commissioning and Engagement

Feasibility assessment of the Implementation of a ME & CFS Consultant-led Service for Norfolk and Suffolk

Report to 6 CCGs in Suffolk and Norfolk

November 2016

Luis Nacul, Eliana Lacerda, Caroline Kingdon

Contents

EXECUTIVE SUMMARY

There is firm commitment from service commissioners, providers and users to work together on changes to the current model of ME & CFS service provision that will allow it to fully respond to the needs and aspirations of service users and is also affordable and sustainable.

A rapid review of the current services for ME & CFS in Norfolk and Suffolk was commissioned by 6 CCGs in Suffolk and Norfolk. A team of experts in ME & CFS, public health, epidemiology, clinical and health services conducted the review and outlined a new model for service delivery with an implementation plan.

The review was based on a rapid appraisal methodology that included observation, interviews, meetings and discussions with stakeholders, and documental data gathering and information analysis. The report is partially structured within a Health Needs Assessment (HNA) framework, and refers to and builds on the ME & CFS HNA conducted in May 2012 in the region. We considered the epidemiology of ME & CFS, the evidence of the effectiveness and cost-effectiveness of interventions, the operation of the health services and the views and input of stakeholders as key components to the review process.

Documental evidence consists of published national and international guidelines, including significant papers related to ME & CFS clinical definitions for diagnostic purposes. Examples are the 2007 NICE guidance for chronic fatigue syndrome and other diseases, the 2003 Canadian clinical working case definition, the International Consensus Criteria, the CDC-1994, and the Institute of Medicine 2015 definitions of ME & CFS, as well as the Service Specification Proposal and other relevant service documents.

The East Coast Community Health Care ME & CFS Specialist Service (from now on referred to as the Service) is commissioned by 7 CCGs in Norfolk and Suffolk, and is managed by East Coast Community Health Care (ECCH) - a non-prescribing outpatient service, which mainly offers face-to-face appointments to individuals referred by their GPs with a suspected or confirmed diagnosis of ME & CFS. Patients are seen in primary care locations across Suffolk and Norfolk by a team comprising part-time locum GPs with a special interest (GPwSI) in and knowledge of ME & CFS; and part-time Specialist Therapists, including Occupational Therapists (OT) and one Physiotherapist (PT); and administrative support staff.

Prevalence studies yield variable results. Based on a commonly used prevalence rate of 0.4% and an annual incidence rate of 0.015%, we would expect 6780 cases in Suffolk, Norfolk and Great Yarmouth at any one time (or 3369 if the prevalence is 0.2%), and 250 new cases per year.

Between 2007/2016, 5687 cases were seen, and an increasing trend in the number of cases seen in the ME & CFS Services has been observed, with 972 cases predicted in 2016-17. Despite the increasing trend, the number of cases seen by year are likely to be approaching a plateau, as a higher proportion of existing cases living in the region are seen, followed by a slow reduction over the years. Improved screening of new cases can accelerate this process, with reduction in the number of inappropriate cases referred to and seen by the Service, and through more efficient management approaches. The improvement in access and education of GPs in primary care can further improve Service efficiency in the medium and long term, though it is possible that it may generate a modest increase in the number of cases being seen in the near term.

There are many factors that can affect the number of new cases seen, including but not limited to the knowledge of ME/CFS of GPs in primary care, the criteria for referral from primary care and for acceptance and management/treatment of patients within the Service, management specification, discharge criteria, service capacity, accessibility and saturation of new cases.

Currently, following a GP referral and initial triage of cases, the first Service consultation aims to confirm diagnosis and plan for therapy; this is undertaken by GPSi in ~ 60% of cases and by lead OT in ~ 40% and is based on the CDC-1994 diagnostic criteria. Management is provided by the therapists in all cases, and comprise 6 to 10 individual sessions. After that period, patients are discharged back to their GPs.

To identify gaps in service provision, a health needs assessment was conducted in 2012 and a new service specification was designed; this current review builds on this knowledge and takes into account the current environment. It aspires to a cost-neutral service model of care, Consultant-led, delivered according to the best evidence with improved coverage and equity - as it includes those who have had little access to the Service, such as the severely affected.

In the review process, some inequalities were observed. In particular the Service has been less active in the care of certain sub-sets of patients: those with poor access to services, such as the severely affected (who are typically house bound) and those without a formal diagnosis or whose disease is not recognised by their GPs. In addition, the proportion of the total existing cases seen living in areas at a distance from the Service are disadvantaged; in West Suffolk, 3.5 times fewer cases are seen than in GYW, the area with the highest proportion of cases seen. Other areas with a lower than average proportion of cases seen are West Norfolk and South Norfolk.

Addressing such inequalities will require the Service to reach out to these sub-sets of the population. This could include offering home-visits for the house-bound, increasing the geographical distribution of clinics to reach areas historically under-covered, and improving the education of GPs in the community to facilitate the recognition and management of cases, as well as the appropriate selection of cases for referral.

To achieve such improvement in a cost-neutral basis and under the current financial model, some efficiency savings are proposed. Savings could be generated by streamlining referral and triaging processes, and by empowering therapists with enhanced training, enabling more independent and accurate diagnosis of ME/CFS, and of GPs in the community through education, by improving referral patterns and in the medium and long term, by giving them confidence to manage cases in the primary care setting.

The recommendations are based on the assumption is that the Service will continue to accept referral of cases of with ME & CFS (estimated as 0.4% of the population), and that of these, 1/3 will require a clinical appointment, with 2/3 managed by OTs without clinical input. The GPs will increasingly be empowered to manage cases in the community, leading to their management of 50% of cases in the longer-term, without need for referral to Service.

We propose a change in the criteria used for a face-to-face clinical appointment, based on compliance with the Canadian or International Consensus Criteria for moderate and severe disease. This could reduce the number of cases seen by a clinician by up to 50%, depending on training, development and testing of new protocols. In the short-term, the clinical team will still be seeing many milder cases meeting the Canadian Consensus definition and a few with uncertainties around diagnosis, but future input from a nurse specialist could further reduce this number.

To bring both efficiency and improved quality and coverage to the Service, whilst addressing priorities identified during this review, a move away from the focus on clinical appointments for many patients is proposed, toward the empowerment of therapists; this will allow more time for specialist consultations for those with the greatest need and will simplify access to therapy for those with lower need. The 5 main priorities for implementation identified were: inclusion of the severely affected, GP education and training, early start of treatment/ management from referral, medical follow-up of ME patients, and liaison with support, education, and occupational services. The new specification also includes provision for further activities such as research and evaluation, which could enhance the quality and profile of services and potentially bring additional resources.

An implementation plan with long and medium term goals is proposed with a step-up approach with gradual implementation of actions, supported by on-going monitoring and evaluation activities. Implementation is possible under the current budget structure and can be facilitated if additional monies are realised through other mechanisms such as funding for training, meetings and evaluation.

I. INTRODUCTION

The Problem: It has been identified that there is scope for improving services for ME and CFS in Suffolk and Norfolk. There is a commitment from service commissioners, providers and users to work together on changes to the model of such service provision that not only responds to the needs and aspirations of service users, but is also affordable and sustainable. Previous attempts to advance the process have not led to the desired change, and the current service continues to fall short of the aspirations of users.

The Process: Following discussions with service providers and the lead Clinical Commissioning Group (CCG), a group of 6 CCGs in Suffolk and Norfolk requested a rapid review of the current services and a feasibility plan for the re-structuring of those services. A small clinical team with expertise in epidemiology, public health, and ME/CFS research has been responsible for this work.

Activities completed: The main activities completed for the review are listed in Appendix1

II. METHODS

A rapid appraisal methodology was used (http://pdf.usaid.gov/pdf_docs/Pnadw105.pdf), with observation, interviews, meetings and discussions with stakeholders, as the main source of data; which was followed by documental data gathering and information analysis. For structuring this proposed assessment, we used the Health Needs Assessment (HNA) framework (Williams and Wright 1998) and the HNA conducted in May 2012 (Appendix 2) as baseline references. We considered the epidemiology of ME/CFS, the evidence of the effectiveness and cost-effectiveness of interventions, the operation of the health services and the views and inputs of stakeholders as key components to the review process.

To complement the information gathered in the activities described in Box 1, we consulted institutional documentation, published national guidelines, and significant papers related to ME & CFS clinical definitions for diagnostic purposes. These include the NICE Guidance (NICE - National Institute for Health and Care Excellence 2007) for chronic fatigue syndrome and other diseases, the Canadian clinical working case definition (Carruthers, Jain et al. 2003), the International Consensus Criteria (Carruthers, van de Sande et al. 2011), the CDC-1994 (Fukuda, Straus et al. 1994), and the Institute of Medicine (IOM) (Institute of Medicine (IOM) 2015) definitions, as well as the Service Specification Proposal (Appendix 3, and other Service documents.

This report does not aspire to offer a full review or full needs assessment for ME/CFS services in the region, but rather an analysis with practical recommendations for rapid service delivery.

III. DESCRIPTION OF CURRENT ECCH ME & CFS SERVICE

East Coast Community Health Care (ECCH) manages the ME & CFS service being considered. It is described as '*a specialist NHS service throughout Norfolk and Suffolk that seeks to meet the needs of people who have a diagnosis of Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS)*'. The Service website also states that they "*provide assessment, diagnosis, management, advice, education and support for people who have a diagnosis of ME/CFS*" (http://www.eastcoastch.co.uk/ServiceCatInfo.asp?id=39).

The ECCH ME & CFS Service (from now on referred to as the Service) is a non-prescribing outpatient service, which mainly offers face-to-face appointments to individuals referred by their GPs with a suspected or confirmed diagnosis of ME & CFS. Patients are seen in primary care locations in Lowestoft, Great Yarmouth, Norwich, Kings Lynn, Halesworth, and Stowmarket. The team comprises 2 part-time locum GPs with a special interest (GPwSI) in and knowledge of ME & CFS; 8 part-time Specialist Therapists, including seven Occupational Therapists (OT) and one Physiotherapist (PT); and administrative support staff. The effort time is distributed among the staff members as follows, 0.2 to 0.4 full-time equivalent (FTE) for the GPwSI, and 6 FTE for the therapists (http://www.eastcoastch.co.uk/). Two additional GPwSI who were doing a small number of clinics have now retired. There is one

GPwSI covering Norfolk and Great Yarmouth and one GPwSI covering Suffolk (from Stowmarket).

A. Referral procedures

The patient's GP completes a **GP Referral Form**, which is reviewed by the lead OT on receipt. The patient is then asked to complete an **Initial Postal Assessment Form**. Together, these documents help the OT decide on the likelihood of the patient meeting the Service criteria for diagnosis of ME & CFS. A decision is then made on whether:

a) diagnosis of ME & CFS is probable, in which case the patient is offered a face-to-face appointment with a therapist (OT) for confirmation of diagnosis and management planning;

b) diagnosis requires further confirmation, and a face to face GPwSI consultation is offered; or,

c) diagnosis of ME & CFS can be excluded or cannot be made without further information from the GP, in which case a letter is sent back to the patient's GP informing them that the patient does not meet the Service criteria for ME & CFS, or requesting further information.

The Service team members estimate – in the absence of any documented audit data, that of all cases referred:

a) the lead OT confirms diagnosis in approximately 40%;
b) GPwSI assessment is needed for confirmation of diagnosis in 55-60%, and,
c) for just 5%, letters are sent to the GPs either informing them that the patient does not meet the Service criteria for ME & CFS, or requesting further information.

Confirmed cases are offered comprehensive care and therapy, usually provided by an OT, with a variable number of sessions ranging from 6 to 10 in total, after which patients are discharged to their GPs. Some patients drop out of therapy without completing the number of scheduled sessions, and before being discharged; however, there is no estimate available for the number of drop-outs. A small number of patients is visited at home. At the time of our visit to the Lowestoft service in July 2016, the waiting times were around 6 weeks for a therapist and 4 months for a GPwSI. On that occasion, the number of active adult patients enrolled in the ME & CFS Service totalled 362 in Norfolk, and 403 in Suffolk. The distribution by location was: Norwich – 229; Stowmarket – 187; Lowestoft – 174; Great Yarmouth – 91; Halesworth – 42, and Kings Lynn – 42. In addition, 70 children were actively enrolled.

The therapists meet bi-monthly to discuss service provision and specific cases. The GPwSi also provides support for OTs in Complex Case Meetings, which can happen bi-monthly or on an ad-hoc basis, as required. Additional services can be accessed in Suffolk through an Individual Funding Request.

There has been little evaluation of the ECCH ME & CFS Service, except for service audits. The most recent audit, from January 2016 (Appendix 4), involved a survey of patients which aimed to assess their perceptions about the Service effectiveness. The response rate was 28%, with only 44 of patients answering the survey questions. Although the survey showed some positive results, as highlighted in Table 1, these need to be interpreted with caution, due to the small number of respondents.

Table 1. Selected results of 2016 Audit of ME/CFS Services

Questions	**Answers**	**Year**	
		2015	**2016**
Q1 Overall my illness has	Improved	56%	55%
	No Change	13%	7%
	Got worse	31%	38%
Q2 My symptoms are	Improved	53%	50%
	No Change	16%	11%
	Got Worse	31%	39%
Q3 I am able to do	Improved	50%	50%
	No Change	23%	11%
	Got Worse	27%	39%
Q4 I am able to cope with my illness	Improved	64%	68%
	No Change	15%	5%
	Got Worse	21%	27%
Q5 I am able to control the severity of my symptoms	Improved	58%	64%
	No Change	19%	11%
	Got Worse	23%	25%
Q6 My feelings about the future course of my illness	Improved	62%	52%
	No Change	11%	16%
	Got Worse	26%	32%

B. An analysis of clinical processes for assessment and management of patients referred to the ECCH ME & CFS Service

1. From referral to enrolment

A random sample of ECCH ME & CFS Service patient forms were reviewed by the lead OT (LH) and discussed with LN, to show how the screening of patients referred to the Service (desk-based triage) happens, and how the diagnostic criteria are applied. The screening process is described in Box 1.

Box 1. Procedures for desk-based triage of patients referred to the ECCH ME & CFS Service

- GP completes a **GP Referral Form** and sends the referral to the ECCH ME & CFS Service,
- The patient is contacted and asked to complete the **Initial Postal Assessment Form,**
- Information from these forms is reviewed by the lead OT, who decides if a face-to-face appointment with a therapist (OT) is sufficient to confirm diagnosis and start treatment or if a GPwSI assessment is needed; the referral may not be accepted, either due to insufficient information provided by the patient's GP or because there is no compliance with ECCH ME & CFS Service criteria.

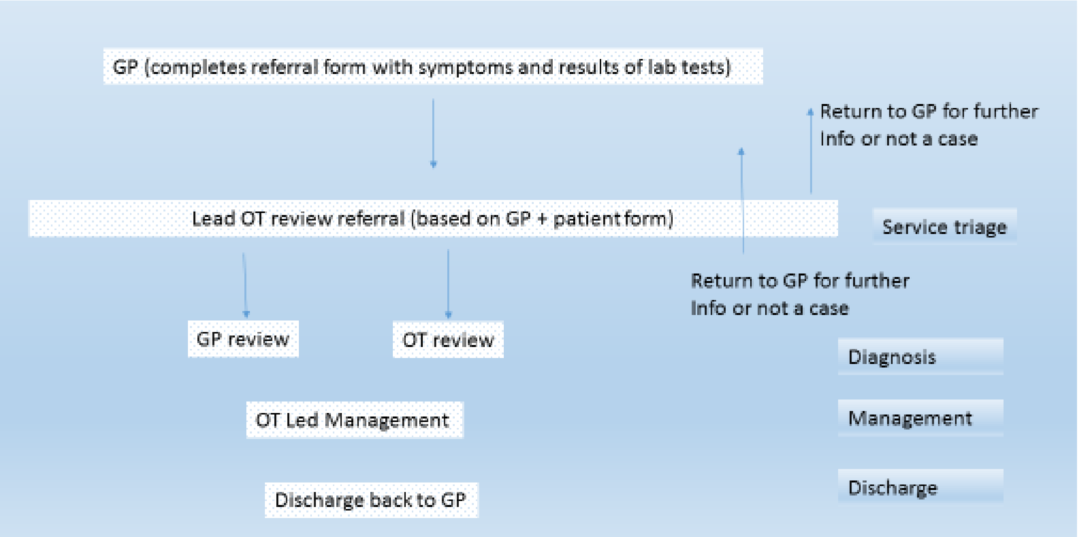
The GP referral letters seen were of variable quality. Some demonstrate good understanding of the disease and knowledge of referral pathways. Other referrals are very brief and not substantiated. The laboratory tests used to exclude other diagnosis follow the NICE guidelines (NICE - National Institute for Health and Care Excellence 2007).

The ECCH **GP Referral Form** has many points in common with those used in Essex and Cambridgeshire.

The **Initial Postal Assessment Form** has been used by Peterborough / Cambridgeshire (PBO&CB) and Essex services as well as ECCH to help screen cases; it may also have been used previously for research purposes. The three districts follow similar models for **pre-clinical assessment**, but in the case of Essex, the **Initial Assessment Form** is completed on the day of the initial face-to-face appointment.

Of the forms seen at the visit, 31% had been screened for further input from GPwSI and 69% were to be evaluated by one of the OTs. This was a small sample (n=16) and the OT commented that it was unusual for such a relatively large proportion to be referred directly to the OT; the more usual rate would be 60% sent to the GPwSI and 40% to the OTs, as reported in the previous section (page 3). The current care pathway is summarised in Figure 1.

Figure 1. Current Care Pathway



a) We learned from this exercise that:

1) The decision to consider a case is very much based on compliance with CDC-1994 criteria (Fukuda, Straus et al. 1994), which has been used for diagnosis purposes, for the exclusion of other diseases, and for the information the patients provide by describing typical symptoms and impact on life. Additionally, considerable weight is given to history of 'post-viral' fatigue to confirm cases of ME &CFS.
2) The **'Initial Postal Assessment Form'** includes standard tools enabling the assessment of fatigue severity, sleep, self-efficacy, mental health, pain and a disability. Although very useful for characterization of patients, these may not be needed, in their current form, to assess compliance with diagnosis of ME & CFS, and therefore for eligibility for management within the Service. There may be licensing issues for at least one of the forms used, and payment of license fees may not be well justified for Service provision, as their use may be more appropriate for research purposes.

3) The assessment tools used for diagnosis - the **GP Referral Form** and the **Initial Postal Assessment Form** - may contain some information that is not relevant to assessment purposes and may just be adding ‘noise’.
4) Better recruitment of patients should start with the GPs. Poor knowledge and recognition of ME & CFS combined with lack of consultation time may have hampered the selection of patients for referral. Although the Service team has attempted to inform GPs about the scope of the specialist service and how they could help their CFS patients, there has been little enthusiasm for the training offered. Part of that education should be the encouragement to allow adequate consultation time to exclude differential diagnoses and prevent inappropriate referrals.

b) There is scope for:

1) Further training and education of GPs, practice nurses and district nurses. New ways of attracting GP and other primary care staff interest, including young and trainee GPs may need to be considered. Part of that education should be to encourage GPs to allow adequate consultation time to exclude differential diagnoses and prevent inappropriate referrals.
2) Reviewing and simplifying of the **GP Referral Form** and the **Initial Postal Assessment Form**, aiming at seeking only to capture a diagnosis from the forms would avoid information overload. These forms should be easy for both GPs and patients to complete.
3) Reviewing and defining the ME & CFS diagnostic criteria and the target clientele for the Service, i.e. whether the target clientele of the ECCH ME & CFS Service is CF cases, CFS cases or ME cases.

c) Consequences:

1) By reviewing the way information is gathered at this stage and how it is interpreted in light of likelihood of diagnosis, it may be possible to reduce the percentage of those who need GPwSI assessment, increasing the proportion of first OT assessments.
2) The diagnostic criteria used and the resulting target clientele will impact the Service scope and budget. This point is covered later in this report.
3) The impact on service dynamics would need piloting and would involve further training.

2. The first assessment - the diagnosis confirmation and therapeutic plan

Whether a GPwSI or a therapist undertakes the first assessment, its aim is diagnosis confirmation [largely based on CDC-1994 criteria (Fukuda, Straus et al. 1994)]and the planning of future patient management, usually based on occupational therapy techniques. Some OTs have cognitive behaviour therapy (CBT) training, and may include CBT techniques in the plan as appropriate.

OTs offer a variable number of consultations, typically between 6 and 10, but may be fewer if the patient does not improve or chooses to drop out. On occasions, further sessions are provided for selected patients, who are deemed likely to benefit further. At the end of the sessions patients are discharged back to their GPs.

OTs also inform patients of their entitlements due to incapacity, and are often asked to provide letters of support for education, work and benefits. Additionally, they review clinical progress on an individual basis.

Medical follow-up is not the norm, but on occasions the GPwSI may be asked to review a case. There are no facilities to direct referral to other specialties or for further investigations in any of the sites, although this may now be changing.

The ECCH ME & CFS Service is non-prescribing, as it is staffed by non-prescribing health professionals (OTs and PT); GPwSIs are involved only in the diagnostic phase, mainly for confirmatory or differential diagnosis.

Re-referrals to the ECCH ME & CFS Service attract new fees only if they occur after a year from the first referral.

3. The situation in neighbouring regions: Essex, Peterborough and Cambridgeshire

Initial assessment in Essex is carried out by a physiotherapist (possibly in combination with an OT); in Peterborough and Cambridgeshire Adult services, it is provided by a nurse.

In Essex, CBT and OT are offered as the main therapies; in Peterborough and Cambridgeshire, therapy is OT led. There is a small number of severely affected patients in Peterborough and Cambridgeshire who are seen at home, and who continue to be followed up by the nurse after the initial period of treatment. Nurse follow-ups are restricted to severe cases on a yearly basis. There are no home visits in Essex.

CDC-1994 (Fukuda, Straus et al. 1994) are used to screen cases for the services in these areas, with NICE guidance (National Institute for Clinical Excellence 2003) used as a secondary reference for recruitment criteria; this may be different in other parts of the country.

OTs provide letters for benefit agencies, employers and schools in Essex and Cambridgeshire, though PTs also prepare letters in Essex, and nurses do the same in Peterborough and Cambridgeshire.

These services are also non-prescribing. Previously there was a consultant in ME & CFS in Essex who prescribed for patients in exceptional cases, for example when the patient’s GP would not prescribe a certain recommended medication for pain and/or sleep problems.

There is no direct referral to other specialties in any of these areas.

C. ME & CFS and the evidence-based approach

Although the evidence-based practice for ME & CFS is still limited, there is some accepted wisdom:

- All the main international guidelines accept that ME & CFS is a serious and disabling disease of long duration from which full recovery is rare
- ME is classified as a neurological disease in the WHO ICD-10th revision (World Health Organization 1992)
- Early management is considered to be an important determinant of severity and prognosis

In general, the NICE guidelines for CFS/ME are followed by health services in the UK. The guidance is based on relatively wide case definitions, though clinical discretion is allowed. However, the broadness of the recommended criteria for diagnosis is inadequate for distinguishing ME & CFS from other conditions that present chronic fatigue as a significant symptom. Management strategies are mainly based on CBT, graded exercise therapy (GET) and other psychological approaches; the guidance also includes specific recommendations against some investigations and treatments. The NICE guidelines do not include service provision, models of care, or treatment of co-morbidities.

A recent review of the evidence of interventions for ME/CFS seriously questioned the validity of CBT, GET and other psychological therapies, when studies using the Oxford Criteria (Sharpe, Archard et al. 1991) were excluded [Agency for Healthcare Research & Quality (AHRQ), 2016]. The AHRQ report shows that for CBT and GET, the evidence of effect on function virtually disappears when studies using Oxford criteria are excluded, with only low level evidence for a positive effect on fatigue using CBT, and no effect on global improvement, quality of life or employment. Counselling and other behavioural therapies, excluding CBT also have low strength evidence in reducing fatigue, and are probably equivalent to CBT in their very modest effects [AHRQ, 2016]. The treatment outcomes in these studies may well have been over-estimated by the use of Oxford criteria, (Green, Cowan et al. 2015). It is expected that the next NICE revision will reflect the reappraisal of the evidence.

Care of the severely affected individual is mentioned in NICE guidelines, but the capacity of services to deliver on that has been limited. Provision of home-based care is expensive and the current models and level of funding of services are unlikely to make the provision of full services to the severely affected viable. Appendix 5 lists some NICE guidance recommendations and an assessment of how the ME & CFS Service has been compliant with these.

a) We identify that:

1) The paucity of systematic reviews on therapeutic approaches for ME & CFS limits evidence-based practice for ME & CFS;
2) The current management approaches for ME & CFS patients rely on rehabilitation strategies, which can be mainly provided by OTs;
3) The therapeutic plan focuses on life adaptations, energy management, pacing, and support for daily activities through benefits, home adaptations and equipment;

4) The medical role includes confirmation of diagnosis of ME/CFS and co-morbidities (where relevant), and the investigation and treatment of co-morbidities;
5) The current restrictions on the use of specific prescribed medicines and other therapeutic approaches not supported by the current evidence prevent their use even when they could be effective for patients;
6) Due to the heterogeneity of patients seen, and the frequency of mental health co-morbidities, access to CBT and other psychological therapies may be beneficial for some patients.

b) There is scope for:

1) Some prescribing and the consideration of additional therapeutic approaches for which there is not yet an evidence-base, but that could be beneficial for patients, in partnership with patients who are able to fully understand the potential risks and benefits. These procedures are in line with the patient-centred approach to care, and could also be linked to research activities, guided by ethical considerations and with fully informed consent.
2) Improved access to social services and psychological therapies. Access to could be made through Improving Access to Psychological Therapies (IAPT) or other mechanisms.

c) Consequences include:

1) A move to a prescribing service, direct access to further investigations, and direct referral to specialties is desirable and may improve efficiency and outcomes.

D. The Epidemiology of ME & CFS

The reported prevalence of ME & CFS has varied by over 100-fold (Brurberg, Fonhus et al. 2014) (Box 2), with inconsistencies largely due to variations on the type and quality of research methods used, particularly in relation to the case definitions applied and the failure to recognize disease sub-types. In the absence of biomarkers for diagnosis, ME & CFS has been defined by a combination of symptoms (Fukuda, Straus et al. 1994; Carruthers, Jain et al. 2003), most of which are non-specific and common to a number of conditions.

Box 2. Median prevalence estimates of ME & CFS according to diagnostic criteria review by Brurberg et al, 2014

Clinical diagnostic criteria for ME & CFS	Median prevalence	Range
Holmes	0.05%	(0 to 0.3%)
Canadian Consensus	0.1%	
CDC-1994	1%	(0.1-6.4%)
Australian-1990	1.2%	(0.04-7.6%)
Oxford	1.5%	(0.4 to 3.7%)

Adapted from Brurberg et al, 2014

The NICE guidelines suggest a population prevalence of at least 0.2 to 0.4%; this is inconsistent with the very broad way in which NICE recommends cases are diagnosed, which would result in a much higher prevalence of between 1.5 and 2.5%. The most consistent findings across countries points to prevalence rates of 0.1 to 0.7%, with **0.2 to 0.4%** often used.

The 2012 ECCH Needs Assessment reads: "*as a minimum there are likely to be at least 2600 adults over the age of 15 in Norfolk and Suffolk who meet Consensus Guidelines for diagnosis. Of these, up to 1250 may be very severely affected. Epidemiology in relation to children is much less clear. The minimum likely number of children under 15 with the condition is 166, but prevalence could be at least twice as much with higher incidence in early adolescence. Of these 40 may be severely affected*". Some of the findings from this document are still relevant, as shown in Box 3.

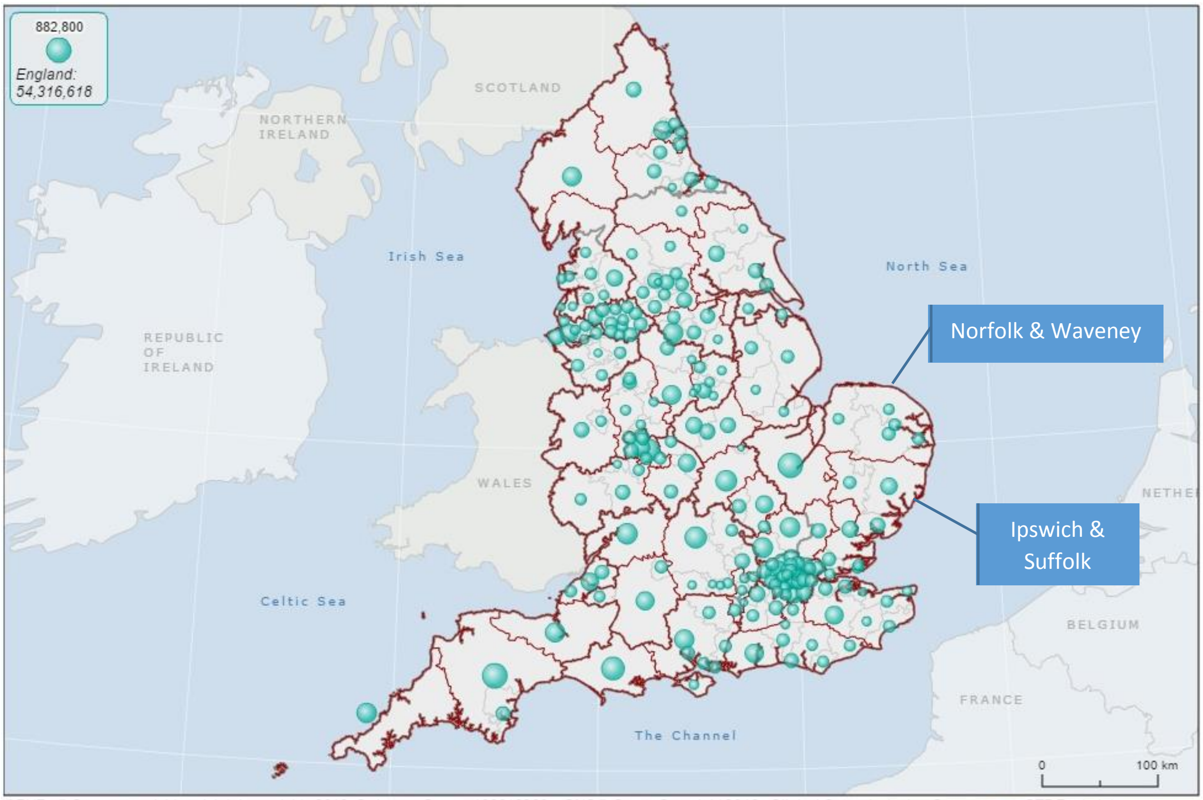
Box 3: Selected findings from 2012 HNA

- *Clinical presentation is very different from case to case and this appears to link with differences in prognosis; however, both the Canadian Consensus and the International Consensus Guidelines provide clear diagnostic criteria*
- *Research into genetic expression suggests that a number of different sub-conditions may be identifiable*
- *The potential for increased risk of early death from direct or secondary causes should be considered when planning ME & CFS services*
- *Patients in services surveyed both locally and nationally felt that their GP had insufficient knowledge of ME & CFS*
- *In the national MEA survey nearly three quarters of respondents felt that the standard of NHS services was inadequate and a number were either looking for support elsewhere or had disengaged from GP services*
- *Almost all carers in the national MEA survey were family members and the level of care need was, in some cases, very high. The lack of support from professional carers may have been from choice, or may reflect lack of recognition of care needs or support for benefit applications*
- *In the absence of robust evidence of long-term effects on quality of life, of the suitability of individuals for the therapy, and of any adverse effects, it is recommended that any decision on commissioning GET be delayed until a redesigned service is in place. The decision should be reviewed by the Consultant service lead following discussion with service user groups.*
- *It is recommended that, as in the management of other chronic and long term conditions, community support for ME & CFS includes a link to the local (IAPT) services and that uptake is monitored to enable the commissioning of sufficient capacity to meet needs*
- *Although referrals to the Service have increased they are far short of the numbers of patients in this area likely to have ME/CFS severe enough to meet Canadian Consensus or CDC criteria*
- *There is no commissioned outreach for severely affected patients*
- *The impact of the Service is difficult to gauge, but a high proportion of patients felt that it had helped them to manage symptoms*
- *Patients' main suggestions for improving the local service were the addition of a Consultant lead, improved training throughout the system, more clinical testing and support with issues such as benefit claims*
- *Issues around the provision of respite care, lack of ongoing support and travel distances to the clinic were also raised*
- *There is no specialist paediatric input to the Service*
- *The Service for children is not clearly defined and does not always link well with education services.*

Adapted from: ECCH Needs Assessment, 2012

1. Epidemiological data for Norfolk and Suffolk

Map of area:



©PHE - © Crown copyright and database rights 2016, Ordnance Survey 100016969 – ONS © Crown Copyright 2016 - Clinical Commissioning Groups —— STP Footprint

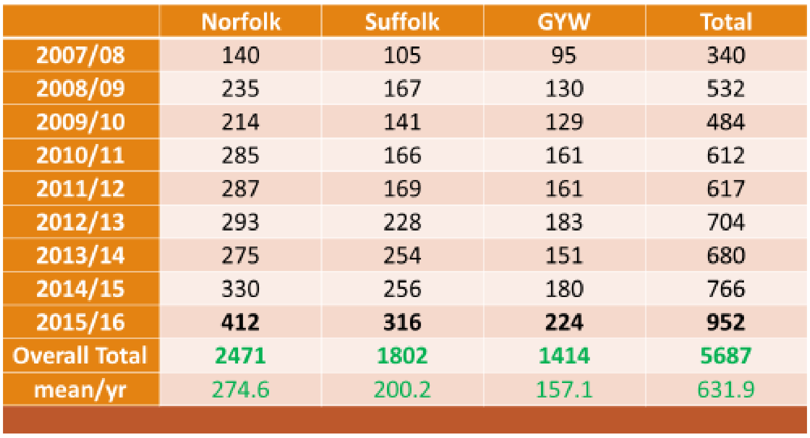
The epidemiological data used here has been updated since the 2012 Health Needs Assessment. The **total population** for 2016-17 in the areas covered by each of the 7 CGs in the ECCH is shown in Table 2.

Table 2. Current population covered by Norfolk and Suffolk Clinical Commissioning Groups.

Clinical Commissioning Group	Total weighted and unweighted populations (2016-17)	
NHS Ipswich and East Suffolk CCG	387,830	401,665
NHS Great Yarmouth and Waveney CCG	259,550	237,344
NHS North Norfolk CCG	181,298	172,053
NHS Norwich CCG	196,299	217,442
NHS South Norfolk CCG	218,767	235,827
NHS West Norfolk CCG	193,335	172,933
NHS West Suffolk CCG	243,366	247,200
All	1,680,445	1,684,466

Table 3 and Figures 2 and 3 show the **number of cases seen per year** since 2007/08, with evidence of an increasing trend in referrals to the ECCH ME/CFS Service - more marked in Norfolk.

Table 3. Patients seen in ME/CFS services between 2007/08 and 2015/16.



	Norfolk	Suffolk	GYW	Total
2007/08	140	105	95	340
2008/09	235	167	130	532
2009/10	214	141	129	484
2010/11	285	166	161	612
2011/12	287	169	161	617
2012/13	293	228	183	704
2013/14	275	254	151	680
2014/15	330	256	180	766
2015/16	**412**	**316**	**224**	**952**
Overall Total	**2471**	**1802**	**1414**	**5687**
mean/yr	274.6	200.2	157.1	631.9

Figure 2. Cases seen annually by the ECCH ME & CFS Service (including 2016-17 prediction, weighted by season) and smoothed regression curve (2007/08 to 2016/17)

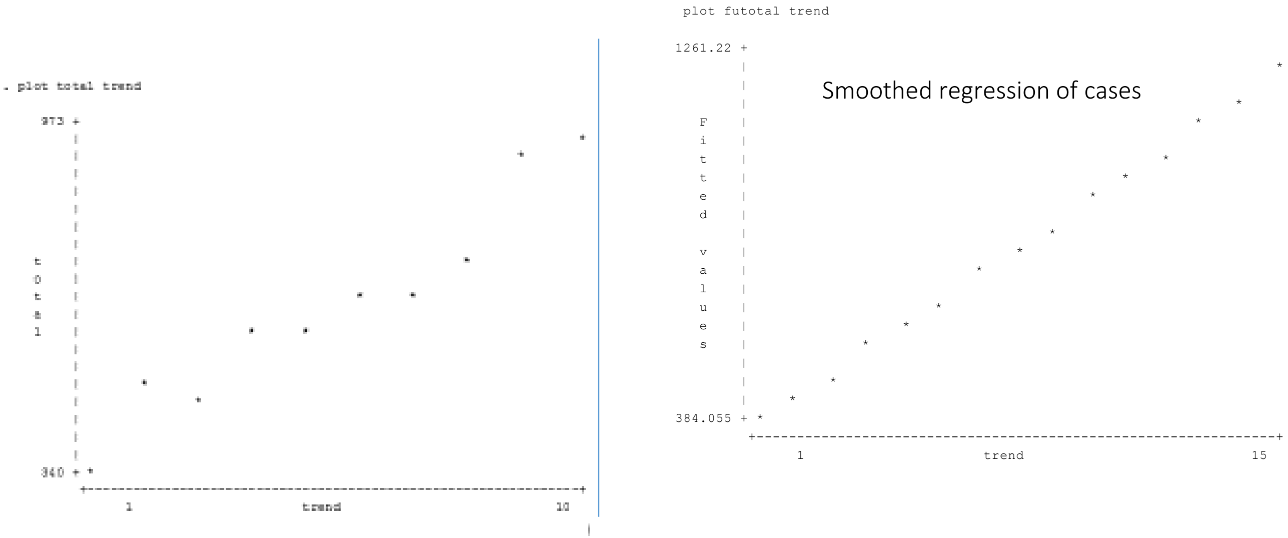
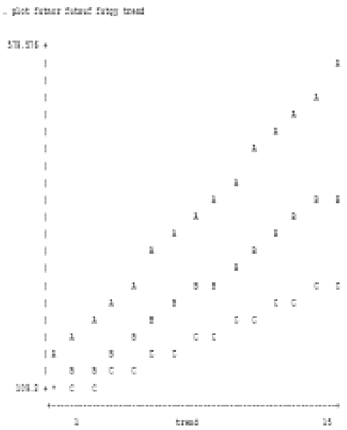


Figure 3. ME/CFS cases seen by ECCH region (2007/08 to 2016/17)



Steady increase in number of cases

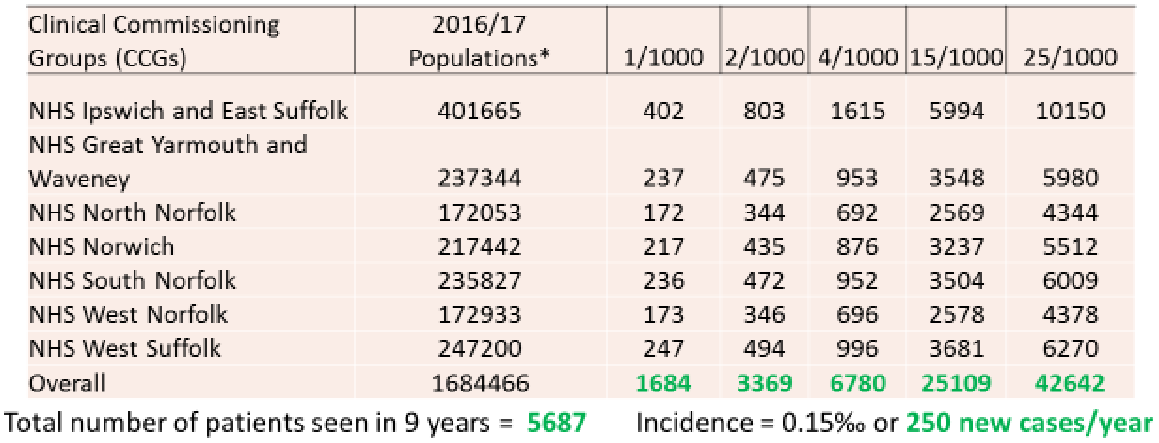
- Proportion of cases per year:
  - in Norfolk: increasing
  - in GY: steady
  - in Suffolk: decreasing

The two GPwSIs currently see about 60% of the patients, which is approximately 600 cases/year. Together they see about 11-12 patients/week, which goes beyond their original job description, and highlights the pressure of coping with the demand for their services

Therapists see 40% of the new patients directly, when diagnosis can be clearly made from the GP Referral Form and the Initial Postal Assessment Form. Direct diagnoses from OT do not bring extra costs for the Service, as patients go straight to therapy.

The assessment of number of cases seen in relation to the total number of existing cases depends on the estimated prevalence of disease, about which there is much uncertainty. This is illustrated in Table 4, which shows the estimated number of existing cases

Table 4. Estimated number of cases of ME/CFS in Suffolk and Norfolk according to assumed population prevalence



Clinical Commissioning Groups (CCGs)	2016/17 Populations*	1/1000	2/1000	4/1000	15/1000	25/1000
NHS Ipswich and East Suffolk	401665	402	803	1615	5994	10150
NHS Great Yarmouth and Waveney	237344	237	475	953	3548	5980
NHS North Norfolk	172053	172	344	692	2569	4344
NHS Norwich	217442	217	435	876	3237	5512
NHS South Norfolk	235827	236	472	952	3504	6009
NHS West Norfolk	172933	173	346	696	2578	4378
NHS West Suffolk	247200	247	494	996	3681	6270
Overall	1684466	1684	3369	6780	25109	42642

Total number of patients seen in 9 years = 5687 Incidence = 0.15‰ or 250 new cases/year

If the estimated prevalence is 0.4%, the total number of cases estimated to exist in the region is 6,780 at any one time [95% Confidence interval (CI) = 6670 to 6805]. We can further assume, for planning purposes, that 1/3 of these meet the Canadian Consensus definition (Carruthers, Jain et al. 2003) or are severe enough to warrant clinical input, and 2/3 meet CDC-94 (Fukuda, Straus et al. 1994) but not the Canadian Consensus definition.

To further illustrate this planning exercise, an estimated prevalence of 1% (not shown) would correlate to 16,840 cases (95% CI= 16,508 to 17,182), while 0.1% corresponds to 1,684 cases (95% CI= 1516 to 1853).

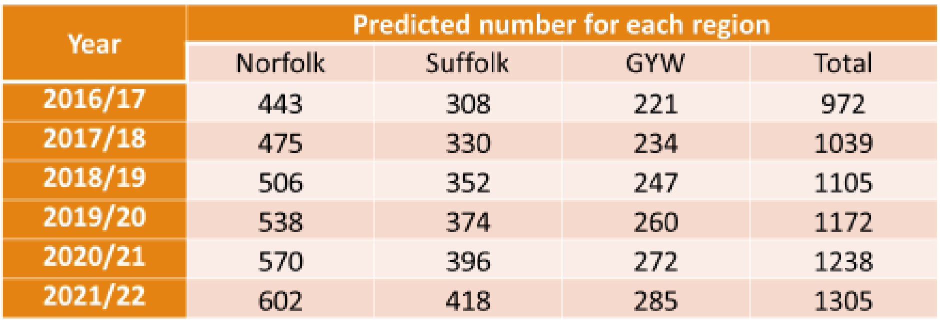
We will consider a prevalence of 0.4% as the baseline for projections. In addition, we will use an incidence estimate of 0.015%, as in (Nacul, Lacerda et al. 2011) which allows us to estimate a median disease duration of 26.7 years (Prevalence = Incidence x Duration).

Predictions

Based on current trend on the number of cases seen by year, we can predict future cases, if the current trend continues (Table 5 and Fig 4). This projection is somewhat artificial as it does not consider a number of factors, and in particular a trend to a plateau and then reduction in the number of new cases as coverage increases and saturation in the number of unseen cases is reached. With the total number of cases seen over 9 years of 5867 and an estimated prevalence of 6780 existing cases, it is tempting to suggest that a natural ‘plateau’ in number of new cases is approaching or has been reached; this is predicted to progressively fall in the next few years to reach a lower plateau in number of cases seen, mainly fed by incident cases, re-referrals and new cases due to improved accessibility.

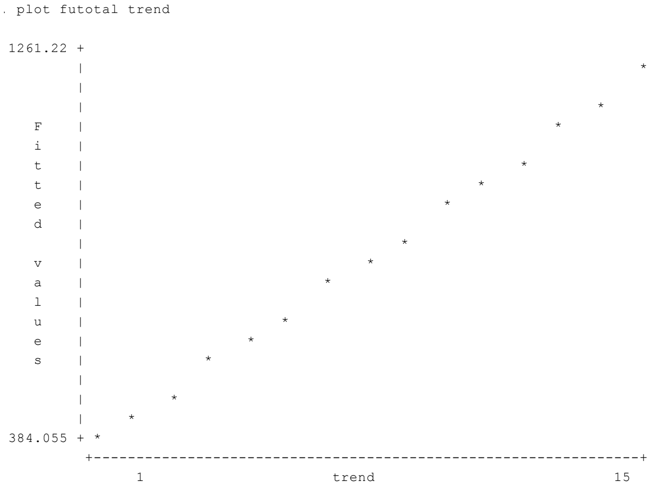
However, we need to build into the interpretation of these, re-referrals which might have been counted as new patients, patients without ME & CFS seen at the Service, incident cases (which can be estimated at 250 new cases/ year) and to a lesser degree the movement of patients into and out of the region.

Table 5. Predicted number of cases referred to the ECCH ME & CFS Service per year



Year	Predicted number for each region			
	Norfolk	Suffolk	GYW	Total
2016/17	443	308	221	972
2017/18	475	330	234	1039
2018/19	506	352	247	1105
2019/20	538	374	260	1172
2020/21	570	396	272	1238
2021/22	602	418	285	1305

Figure 4. Predicted increase of cases per year based on current trend



Box 4 shows factors that could affect the future number of new cases and of cases receiving treatment at any one time.

Box 4. Factors affecting number of cases seen by the Services

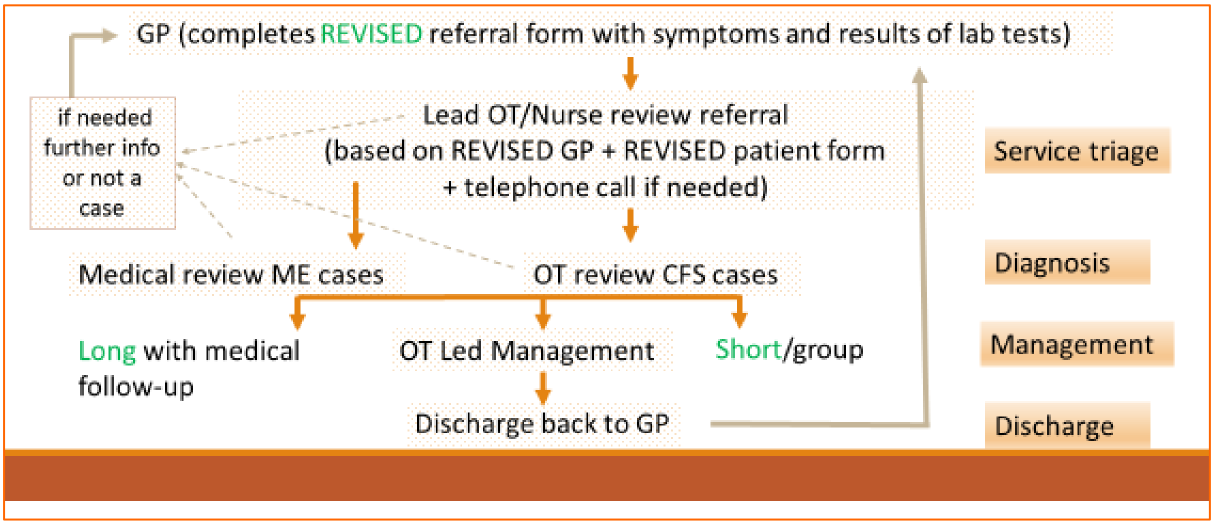
a) Level of recognition of ME & CFS in primary care
b) Referral criteria used
c) Agreed ME & CFS Service criteria for the acceptance of cases (related to referral criteria, and directly related to case definition)
d) Duration of treatment, including number of and time interval between follow-ups
e) Time to first appointments and discharge criteria
e) Accessibility to services and time to first appointment
f) Saturation of new cases with ME & CFS
g) Ability of GPs to treat milder cases in the community (linked to their knowledge and empowerment)

These factors not only depend on service capacity, but also on chosen care pathways, the GPs’ knowledge of ME & CFS and of the ECCH ME & CFS Service, all of which are affected by GP education.

IV. A MODEL FOR A SERVICE THAT MEETS THE NEEDS OF PEOPLE WITH ME & CFS

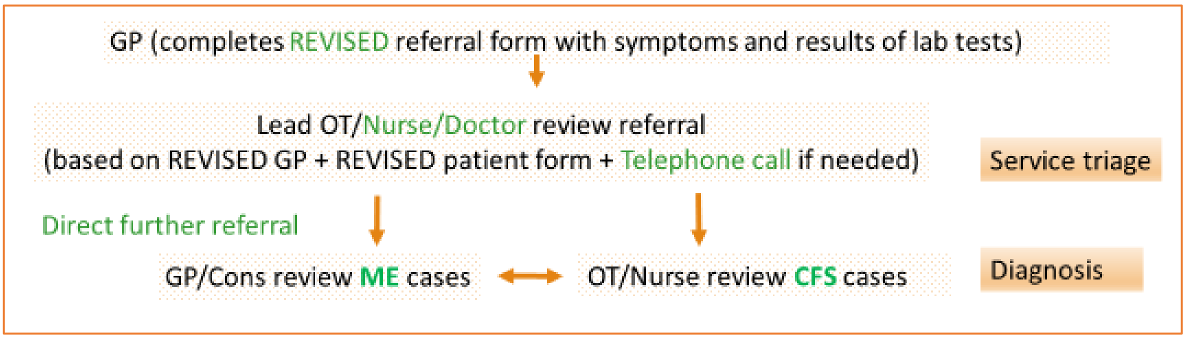
Based on the findings described in the previous sections, the following model is proposed to approximate the ECCH ME & CFS Service to the ‘Specification of Services document’, and take into account resource limitations. This model is summarised in Figure 5, and presented in more details in Figures 6 to 9.

Figure 5. Summary of proposed care pathway for ME & CFS Services in Suffolk and Norfolk



To enable the inclusion of a larger number of cases, it is essential to rationalise the management options. Improvements to the **GP Referral Form** and the **Initial Postal Assessment Form** could enable a higher yield of ‘**desk-based’ diagnosis** confirmations, reducing the number of cases requiring a GPwSI face-to-face appointment to confirm diagnosis. Moreover, clinical input into the ‘desk-based’ screening could further improve it. This could be enabled by a review of selected cases by the medical team (Consultant, GPwSi or, potentially, a clinical nurse specialist) when there is uncertainty, with patient contact when necessary by telephone (or video when appropriate and possible) to decide whether diagnosis according to criteria for acceptance to the ECCH ME & CFS Service can be established.

Figure 6. Proposed care pathway: Triage and diagnosis of cases



A major decision relates to which cases should be accepted and managed by the ECCH ME & CFS Service, and this depends on the diagnostic criteria used and on the mission of the Service, whether they propose seeing only those people with ME & CFS that meet specific criteria (such as the Canadian or ICC) or whether they aim to serve a broader population of people with chronic fatigue syndrome or chronic fatigue (e.g. those meeting NICE criteria for CFS).

The former may be too restrictive and exclude too many patients who have no other options for care; the latter could be too inclusive and unmanageable in secondary care. The 2012 HNA concluded with the following recommendation (Box 5).

Box 5. HNA Recommendations on criteria for service acceptance

If the intention is to provide a service specifically for ME/CFS then two possible approaches to system planning would be:

1. *Use the ICC as the entry point to the Service. The advantage is that they are clear, provide guidance to clinicians and target resources to the most serious cases. Those who do not meet the ICC but do meet CDC criteria could be kept under review with advice on pacing and referred to the Service after 6 months should no other cause for fatigue be found or at such earlier time as the GP thinks appropriate should symptoms worsen, or*
2. *Refer any patient who meets the CDC Criteria and allow the Specialist Service to decide whether further treatment or follow up is appropriate.*

Source: HNA 2012

We recommend a variation of the Option 2 (*refer any patient who meets the CDC Criteria and allow the Specialist Service to decide whether further treatment or follow up is appropriate).* At present, primary care is not well prepared to deal with cases of ME & CFS. However, this approach will ensure that cases meeting the most widely used diagnostic criteria (CDC-1994) have the opportunity to benefit from the ECCH

ME & CFS Service. The advantages of that have been noted in the 2012 HNA and are key principles of NICE and other guidelines (Box 6).

- Option 1 (*continuous review and potential re-referral in 6 months*) can be used for borderline cases, who meet neither CDC-1994 nor Canadian criteria. However, this could become the preferred option in the future, pending the successful education of GPs who would be enabled to manage CFS cases in primary care.
- Option 2 is in line with current NICE guidelines, which suggest that 50% of cases need referral to Specialist services, and the rest can be managed in primary care. While this should be a clear aim of the ECCH ME & CFS Service, it is not currently feasible due to the low level of recognition and understanding of ME & CFS in primary care.

Box 6. The key needs of people with ME & CFS

There is a need for:

- *a clear and accurate diagnosis as soon as possible. This is vital not only for management purposes but to enable individuals to adjust their lives and relationships*
- *empathy, listening and understanding from health professionals and the recognition that the impact of having to fight for recognition can, in itself, cause a deterioration in health*
- *reliable information for carers, patients and families*
- *support with disease management, reprioritisation and the minimisation of social isolation*

Source: NICE, 2003

It follows that 'desk-triage' could potentially correctly diagnose those meeting CDC-1994 criteria and offer them consultation at the Service; those not meeting the criteria would be referred back to the GP, explaining the reasons for non-acceptance and providing guidance on management of chronic fatigue in primary care. These cases should be few if the GP Referral Form is made more objective.

A basic assumption is that the Service will be seeing the 0.4% of the population, which is the estimated prevalence of ME & CFS, and that of these, 1/3 will require a clinical appointment, with 2/3 managed by OTs

We propose a change in the criteria used for a face-to-face medical appointment, based on compliance with the Canadian or ICC for moderate and severe disease. This could reduce the number of cases seen by a clinician by 50%, depending on training, development and testing of new protocols. In the short-term, the clinical team will still be seeing a number of milder cases meeting the Canadian Consensus definition and a few with uncertainties around diagnosis.

The GP in primary care should be empowered to make a diagnosis of ME & CFS and to manage many individuals independently

In the medium and long-term, GPs in the community should be able to manage at least 50% of cases, given an effective educational programme for GPs.

Fig 7 shows the potential ramifications and opportunities created if the above recommendations are implemented.

Figure 7. Proposal for procedures for diagnosis and insertion of patients into the Service

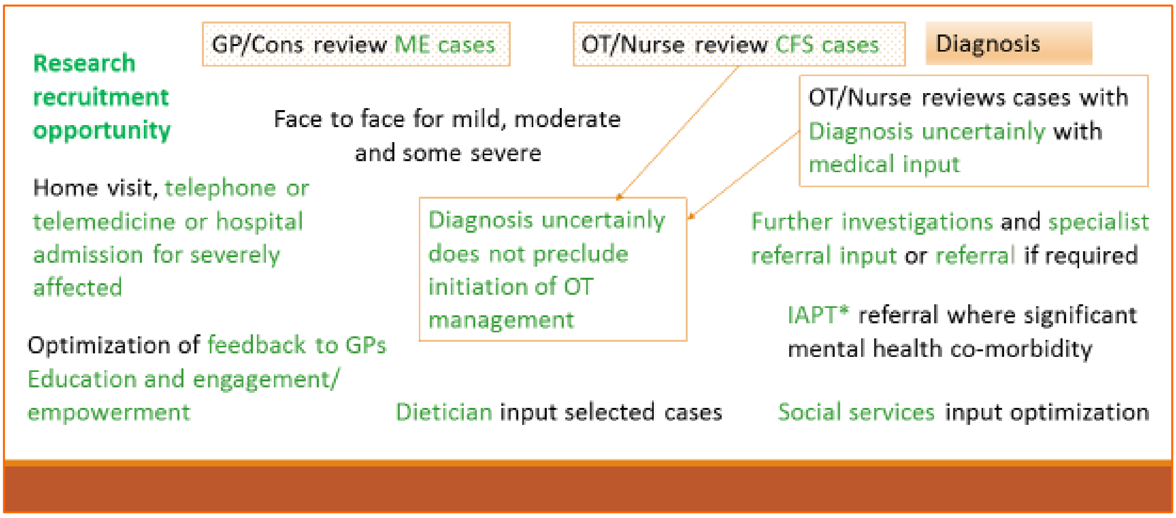
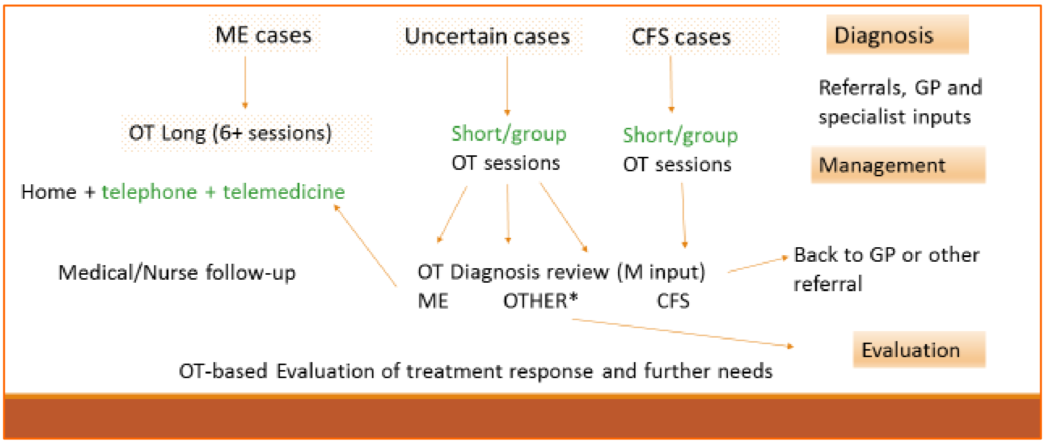


Fig 8 includes a proposal for a 2-tier management protocol, where people with ME & CFS (i.e. those meeting Canadian criteria including the most severely affected) are seen by the clinical team and are offered a more comprehensive follow-up, with a larger number of OT sessions, and will have at least one clinical follow-up after the first consultation (and before discharge). On the other hand, those with CFS (meeting CDC-1994 or other relevant criteria but not Canadian) may be offered group sessions, with the number of sessions reduced to 6 (rather than 10). In addition, a pilot scheme for a reduced number of sessions (3 or 4 individual sessions combined with a group session) could be attempted, to ascertain if a further reduction in number of sessions would be adequate for some patients.

Figure 8. Proposal for a two-tier system for managing cases of ME & CFS



These suggestions depend on some changes in job descriptions and in role descriptions, with the incorporation of a new consultant role (Box 7), and initial management by OTs where there is diagnostic uncertainty between CFS and ME.It is essential that the payment model is not changed (i.e. fixed fees to service for patients referred to the service); the rationale of optimising therapist (OT) input per indivudual patient aims to release OT time for seeing a larger number of patients without medical input and for other essential activities. Any reduction of income to the Service as a result of that would be counter-productive.

Box 7. Proposed roles for ME & CFS Service staff

Role variation

OT

- Early start of treatment when diagnosis uncertainty
- New models of OT care with less sessions for CFS patients
- Active evaluation of response to therapy
- Empowered to make decisions on diagnosis

GPSi

- Direct referrals, investigations and direct prescribing
- Clinical assessment of new cases
- Concentrate on ME cases
- Home and telephone contacts
- Follow-ups
- Support to OTs

Consultant input

Leadership role

- Research
- Education
- Evaluation
- Protocol
- Liaising with stakeholders/services
- Training and Supervision

Direct clinical input

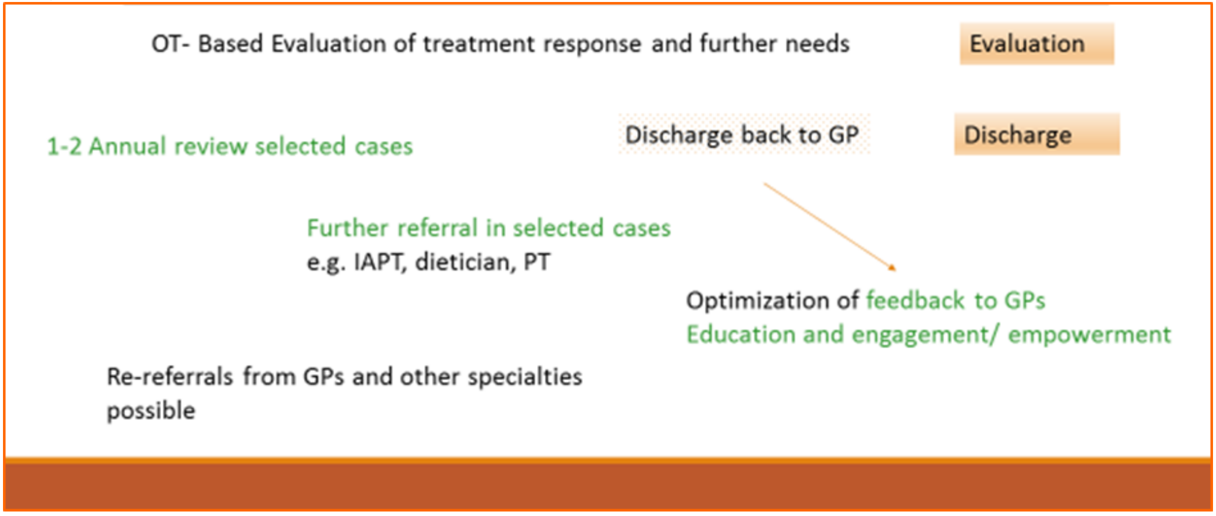
- New cases
- Follow-ups

Indirect clinical input

- Reviews, opinion

Figure 9 shows what happens towards the end of treatment, with mechanisms in place to ensure patients with on-going needs are looked after in primary care or through other Service referrals (e.g. IAPTs), and in some cases offered further input within the Service. Yearly follow-ups would be planned for selected cases in the medium to long-term, and could prioritise those severely affected or more likely to benefit from further follow-up based on clinical or OT assessment, which may include those with poor response to therapy.

Figure 9. Proposal for discharge of patients from ECCH ME & CFS Services



OT- Based Evaluation of treatment response and further needs

Evaluation

1-2 Annual review selected cases

Discharge back to GP

Discharge

Further referral in selected cases
e.g. IAPT, dietician, PT

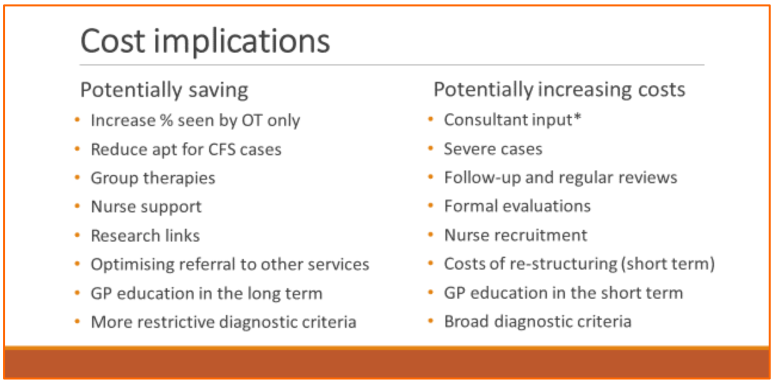
Optimization of feedback to GPs
Education and engagement/ empowerment

Re-referrals from GPs and other specialties possible

The challenge of the proposed care pathways is to balance cost-saving and cost-generating activities in such a way as to maintain cost-neutrality, while other options of income generation, for example research and, perhaps, educational activities are explored and put into practice.

Box 8 summarises some economic implications of the proposal, justifying the need for priority setting and for an incremental approach to the implementation of actions coupled with monitoring and evaluation activities to guide success and strategic re-planning.

Box 8. Cost implications of implementation of new service specification



Cost implications

Potentially saving

- Increase % seen by OT only
- Reduce apt for CFS cases
- Group therapies
- Nurse support
- Research links
- Optimising referral to other services
- GP education in the long term
- More restrictive diagnostic criteria

Potentially increasing costs

- Consultant input*
- Severe cases
- Follow-up and regular reviews
- Formal evaluations
- Nurse recruitment
- Costs of re-structuring (short term)
- GP education in the short term
- Broad diagnostic criteria

An essential concept is therefore that of an incremental approach to ECCH ME & CFS Service changes to ensure that patients are not disadvantaged by changes. To better inform this process, a discussion with stakeholders was held on 20 September 2016, which included a Prioritisation Exercise, where various stakeholders discussed their views on which of the actions should take priority for implementation, considering the limits in resources.

V. SETTING OF PRIORITIES FOR IMPLEMENTATION

Successful implementation requires consideration of a number of critical factors: economics, benefits, risks, and needs and preferences. To enable a cost-neutral and effective option for implementation, some degree of rationalisation is necessary. To ascertain the preferences of different stakeholders, we conducted a group discussion with input from representatives of CCGs, the ECCH ME & CFS Service, ME & CFS patients and patient representatives. Using the (aspirational) ECCH ME & CFS Service model as described above as a starting point for discussions, we formed 3 groups (a patient group; a CCG group; and a mixed group with Service, patient and external expert input). We asked the groups to score and prioritise a list of 9 items in order of importance, while taking into account cost-effectiveness, population coverage, feasibility (e.g. availability of resources and technology); acceptability (by target population); equity; and ethical, legal and social issues (Appendix 6).

All participants were asked to give individual scores from 1 (lowest importance) to 5 (highest importance) to each of the 9 items, and also to rank them from 1 (highest priority to 9 (lowest priority). The scores and ranks were then averaged within each of the groups, and aggregated into 2 priority indications (overall ranking of scores and overall ranking of ranks), based on the arithmetic overall mean of means in each group (with equal weighting of 1/3 given to each group). The 2 resulting indicators were averaged across the groups, generating the following (Table 6).

Table 6. Items in final priority order (from highest to lowest priority)

1	Inclusion of the severely affected
2	GP education and training
3	Early start of treatment/ management from referral
4	Medical follow-up of ME patients
5	Liaison with support, education and occupational services
6	Prescriptions, direct referral and investigations
7	Research and service evaluation
8	Distinction between ME and CFS
9	Treatment/management outside NICE

The 3 top priorities: ‘education and training of GPs’, ‘inclusion of severely affected’ and ‘early start of treatment from referral’ were highly ranked by all. ‘Research and service evaluation’ was the item with the most variability within opinions, with strong support from some, but was a low priority for those more directly involved in service commissioning and delivery.

Limitations included lack of time for lengthy discussions, the restriction of the priorities to just 9 (to be manageable), lack of weighting for different criteria (but incorporation of a range of criteria for decision making), and the uneven representation of different stakeholders, with only one Service representative, and significant representation from severely affected patients. Priorities for paediatric patients were not addressed in detail, and the suggestion is that for children the mechanism continues to be based on referral from a paediatrician who makes the initial diagnosis.

Implementation option

Examining the main priorities, there seems to be a consensus on the need for increased coverage (particularly for the severely affected), increased speed from referral to first appointment, and the education of health professionals (GPs in particular).

Addressing these needs has to be achieved within a cost-neutral model and the current payment of services structure, i.e. based on volume, with a fixed fee for each patient referred to the ME & CFS Service. Fees should be maintained at current levels adjusting only for inflation, with adjustments for periods of time of up to 6 months to allow for costs of implementing new activities, which may require minimal extra funding, and provisional compensatory measures to avoid over-spending. If other funding mechanisms were available, for example funds for education, training, and evaluation activities, then implementation could be achieved without any such temporary changes to the payment model. The rationale for the model is that the actual resources used for each patient will vary depending on individual needs, but Service income is the same for each patient, with those requiring fewer resources compensating for those requiring more. A departure from this payment model may invalidate this proposal.

Time gains from referral to first patient contact (the 3rd priority) with the ECCH ME & CFS Service may be facilitated by changes in the GP Referral Form and the Initial Postal Assessment Form and the more efficient “flow” of patients. This could lead to more efficiency in the desk-triage process. However, offering new face-to-face consultations depends on improved outcomes leading to quicker discharge, a reduction in direct time with each patient, or increased availability of staff to see new patients, all of this within the current (or an improved) payment system of per patient fee for referral to the Service. This could be generated by a reduction in number of sessions, by using group therapy sessions, and perhaps in the medium-term, by using telephone and “video” consultations to replace some face-to-face consultations.

The combined shift to a lower number of one-to-one average consultations per patient, with fewer patients being seen by clinician and a higher number being seen by OTs would further enable a more agile ‘processing’ of first and subsequent appointments. The recruitment of a nurse-specialist to the ECCH ME & CFS Service could help to refine the desk-triage, to better manage first appointments in cases of diagnostic uncertainties, and to reduce the number of patients needing a medical consultation. This could free doctor-time and enable other activities to be introduced, including priority activities such as more inclusion of the severely affected (the 1st priority), who may require home visits; and education – aiming in the short term at a better referral process, and in the longer term at enabling GPs to provide effective care of patients with ME & CFS in the primary care setting, by reducing the number of referrals of milder cases and increasing the number of referrals of severely affected patients.

Medical follow-up of patients (4th priority) could be introduced as a next step, aiming at one follow-up by clinical team (doctor or nurse) before discharge (medium-term aim) and the introduction of long-term yearly follow-ups of the severely affected (long-term aim).

Liaison with other services (5th priority) could be strengthened through networking activities, but this is an activity that is already in place.

Direct referrals and investigations, (the 6th priority), are probably easy to implement, due to new guidelines within the CCG, and move to a prescribing service could be considered as a medium-term goal.

Distinguishing between ME and CFS scored quite low, indicating a need to continue to cater for cases of ME and CFS alike, though different pathways (as above) can be implemented with more or less intense patient-contacts depending on their needs (with ME cases more likely to require more frequent or a greater number of appointments).

Research and evaluation activities scored low, as there is a perception that research is not a core ECCH ME & CFS Service activity. There was a consensus, however, that research activities should be encouraged, and other sources of funding sought. In this respect, the close relationship with a Patient Research Organisation together with academic links would be essential to unlock the research potential within the Service, in such a way that adds capacity and resources, without affecting core activities of service provision. Evaluation is a core activity of service and governance, and should continue in the form of audits and monitoring of outcomes. This, though not highly ranked in the prioritisation exercise, should be incorporated more fully within clinical care, as an activity that is by nature integral to clinical care (medium-term goal).

Finally, treatment outside NICE received the lowest priority, indicating that in spite of the limitation of the NICE guidelines, there is no perceived need for the Service to function in a way that departs from the guidance. This is perhaps facilitated by the broad nature of many of the NICE recommendations, the consideration they are meant to be used as a guide but do not restrict the doctor's independence (e.g. on investigations and prescribing); that co-morbidities are not addressed as part of NICE, and therefore they can be addressed proactively without departing from core guidance. Finally, but perhaps most importantly, the fact that there is very little evidence on what works and what does not work, and the pragmatic approach that patient support through legitimation, symptomatic treatment, rehabilitation and guidance on occupation/ education is the best that can be offered at the moment, while the Service waits for and contributes where possible to more research evidence.

VI. CONCLUSIONS AND SUGGESTED IMPLEMENTATION PLAN

This rapid review shows that it is possible to implement many of the aspects of the n specification for ME & CFS Services in a relatively short period of time. Proposed measures will address many of the needs of people with ME & CFS that remain unmet or only partially met, and improve equity in a cost-effective way and without changes to the current system of payment for the Service. This can be achieved with a step-wise approach to implementation of actions (with piloting, wider implementation and monitoring of specific actions). Key activities include training, education and empowerment of Service staff and health professionals in primary care, the recruitment of a part-time medical lead and ideally a part-time nurse specialist, the further development of pathways for care with the Service focus and provision according to patient need, with fewer patients receiving direct medical care, and those with less need receiving less intensive input from specialists. There will remain options for all to receive further treatment in primary care and where appropriate from other health care teams. The development of the Service will offer opportunities for funding from other sources, such as through research and training grants, and the prospect of the creation of a service that can more fully meet the needs of people with ME and CFS in the region, and as a model for ME/& CFS and other complex diseases nationally and internationally. The risks are low compared to the potential benefits, and the preservation of the payment model with only modest inputs from education and training budgets in the short term, will ensure that all activities are implemented with minimal budgetary implications. An implementation plan is outlined below. The timelines are achievable with a modest extra funding in the first 6 months to enable the implementation of the first action. In the absence of extra funding, it should still be possible to achieve all aims, although there may be a need for an extension of the initial period.

1. First 6 months
    - Recruitment of staff
    - Review of job plans
    - Review of forms
    - Pilot of new forms
    - New protocol for desk-triage
    - Planning of educational activities
    - Internal training and standardisation activities
    - Reduction in number of patients waiting too long for consultation (extra clinics)

2. 6-12 months
    - Introduction of new procedures (e.g. forms, pathways)
    - Educational activities primarily aimed at GPs
    - Planning for evaluation/audit activities
    - Exploring and integrating research opportunities
    - Seeking funding for research and other activities
    - Introduce follow-ups (pilot first)
    - Seek better integration with secondary care, social and occupational services
    - Explore ways to increase coverage of vulnerable and severely affected
    - Evaluation end of Year 1

3. Year 2
    - Review of procedures and protocols as needed
    - Good coverage of severely affected achieved (30% of severely affected?)
    - Review pathways for sub-groups e.g. paediatric patients
    - Establish follow-up of patients (30% to have one clinical follow-up)
    - Pilot follow-up of severely affected beyond 1 year
    - Explore telemedicine opportunities
    - Actively incorporate research into the Service (cost-neutral)
    - Consider inclusion of service expansion to secondary care (hospital based)

- Prescribing service status with direct referral and investigations achieved
- Intensify educational activities to GPs and other primary care staff
- Educational activities aimed at schools and employers
- Develop disability assessment protocol
- Review of evidence
- End of Year 2 evaluation

Year 3 and beyond

- Consolidate and adapt service model
- Primary care enabled to manage up to 50% of people with ME & CFS
- Streamline referrals according to need
- Coverage includes severely affected (50%+ of severely affected within the system)
- Coverage of population with ME & CFS (of at least 50% population seen)
- Follow-ups of patients with higher needs before discharge (30%?)
- Follow-up of selected patients beyond one year
- Telemedicine models implemented
- Research active service
- Dissemination activities to other services
- Service integrated with other services offered at primary and secondary care and some patients seen in secondary care

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Norfolk and Suffolk ME/CFS Service

Summary of Patient Change Audit 2012-2016

Questions:

1. Overall my illness has:

	2012	2013	2014	2015	2016
Improved	52%	57%	60%	56%	55%
No Change	27%	22%	17%	13%	7%
Got Worse	21%	21%	23%	31%	38%

2. My symptoms are:

	2012	2013	2014	2015	2016
Improved	43%	51%	54%	53%	50%
No Change	27%	20%	20%	16%	11%
Got Worse	30%	29%	26%	31%	39%

3. I am able to do:

	2012	2013	2014	2015	2016
Improved	46%	53%	53%	50%	50%
No Change	20%	30%	20%	23%	11%
Got Worse	34%	17%	27%	37%	39%

4. I am able to cope with my illness:

	2012	2013	2014	2015	2016
Improved	61%	69%	73%	64%	68%
No Change	20%	16%	13%	15%	5%
Got Worse	19%	15%	13%	20%	27%

5. I am able to control the severity of my symptoms:

	2012	2013	2014	2015	2016
Improved	64%	61%	50%	58%	64%
No Change	26%	19%	27%	19%	11%
Got Worse	10%	20%	24%	23%	25%

6. My feelings about the future course of my illness:

	2012	2013	2014	2015	2016
Improved	68%	56%	67%	62%	52%
No Change	12%	23%	7%	11%	16%
Got Worse	20%	21%	26%	27%	32%

7. Would you recommend the ME/CFS service to someone else:

	2012	2013	2014	2015
Yes	87%	95%	90%	89%
No	13%	5%	10%	11%

Response rates:

	2012	2013	2014	2015	2016
Number of questionnaires sent out	135	99	84	657	162
Number returned	60	46	30	133	45
% response rate	44%	46%	36%	20%	28%

east coast
community healthcare

NHS

Patient Change Audit – January 2016

ME/CFS Change Questionnaire

1. Introduction/Background

1.1 Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a complex condition with a range of symptoms, with each sufferer experiencing their own personal combination. Physical and/or mental fatigue is the most well-known symptom, but others include pain, disturbed sleep, and gastrointestinal problems.

1.2 ME/CFS is a relatively common condition – affecting 2-4 people in every thousand – that imposes a substantial burden on the health of the UK population.

1.3 The Norfolk and Suffolk ME/CFS service was set up in approximately 1999 and aims to provide a specialist resource to all health care professionals and patients on assessment, diagnosis and management of ME/CFS.

1.4 Patients with a confirmed diagnosis, and their carers, are given support by the team to devise a strategy, which will enable management of ME/CFS within the individual's lifestyles. The aim of treatment is to maximise opportunity for recovery.

1.5 The questionnaire aims to capture how the service has improved the lives of patients with this debilitating condition.

2. Aims and Objectives

2.1 The aim of the clinical audit was:

2.2 To determine whether the ME/CFS service is making a difference to patients suffering from the condition.

2.3 The objectives were:

1. To gauge whether patients feel that they are improving since having contacted the ME/CFS service
2. To determine whether patients are better able to manage their symptoms since contact with the ME/CFS service
3. To determine whether patients' outlook for the future is positive
4. To determine demographics of those patients responding to the audit
5. To ascertain patients perception of doctor and therapists view of ME/CFS
6. To ascertain patients view of the quality of the initial assessment report

7. To gauge whether changes to questionnaire have been useful

8. To compare results from previous audit in January 2015 to see if changes implemented as a result of audit have improved patient care

3. Project Team

3.1 The project team were:

- Jo Wiggins – Specialist Practitioner Occupational Therapist
- Louise Halliday – Specialist Occupational Therapist
- Donna Edwards – Administrator/support secretary

4. Methodology

4.1 All patients who were referred to the service between January – June 2014 and who received a diagnosis of ME/CFS were sent a questionnaire to complete, along with a freepost return envelope. There were six questions, each with a sliding scale from minus 5 (worse) to plus 5 (better) along with a question about whether the patient would recommend the service to other people and space for comments. This year we also added questions regarding patient's opinion on the severity of their illness, the views of the Doctor/therapist they saw, the quality of the report they received and functional improvements/deterioration that may have occurred.

4.3 The letter sent to patients explaining about the survey is attached at Appendix 1.

4.2 The questionnaire is attached at Appendix 2.

4.3 The total number of questionnaires sent out was 162.

5. Results/Findings

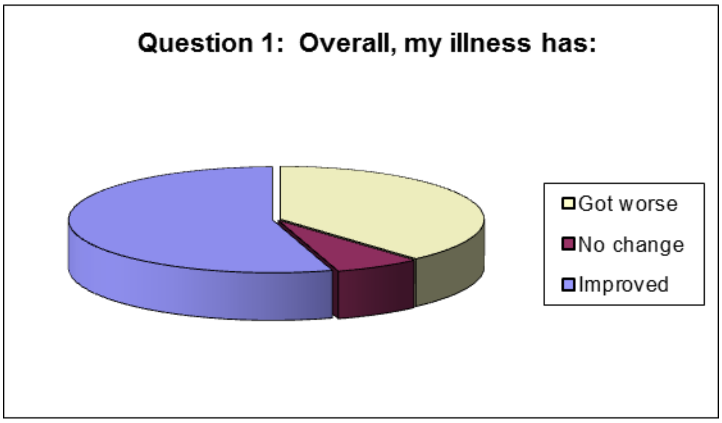
5.1 45 questionnaires were returned which represents a return rate of 28%. However one patient did not complete any of the following 6 questions so all results are out of 44.

Question 1

Overall, my illness has…

55% of respondents stated that overall their illness has improved since contacting the ME/CFS Service.
7% of respondents stated that overall their illness had not changed since contacting the ME/CFS Service.
38% of respondents stated that overall their illness had got worse since contacting the ME/CFS Service.

Got Worse -5	1	2%
Got Worse -4	5	11%
Got Worse -3	4	9%
Got Worse -2	6	14%
Got Worse -1	1	2%
No Change	3	7%
Improved 1	12	27%
Improved 2	4	9%
Improved 3	4	9%
Improved 4	3	7%
Improved 5	1	2%

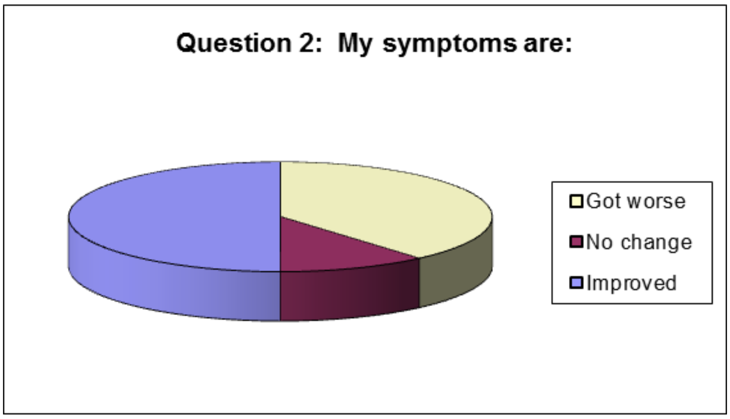


Question 2

My symptoms are:

50% of respondents stated that their symptoms have improved since contacting the ME/CFS service.
11% of respondents stated that their symptoms have not changed since contacting the ME/CFS service.
39% of respondents stated that their symptoms have got worse since contacting the ME/CFS service.

Got Worse -5	0	0%
Got Worse -4	6	14%
Got Worse -3	4	9%
Got Worse -2	5	11%
Got Worse -1	2	5%
No Change	5	11%
Improved 1	92	20%
Improved 2	6	14%
Improved 3	4	9%
Improved 4	3	7%
Improved 5	0	0%

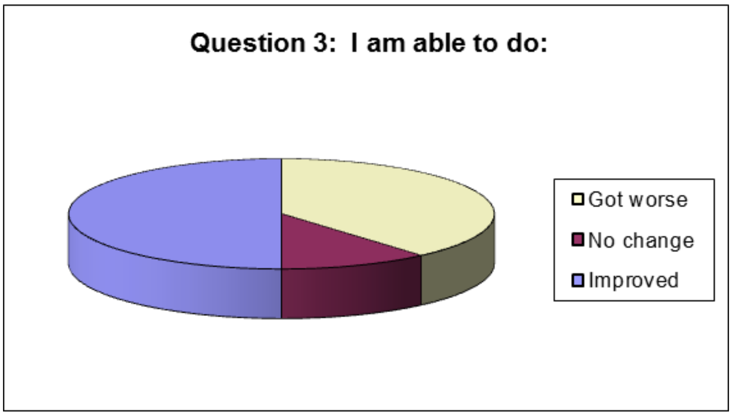


Question 3

I am able to do…

50% of respondents stated they are able to do more since contacting the ME/CFS service.
11% of respondents stated that there has been no change in how much they are able to do since contacting the ME/CFS service.
39% of respondents stated they are able to do less since contacting the ME/CFS service.

Got Worse -5	1	2%
Got Worse -4	7	16%
Got Worse -3	3	7%
Got Worse -2	6	14%
Got Worse -1	0	0%
No Change	5	11%
Improved 1	12	27%
Improved 2	4	9%
Improved 3	4	9%
Improved 4	2	5%
Improved 5	0	0%

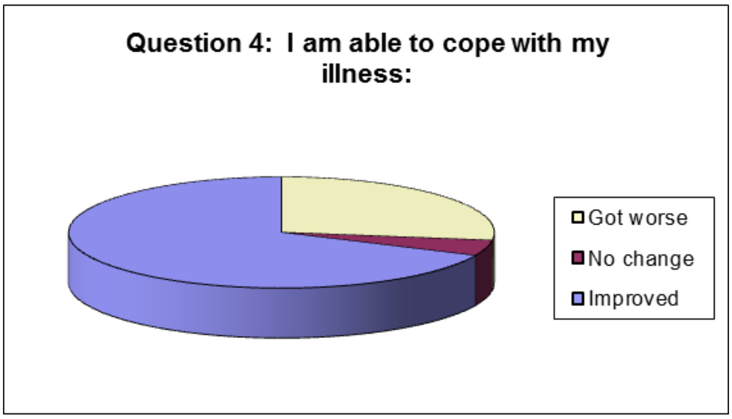


Question 4

I am able to cope with my illness…

68% of respondents said that they are better able to cope with their illness since contacting the ME/CFS service.
5% of respondents said that there has been no change in their ability to cope with their illness since contacting the ME/CFS Service.
27% of respondents said that they were less able to cope with their illness since contacting the ME/CFS service.

Got Worse -5	0	0%
Got Worse -4	5	11%
Got Worse -3	1	2%
Got Worse -2	4	9%
Got Worse -1	2	5%
No Change	2	5%
Improved 1	8	18%
Improved 2	6	14%
Improved 3	12	27%
Improved 4	2	5%
Improved 5	2	5%

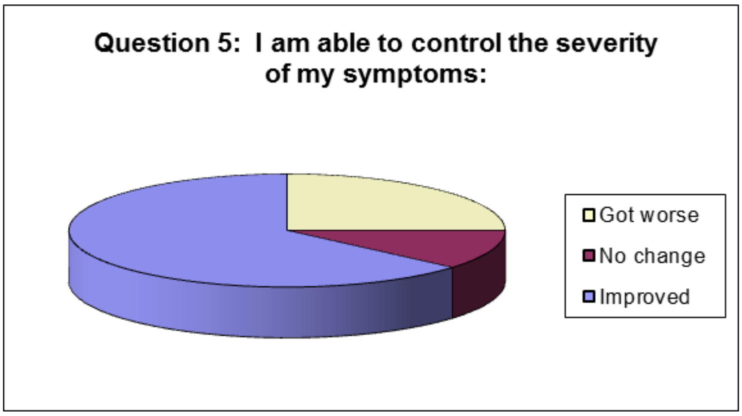


Question 5

I am able to control the severity of my symptoms…

64% of respondents stated they were better able to control the severity of their symptoms since contacting the ME/CFS service.
11% of respondents stated that there was no change in their ability to control their symptoms since contacting the ME/CFS service.
25% of respondents stated that they were less able to control the severity of their symptoms since contacting the ME/CFS service.

Got Worse -5	0	0%
Got Worse -4	4	9%
Got Worse -3	2	5%
Got Worse -2	4	9%
Got Worse -1	1	2%
No Change	5	11%
Improved 1	9	20%
Improved 2	10	23%
Improved 3	5	11%
Improved 4	3	7%
Improved 5	1	2%

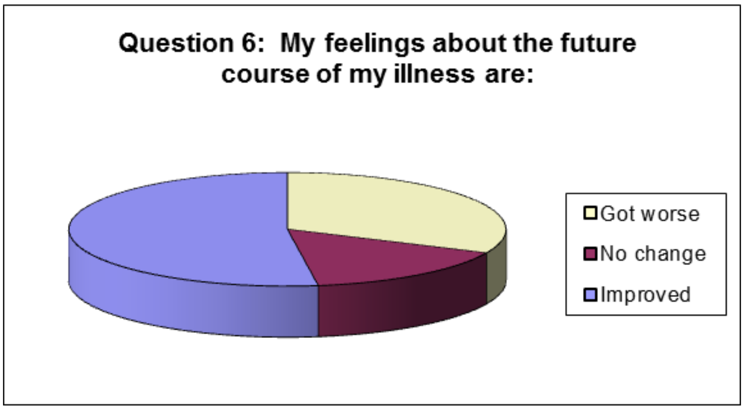


Question 6

My feelings about the future course of my illness are…

52% of respondents were more positive about the future course of their illness.
16% of respondents report no change in their feelings about the future course of their illness.
32% of respondents were more negative about the future course of their illness.

Got Worse -5	1	2%
Got Worse -4	5	11%
Got Worse -3	2	5%
Got Worse -2	4	9%
Got Worse -1	1	5%
No Change	7	16%
Improved 1	8	18%
Improved 2	6	14%
Improved 3	3	7%
Improved 4	5	11%
Improved 5	1	2%



Demographic Questions:

- Patient considers themselves:

  Mild: mobile and able to self-care, able to do light domestic tasks with difficulty, likely to be in work/education, but stopped all leisure pursuits and need to take time off or use weekends to rest

  Moderate: reduced mobility, restricted in all aspects of daily living, symptoms fluctuate. Usually stopped work/education, need rest/sleep during the day and experience poor quality sleep at night

  Severe: significantly reduced mobility, spend much of the day in bed, rarely able to leave the home, minimal daily tasks only, severe cognitive difficulties, sensitive to light and noise and severe prolonged after effects from effort

  Very severe: unable to mobilise or carry out daily tasks, restricted to bed, often unable to tolerate any noise and likely extremely sensitive to light and touch, may be unable to speak or swallow

	Mild	Moderate	Severe	Very Severe	Question not completed
Number of patients	17	17	6	3	2
% of patients	37.8	37.8	13.3	6.7	4.4

1. If you did not receive a diagnosis of ME or CFS, was a report sent to you and your GP with an explanation and recommendations for further investigations?

Yes:	5	(11%)
No:	1	(2.2%)
Not applicable:	38	(84.4%)
Not completed:	2	(4.4%)

2. Is this your first referral to the ME and CFS Service or have you been re-referred?

First Referral:	31	(68.9%)
Re-referral:	14	(31.1%)
Not completed:	0	(0%)

3. When you accessed the ME and CFS Service did you see:

A doctor:	17	(37.8%)
A therapist:	15	(33.3%)
Both:	13	(28.9%)
Not sure – enter their name(s) here:	0	(0%)
Not completed:	0	(0%)

4. Did your doctor believe your ME or CFS to be:

A physical illness:	14	(31.1%)
A mixture of physical and psychological illness:	18	(40%)
A psychological illness:	0	(0%)
Didn't see a Doctor:	4	(8.9%)
Not completed:	9	(20%)

Excluding those who did not see a doctor or complete the question:

A physical illness:	14	(43.8%)
A mixture of physical and psychological illness:	18	(56.3%)
A psychological illness:	0	(0%)

5. Did your therapist believe your ME or CFS to be:

A physical illness:	18	(40%)
A mixture of physical and psychological illness:	13	(28.9%)
A psychological illness:	0	(0%)
Didn't see a therapist:	3	(6.7%)
Not completed:	11	(28.4%)

Excluding those who did not see a therapist or complete the question:

A physical illness:	18	(58.1%)
A mixture of physical and psychological illness:	13	(41.9%)
A psychological illness:	0	(0%)

6. How would you describe the report sent back to you following assessment by the doctor?

All respondents:

Excellent:	11	(28.4%)
Good:	16	(35.6%)
Average:	8	(17.8%)
Poor:	0	(0%)
Very Poor:	0	(0%)
Didn't see a doctor:	7	(15.6%)
Not completed:	7	(15.6%)

Excluding those who did not see a doctor or complete the question:

Excellent:	11	(31.4%)
Good:	16	(45.7%)
Average:	8	(22.9%)
Poor:	0	(0%)
Very Poor:	0	(0%)

7. How would you describe the report sent back to you following assessment by your therapist?

Excellent:	14	(31.1%)
Good:	9	(20%)
Average:	6	(13.3%)
Poor:	0	(0%)
Very Poor:	0	(0%)
Didn't see a therapist:	7	(15.6%)
Not completed:	9	(20%)

Excluding those who did not see a therapist or complete the question:

Excellent:	14	(48.3%)
Good:	9	(31.9%)
Average:	6	(20.7%)
Poor:	0	(0%)
Very Poor:	0	(0%)

8. Please tick the box that most describes you.

Since my referral or re-referral to the ME and CFS Service I have:

Improved		***No Change***		***Deteriorated***	
Returned to work or education full time	11	Had no change in work, education, voluntary work	14	Reduced work, education or voluntary work	3
Returned to work or education part time	6	Had no change in hobbies, social activities	7	Reduced participation in hobbies and/or social activities	8
Undertaken some voluntary work	3			Stopped work, education, voluntary work	8
Increased participation in hobbies and/or social activities	8			Stopped participation in hobbies and/or social activities	8

Not completed: 3 forms

5.2 Comments

5.2.1 Comments from respondents are attached at Appendix 3.

6. Conclusions

6.1 All of the questions showed that the ME/CFS Service is helping patients to manage their symptoms and generally improve their condition.

6.2 Over half (55%) of the respondents stated their illness had improved since contacting the service and over two thirds (68%) stated that they are better able to cope with their illness since contacting the service. This is a small deterioration to last year's where 55% stated their illness had improved, however an improvement in those who felt better able to cope with their illness from 64% last year to 68% this year. There was also an improvement in the number of people who felt they were better able to control their symptoms from 58% to 64%. There was some deterioration in those who felt their symptoms had improved from 53% to 50%. There was also a deterioration in those who felt more positive about the future course of their illness from 62% to 50%.

6.3 At the time these patients were seen the service consisted of four part time GPwSI, four full time OT's, three part time OT's and one part time physiotherapist. The service make up has changed since that time. It now has 2 GPwSI, four full time OT's, two part time OT's (one of whom is going on maternity leave in January 2016) and one part time physiotherapist. We are in the process of recruiting an extra 0.4 WTE OT/PT.

6.4 There was a response rate of 28%. This is an increase from 20% returning the questionnaires last time. However we excluded this time all those who did not have a diagnosis of ME/CFS following their initial appointment or those who had never had an initial appointment (e.g. DNA'd first appointment, did not complete paperwork. There were a number of comments on the questionnaire that it was confusing and took a long time to complete "it took me 2 hours to fill this form in and now I'm knackered", "sorry too confusing for me". A number of individuals particularly commented about question 4 and 5 in section 1, that they were unsure whether this was about their own G.P or the GPwSI/therapist they saw in clinic "which doctor? My G.P?" "?", "my G.P gave no indication of what she thinks", "is it a therapist at the ME clinic".

6.5 We asked a number of new questions in this questionnaire. In terms of demographics 75.6% of patients considered their condition to be mild or moderate, 13.3% considered their condition to be severe and 6.7% considered themselves to be very severely affected.

6.6 68.9% of those who returned questionnaires were new referrals to the clinic and 31.1% were re-referrals.

6.7 Excluding those who did not see a doctor or who did not complete the question 43.75% felt the doctor they saw believed the illness to be physical and 56.25% felt the doctor thought it was a mixture of physical and psychological. Excluding those who did not see a therapist or complete the question 58.1% felt their therapist believed the illness to be physical and 41.9% felt their therapist believed it to be a mixture of physical and psychological. No one indicated that either the GPwSI or therapist they saw felt that the illness was a psychological illness.

6.8 Excluding those who did not see a doctor or did not complete the question 77.1% of respondents felt that the report they received following their initial assessment was either "excellent" or "good". 22.9% felt that it was average. Excluding those who did not see a therapist or did not complete the question 79.3% of respondents felt that the report they received following their initial assessment was either "excellent" or "good". 20.7% felt that it was average. None of the respondents indicated that the report they had received from either the GPwSI or therapist was poor or very poor.

6.9 Overall 28 respondents reported there had been improvements in being able to do more e.g. returning to work/education or participating in hobbies or voluntary work. 21 felt there had been change in these and 27 felt there had been a deterioration (a number of people ticked more than 1 response).

7. Recommendations

7.1 To look at questionnaire to make it easier to complete (may increase response rate) and to look at questions 4 and 5 in section 1 so that they are more easily understandable.

7.2 To do thematic response analysis of comments and produce action plan from this.

7.3 Recruit to current therapy vacancy

8. Action Plan

Recommendation	Action to be Taken	Lead Person	Timescale
Thematic analysis of comments and action plan from this	As per recommendation	Louise Halliday	June 2016
Discuss comments/results with team	Audit results and comments to be discussed with whole team at next staff meeting	Louise Halliday	April 2016
Recruit to current therapy vacancy	Vacancy advertised – to continue with process	Louise Halliday	April 2016

Jo Wiggins/Louise Halliday
Specialist Practitioner Occupational Therapist

Appendix 1

ME/CFS Service
Kirkley Mill Health Centre
Clifton Road
Kirkley
Lowestoft
Suffolk
NR33 0HF

Dear

We are writing to you on behalf of the Norfolk and Suffolk ME/CFS Service. The service is currently carrying out an audit to measure how the treatment you received may have affected your condition.

We would be grateful if you could complete and return the enclosed short questionnaire in the prepaid envelope provided. Your answers and comments will be treated as entirely confidential.

The data collected will help the service to assess the overall progress of patient's that are seen and improve what we can offer.

Please note that pages 5 and 6 are simply there to help you complete the questionnaire and do not need to be returned to us.

If you are happy to complete and return the questionnaire, we ask you to do so by **6th January 2016.**

Thank you for your co-operation.

Yours sincerely

Donna Edwards
Support Secretary
<u>Norfolk and Suffolk ME/CFS Service</u>

SECTION 1

To enable us to fully assess the results of this survey can you please let us know how severely you are currently affected by ME or CFS:

☐ Mild: mobile and able to self-care, able to do light domestic tasks with difficulty, likely to be in work/education, but stopped all leisure pursuits and need to take time off or use weekends to rest

☐ Moderate: reduced mobility, restricted in all aspects of daily living, symptoms fluctuate. Usually stopped work/education, need rest/sleep during the day and experience poor quality sleep at night

☐ Severe: significantly reduced mobility, spend much of the day in bed, rarely able to leave the home, minimal daily tasks only, severe cognitive difficulties, sensitive to light and noise and severe prolonged after effects from effort

☐ Very severe: unable to mobilise or carry out daily tasks, restricted to bed, often unable to tolerate any noise and likely extremely sensitive to light and touch, may be unable to speak or swallow

9. **If you did not receive a diagnosis of ME or CFS, was a report sent to you and your GP with an explanation and recommendations for further investigations?**

☐ Yes

☐ No

☐ Not applicable

10. **Is this your first referral to the ME and CFS Service or have you been re-referred?**

☐ First Referral

☐ Re-referral

11. **When you accessed the ME and CFS Service did you see:**

☐ A doctor

☐ A therapist

☐ Both

☐ Not sure – enter their name(s) here:

12. **Did your doctor believe your ME or CFS to be:**

☐ A physical illness

☐ A mixture of physical and psychological illness

☐ A psychological illness

☐ Didn't see a Doctor

13. **Did your therapist believe your ME or CFS to be:**

☐ A physical illness

☐ **A mixture of physical and psychological illness**

☐ **A psychological illness**

☐ **Didn't see a therapist**

14. **How would you describe the report sent back to you following assessment by the doctor?**

☐ **Excellent**

☐ **Good**

☐ **Average**

☐ **Poor**

☐ **Very Poor**

☐ **Didn't see a doctor**

15. **How would you describe the report sent back to you following assessment by your therapist?**

☐ **Excellent**

☐ **Good**

☐ **Average**

☐ **Poor**

☐ **Very Poor**

☐ **Didn't see a therapist**

16. **Please tick the box that most describes you.**

Since my referral or re-referral to the ME and CFS Service I have:

Improved		***No Change***		***Deteriorated***	
Returned to work or education full time		Had no change in work, education, voluntary work		Reduced work, education or voluntary work	
Returned to work or education part time		Had no change in hobbies, social activities		Reduced participation in hobbies and/or social activities	
Undertaken some voluntary work				Stopped work, education, voluntary work	
Increased participation in hobbies and/or social activities				Stopped participation in hobbies and/or social activities	

SECTION 2

Please circle a number for each of the questions below to indicate how you feel **now** compared with how you felt **before** contact with the ME and CFS service.

If you circle 0 this would indicate no change. The higher the number in either direction, the greater the change.

1. Overall, my illness has:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **Got worse** **No change** **Improved** →

2. My symptoms:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **Are worse** **No change** **Have improved** →

3. I am able to do:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **Less** **No change** **More** →

4. I am able to cope with my illness:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **Less well** **No change** **Better** →

5. I am able to control the severity of my symptoms:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **Less** **No change** **More** →

6. My feelings about the future course of my illness are:

-5 -4 -3 -2 -1 0 1 2 3 4 5

← **More negative** **No change** **More positive** →

If you have any comments you would like to make, please write them on the next page.

7. Comments

Thank you for your time and help in completing this questionnaire.

Please return in the enclosed prepaid envelope.

In conjunction with The Patient and Carers Group, the Norfolk and Suffolk ME and CFS Service is in the process of being redesigned. The Patient and Carers Group website - http://nandsme.blogspot.co.uk/ - provides an overview of progress of work being undertaken. N.B. Please note that ECCH is not responsible for the content of this site and the information provided within.

Feedback to the Patient and Carer group regarding the service is also welcomed, and can be anonymous if you prefer. Email meandcfs@zoho.com or ring 07909 177 236. Help and support is available from ME Support Norfolk (you can also join if you live in Suffolk) email mesnorfolk@btinternet.com or ring 01263 861521. Total Voice Suffolk provide an independent NHS Complaints advocacy service, ring 01473 857361 for more information.
See - Curruthers et al. Myalgic Encephalomyelitis: International Consensus Primer for Medical Practitioners (2012)

Symptom		Mild	Mod.	Severe
Post-Exertional Neuroimmune Exhaustion				
	Physical or mental exertion (which maybe minimal) causes rapid exhaustion, which is unrelieved by rest, and which can be debilitating and result in relapse			
	Loss of physical and mental stamina which substantially reduces activity levels			
	Symptoms made worse following exertion			
	Post-exertional exhaustion: maybe immediate or delayed by hours or days			
	Long recovery period from exertion, usually more than 24 hours			
Neurological Impairments				
	Poor short term memory			
	Confusion, difficulty concentrating, difficulty in making decisions ('brain fog')			
	Difficulty in retrieving words or saying the wrong word			
	Pain: may include muscles, joints, abdomen, chest, headaches			
	Sleep Disturbance: may include non restorative sleep, insomnia, prolonged sleep, vivid dreams, early waking, frequent waking, sleep reversal			
	Sensitivities: may include to light, noise, vibration, odour, taste, touch			
	Inability to focus vision			
	Impaired depth perception			
	Muscle weakness: may include twitching, poor coordination, feeling unsteady on feet, ataxia (can affect balance, walking, speech, swallowing, vision, motor control – e.g. writing, eating)			
Immune, Gastrointestinal & Genitourinary Impairments				
	Recurrent flu like symptoms which often worsens with exertion			
	Recurrent sore throat / tender/enlarged lymph nodes in neck / under arms			
	Susceptibility to viral infections with prolonged recovery periods			
	Gastrointestinal tract symptoms: may include nausea, bloating, IBS, diarrhoea, abdominal tenderness			
	Genitourinary disturbances: may include urinary urgency or more frequent urination, needing to urinate more than once during the night			
	Sensitivities to food, medications, alcohol, odours or chemicals			
Energy production/transportation impairments				
	Cardiovascular: may include dizziness/light-headed when upright/standing, palpitations, extreme pallor			
	Respiratory: may include laboured breathing, air hunger, fatigue of chest wall muscles			
	Loss of thermostatic stability: sweating, cold extremities			
	Intolerance of extremes of temperature			

Appendix 2: Sleep and Pain Profile

Name: Date: to

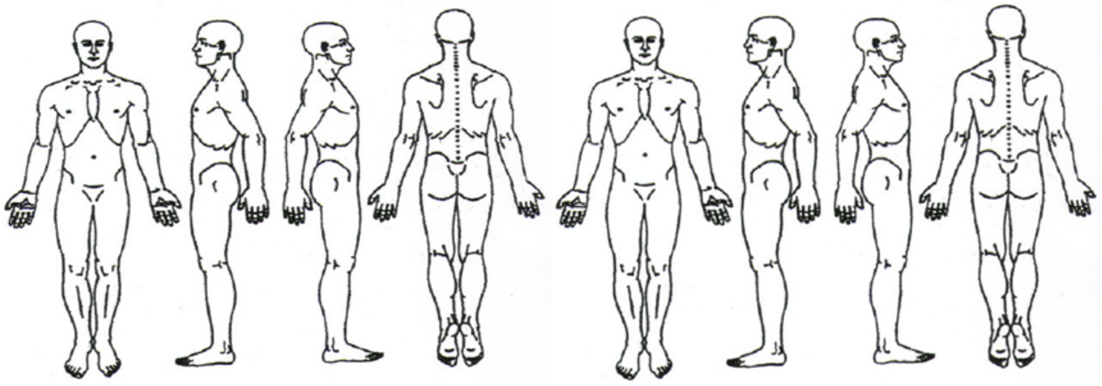
Date	Energy % a.m.	Pain 0-10	HR	BP	Activities/Factors	Energy Day ↑↓	Pain Day↑↓	Body temp.	Min. to fall asleep	Time Slept	Awake # of min.	Depth 1-5	Refreshed 0-10
Sun													
Mon													
Tues													
Wed													
Thur													
Fri													
Sat													
Sun													
Mon													
Tues													
Wed													
Thur													
Fri													
Sat													

Pain Visual Analog Scale (PAIN VAS): Indicate the amount of pain you have had in the last 48 hours by marking a '/' through the line.

0 1 2 3 4 5 6 7 8 9 10

No Pain **Excruciating Pain**

Body Pain Diagrams: **Aching: ===== , Burning Pain: xxxxx, Stabbing Pain: //////, Pins & Needles: ooooo, Joint Pain: •••••**
Other Pain: ppppp Describe:



Pain on Day 1

Pain on Day 14

Visual Energy & Pain Chart **Blue line: Energy** **Red line: Pain**

	Sun.	Mon.	Tues.	Wed.	Thur.	Fri.	Sat.	Sun.	Mon.	Tues.	Wed.	Thur.	Fri.	Sat.
100%														
90%														
80%														
70%														
60%														
50%														
40%														
30%														
20%														
10%														

1. No comment
2. I am writing this on behalf of **** who has had no help since Dr Mitchell retired several years ago. What **** and other very severely affected patients need is a specialist who can liaise with their GP and refer to other Health professionals who may be able to help and advice. **** has been ill since 1992 and in that time she has had no help whatsoever from the ME Service. The severely affected are neglected and forgotten about. It is time that the Health service appointed a specialist who will re-organise the ME service and make the severely affected their first priority.
3. Having ****, my ME Specialist Occupational Therapist is good as it's someone to fight my corner. She also puts my mind at ease. I may report a set of symptoms and she shall say "A lot of my patients say that happens when they get over tired". Please find a cure I want my life back. I contemplate suicide so often as this is no life. Please don't stop this service it's the only hope I have. P.s To give you some idea it took me 2 hours to fill this form in and now I'm knackered.
4. No comment.
5. I found having access to the service was key to my recovery because even though I had read widely on the subject, having personal contact with a specialist was so valuable. Having a human link to support made a big difference psychologically. Knowing someone was there was a big help when I felt quite fragile and vulnerable, even though I never actually made any additional appointments. Reading between the lines of the questionnaire and what you are considering as you redesign the service, I would say that from my point of view the important thing would be being able to provide a good level of contact and support post diagnosis.
6. Since visiting my OT I have actually listened to her and I now try to pace and take things easier. This has really helped me as I'm not so exhausted and in agony at the end of each day, so taking less pain relief too. It's been very difficult for me to slow down as I've always been very active, coming to terms with having ME/CFS has been hard but my OT has given me hope that I can keep it under control and who knows one day be able to be a lot more active and pain free again.
7. I have felt that **** the therapist I have seen on several occasions to be very helpful and understanding.
8. Before I had contact with the service, I was working fulltime as a solicitor. I contacted the service for help as I was becoming unwell. They were great and gave me advice on how to manage, but my employer had other ideas to ensure I couldn't manage, to force me out. As a result of my employer's actions my health continued to deteriorate until I had to leave work completely, I was devastated by this. I have been very unwell ever since, with brief periods of improvement. My deterioration and/or improvements have not been affected by the ME service. They have been supportive however and in that respect the service has been vitally important. There are no treatments, but having contact with a service whilst I'm otherwise left to languish in my bed for the last 6 years, has helped me keep going. Stopped me becoming more depressed about my situation. That being said as I was erroneously discharged whilst still really unwell, this was pretty devastating. Want the service to offer the following: 1 Help to resolve insomnia. I was eventually put on Mirtazapine by GP and slept properly for the first time in many years. This improvement allowed me to recover to an extent and I was also a volunteer until I relapsed again, increasing the dose produced listlessness, languor and inertia. 2 Help to improve immune system. My private doctor put me on a low dose of Naltrexone. This helped; also it helped me sleep a little. 3. The body develops deficiencies and abnormalities as a result of mitochondrial dysfunction when suffering from ME. Assessment and treatment of this indemnisable (sic) issues, would help.
9. The relaxation techniques and advice offered by OT have helped ne to structure my day (activity/rest balance) more effectively. I have fibromyalgia which has similar ME/CFS symptoms. Physically I am struggling more with daily life skills.

10. I was diagnosed as having ME/CFS by Dr **** re q4. I do not know how he views the condition. And I did not see a therapist unless that means the ongoing appointments at clinic but it said about an assessment on questionnaire so I guess not. And I do not know how they view it either? (q5,q7) The form does not ask how I view it but would answer a mixture of physical and psychological. The benefit I gain from having an appointment for half an hour every 3 months is to know that someone understands the condition and am not totally alone. But I won’t see now the service can affect the scale ratings overleaf as it is so minimal. But still appreciated thanks.
11. When I first saw the OT I was in education part time on a lower course than I would have been capable of prior to ME/CFS. She wrote to the college with helpful information to make my life easier. Most of these things were not possible for them to implement and after recurring symptoms and infections my energy and thinking capacity declined even more and I could no longer attend. The OT mainly tried to help with pacing but after three weeks of daily pushing and resting I crashed and had to have complete rest and was very limited to what I was able to achieve in a day. On returning to the OT I was advised that to help myself I needed to pace myself and try to lift my mood. I was aware both things were a positive step to recovery but no matter how much I wanted to be doing more, my body and mind wouldn’t let me without suffering big consequences for weeks, I am still in bed the majority of time and would say if I can do something once a fortnight I am lucky. Don’t know where I go from here as pain relief for constant headaches/migraine hasn’t been effective although GP/ME/CFS specialist has tried all medications and referred to head pain specialist at N/N hospital. He has tried medication, injections etc. and referred to physiotherapy via GP for treatment of head, back, neck pain. The Physiotherapist has said it would probably not achieve anything. On the attached list that came with this form (pg. 5) I have around 90% of symptoms.
12. No comments
13. It was getting steadily worse before my referral although the programme has been unable to halt the deterioration I have found it useful. I didn’t understand how to use pages 5 and 6 to help in the completion of this questionnaire.
14. ME is wrecking my life. I am continually and increasing tired, At 65 I expected to enjoy retirement now it’s just an extreme battle to do anything. I use to be extremely strong, active and alive now I am lazy, unbalanced, inept, clumsy, tired, unmotivated, anti-social and miserable. I am making my wife unhappy because along with depression this is the pits.
15. I have not been seen by a therapist both appointments, both appointments one in October and one in November have been cancelled by the Therapist. I am waiting my 1st appointment.
16. No comments
17. No comments
18. It’s difficult to answer the questions when some days I feel relatively normal, and some days I feel ill and fluctuations during day. Intense pain from right shoulder down right arm which comes and goes seemingly haphazardly probably lasts a couple of hours Stress e:g driving a route I’m not familiar with and trying to find my way can make me feel very ill like (shaking on the inside and weak). If I eat something and (ideally) lie down, I can recover quite quickly. It is still the case that mental exertion drains me much more quickly than physical. Nov 2014 – June 2015: - Felt a lot better July 2015 to now: Trying to be more normal and back where I started or worse. I’m not sure if this questionnaire has been sent to me because I phoned to request an appointment or it’s just coincidental.
19. I was diagnosed with ME/CFS at JPH in 2009, I went from being a very active mother and housewife to bed bound 24 hrs a day. The deterioration from feeling unwell and being completely bed bound was about 1 year period. I now only manage to get up for hospital and doctor appointments. I have no social life; have lost friends because of not understanding. My husband had to give up career to care full time

for me and look after children. No amount of pain relief or medication helps. There is zero help for ME/CFS sufferers, or no help for someone who is unwell as myself. There seems to be no one who can help or has complete knowledge to help me. I am unable to exercise as advised to do as I am in severe pain and bed bound. Any physical or mental stress i: e talking, doctors/hospital makes me worse and I can be worse over a week after an appointment. Going out for pleasure/holidays or family pleasure/normality/ fun is impossible. P.s If my dog was as ill as me I would have him put down.

20. Being referred to the Norfolk and Suffolk ME/CFS service has been a great support to me. My illness does seem to be worse but I do have a more positive outlook. I work full-time and I really struggle with this, but I don’t have an option financially. I know I would feel much better if I could rest more. Your service has given me a better understanding of ME/CFS and has really made me feel cared for. Sarah is brilliant and she has helped me to reduce some of my responsibilities at work. I feel very lucky to have been offered this service. Sorry about my muddly answers. My doctor referred me to a specialist who referred me to ****.
21. I would be good to have a little more pro-active response than seeing a therapist 3 to 4 times a year. It would also be good to be kept up to date with medical advances in the field or a discussion with someone about chasing down symptoms not picked up by conventional GP tests. E:g tests for mitochondrial DNA or similar to try to find out what underlies the symptoms.
22. I would really just like to thank **** for all the help and education he has given me when it comes to CFS/ME, so far.
23. I was first diagnosed I believe 2005. I have good days still get very bad days. I also have fibromyalgia, Rheumatoid arthritis and osteoporosis as well as ME. On a lot of medication but de feel some affect the ME. On a good day I can’t concentrate and I can’t even fill this in properly. My pain, migraine, tiredness is mostly moderate. I am always cold even in warm weather. I have walked in to windows and doors.
24. No-one helped me. Felt like I was just fobbed off. ME clinic appointments were so far apart and then cancelled -they were very unhelpful and to them I was just a number. I have learnt I’m on my own with this so mange the best I can.
25. 1, the session with an OT/Physio, arranged reasonably near home, have been an enormous help. I am totally convinced I wouldn’t have made the progress I have without them. I’m coming to the end of mine now; I would urge that such sessions continue to be offered to newly diagnosed patients. 2, prior to referral I had seen 2 GP’s. One told me to ignore all my symptoms, carry on as normal and symptoms would disappear. One (who referred me goodness) said she thought I had ME and more or less said I would be bedridden for the rest of my life. (I tried the first ones advice – it did not work). It was such a relief to be seen by medical staff who completely accepted my symptoms and who could give me helpful, realistic advice to help them.
26. Being involved and talking to **** had helped me keep working and be more positive. I feel that you have to keep moving forward as it’s very easy to stop and not get going again. Fortunately the company I work for have been very good at adjusting my hours and work pattern/rota etc.
27. My symptoms fluctuate from day to day. If I was not retired I would not be able to go out to work. My husband does a lot in the house which I haven’t the energy to do.
28. No comments
29. No comments
30. This service is very good. Please lengthen the referrals as there is little support from people who have knowledge. I go to the doctor and he sympathies but I can’t keep going to him. It’s been 10 years now. I need a service like this.
31. No comments

32. Most of my issues come from work. As a teacher it is difficult to rest through the day. The service has been useful and I manage things better as a result but its impact is only small as my employers haven't really helped me. I fear for the future as I'm not sure how long things can remain as they are.
33. I was referred to the ME/CFS clinic a year ago, and was diagnosed with ME/CFS. My symptoms of extreme fatigue and weakness have deteriorated markedly over the past year. I also suffer with near-constant symptoms of general neuralgia or flu like and IBS like symptoms. I used to have good and bad spells with all of this but it's all pretty much constant now. I have been referred back to my GP for another battery of tests all of which came back clear as usual. So I have little hope of ever understanding what is causing this debilitating illness, let alone having any prospect of getting better. I'm basically just ticking days off, suffering all the while and hopefully after enough months and years have disappeared I'll suddenly wake up one day and feel some improvement. I've tried everything, various medications, no medications, light exercise (when I was able), no exercise, cutting out gluten, dairy etc., eating normally. It's over two years since I gave up work to concentrate on getting better and I am much worse. My appointments with the OT over the past year have not helped, my symptoms are worse now.
34. While my health has deteriorated since my diagnosis, the care and support I have received from the Norfolk and Suffolk ME/CFS Service has been excellent – particularly from my OT. I cannot praise the service enough.
35. I feel as if my illness has gotten a lot better over the past few months. I am still not 100% better but I am able to participate in a lot more social situations and spend more time outside of the house enjoying myself. I have been able to participate in more physical and sporting activities since learning to manage my illness which has made me become a lot happier within myself as when I couldn't do exercise it made me feel upset and angry with myself. Overall I am not completely better as I still have a few bad days to deal with when the CFS flares up a bit. But I am satisfied that my health has improved and I have learnt how to manage it and cope with it a lot better since getting help.
36. I have recently been under stress due to family, and have recently had blood tests including thyroid. I am using wellbeing service and have attended an overview for stress courses.
37. Learning to live with it.
38. Due to great concern in the continued decline of our daughter's health we have been researching for any ideas to possible causes and tests to be done. This is causing us personally stress and health problems.
39. No comments
40. No comments
41. No comments
42. The Dr who did my initial assessment then referred me to **** who suggested Mindfulness. I have found this very helpful. Chris Edwards emphasised the use of mindfulness, helped with pacing advice and how to adapt to illness. He has been very helpful with letters to my University and is good at reminding me to cut back, cut back and find a stable base (which I haven't quite managed yet). If I am very careful do little and meditate/rest, my sleep is now fairly good but otherwise don't feel like I am improving. I don't have the boom and bust like used to but I do/can do much less. Perhaps this is due to not finding stable base yet. It's been almost 18 months at service though. I am very grateful to have the service but there is definite room for improvement and I am hugely relieved that it's going biomedical. I would particularly like to draw attention to: No offer of further tests to rule out alternative conditions or exploration of family history etc. No info on current research/possible causes. No support outside of restrictive NICE guidelines e.g. diet and nutrition, supplements etc. No mechanism for referral onto research-service at prime position to trial diets etc. if nothing more co-ordinated. Very limited contact with a therapist not a GP. My GP not brought up to date re ME/CFS. No real improvements. Both DR and therapist emphasised I

have a good chance of recovery due to positivity. How long can this last? I'm not making progress am I not positive enough.

43. I would like to thank the service for firstly giving me a diagnosis and also for the valuable advice on how to manage ME/CFS. I have managed to get back to work 4 days a week and back to dancing once a week. I worried in the early days of my illness that this would not be possible. I took advice to self-refer to the Wellbeing service which helped so much with the anxiety I was experiencing. The opportunity to meet with **** over the last year has been so helpful, being able to talk things through and to get advice on how to cope. He also helped with my phased return to work which I will always be grateful for. Thank you
44. No comments
45. No comments

Background

The ME/CFS service user group have expressed strong views surrounding the provision of CBT or graded exercise therapy for the management of ME or CFS. This conflicts with NICE guidance and the clinical views of the local paediatricians, in line with NICE, is that such interventions should have a place and they would not be happy to refer into a community service which would not offer these as part of their menu of interventions.

The purpose of the ME/CFS children and young people's questionnaire was to gage their views on the current service provision and whether they had found an individual activity management plan and psychological input beneficial.

The questionnaire was sent to 59 children and 14 questionnaires were returned giving a 23.7% response rate

Questionnaire audience

- Children and young people
- Parents and carers

Structure of the questionnaire

Children and young people

The questionnaire contained 7 questions and free text boxes were included for comments. The responses to questions were a mixture of tick boxes, rating the service 1 -10 (1 being the lowest and 10 the highest) and from very helpful to non-helpful.

Parents and carers

The questionnaire contained 9 questions and focused on service provision and the workforce. Questions were responded to on a scale of poor-excellent and free text boxes for comments were included.

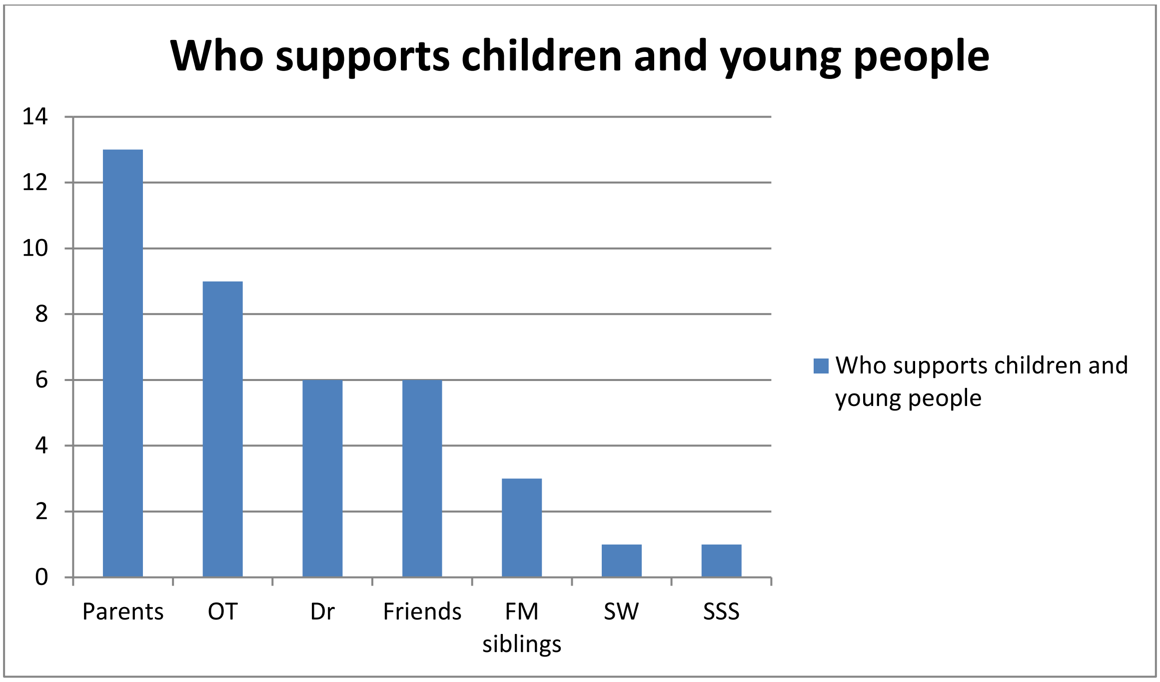
Results

These will be shared with the provider East Coast Community Healthcare, Child Health and Maternity Board and the ME/CFS service user group.

Results

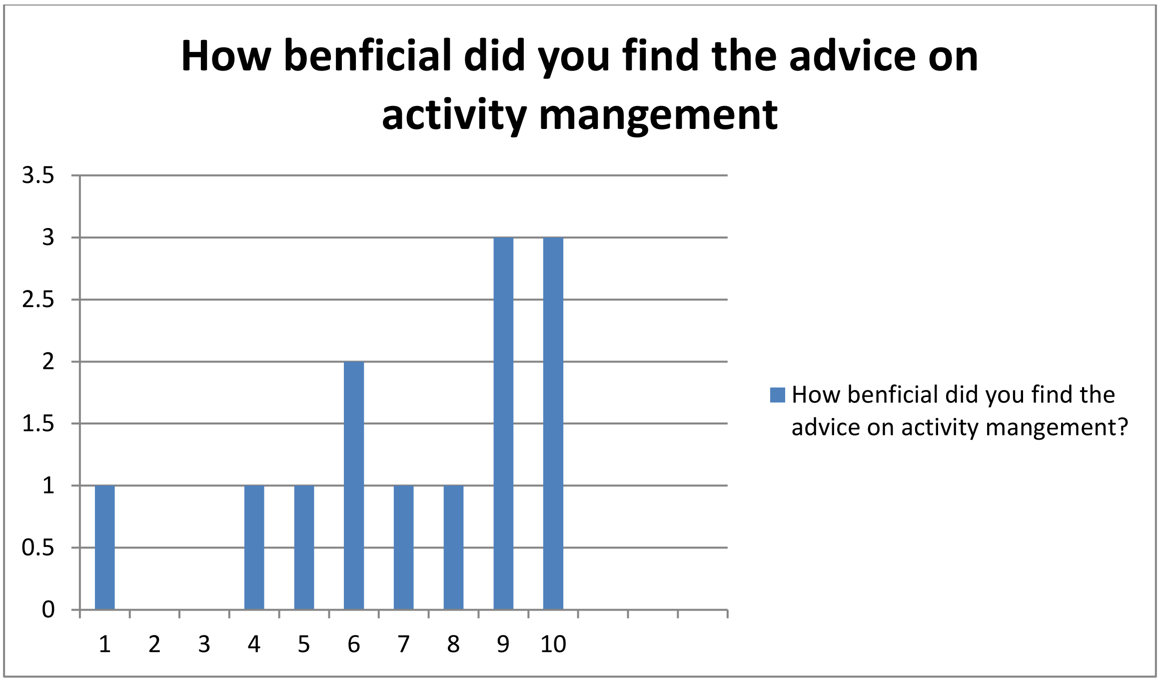
Children and Young People

Q1 Who supports you/helps you at the moment?

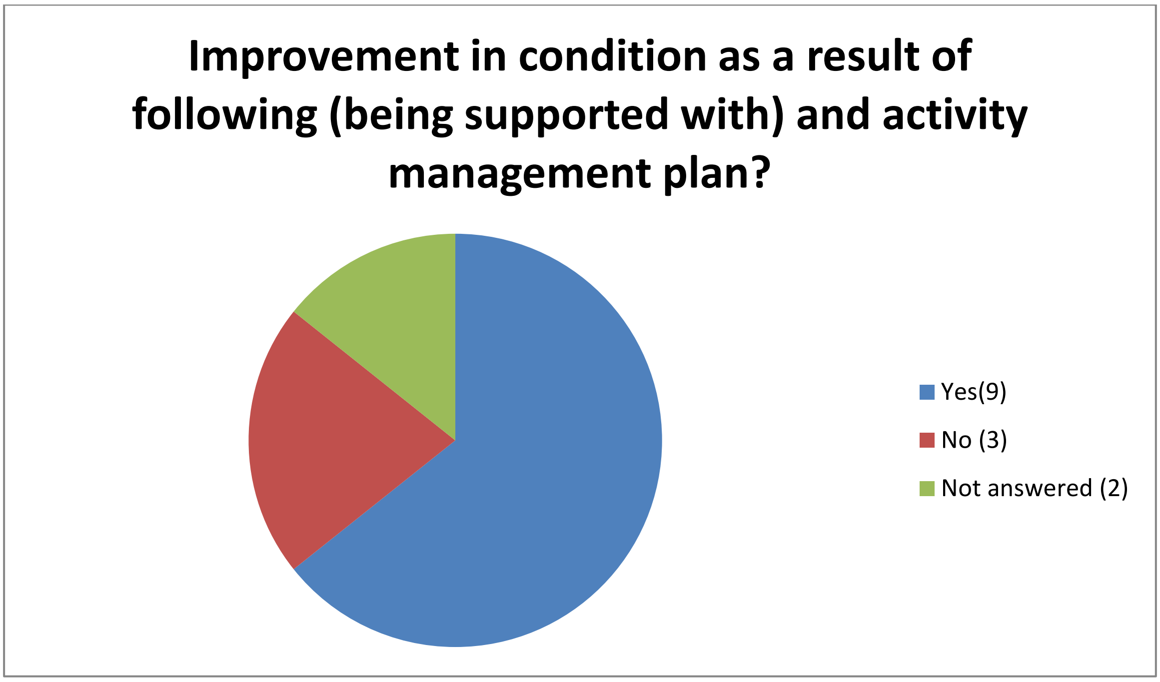


The majority of children of children are supported mainly by their parents. In terms of allied healthcare professionals occupational therapists provide the most support.

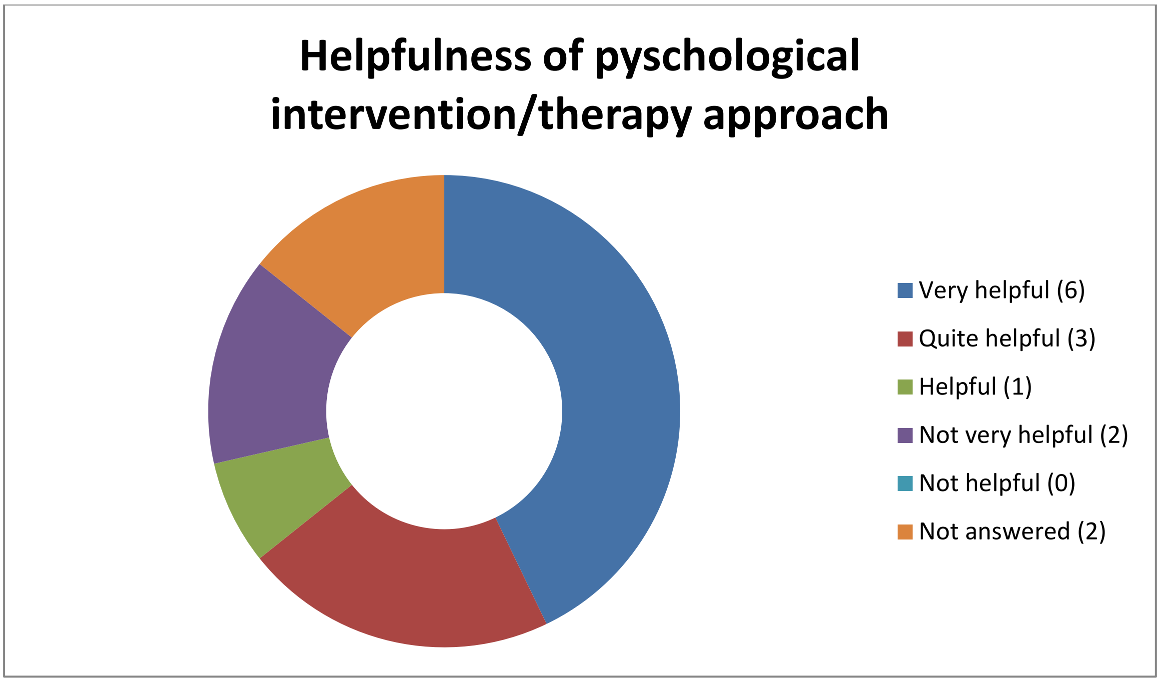
Q2 How beneficial did you find the advice on activity management? This was scored on a scale of 1-10 with 1 being the lowest and 10 the highest.



Q3 Did you find an improvement in your condition as a result of following (being supported with) an activity management plan? Answer options and results shown in graph



Q4 How helpful did you the psychological intervention/therapy approach i.e. advice to help you manage your lifestyle adjustment/low mood? This question was ranked as very helpful, quite helpful, helpful, not very helpful and not helpful.



Numbers in bracket indicate responses received. The results indicate that 6 of the 14 respondents (42.8%) found psychological intervention /therapy very helpful. It could be said in terms of helping 10/14 (71.4%) respondents have found psychological intervention/therapy helpful.

Q5 What else do you think might help you?

Comments included:

- School visit by OT
- Not all teachers are able to see when xxxxx becomes ill except for the two SENCOS and her assistant

Parent/Carer questions and responses

Summary of results

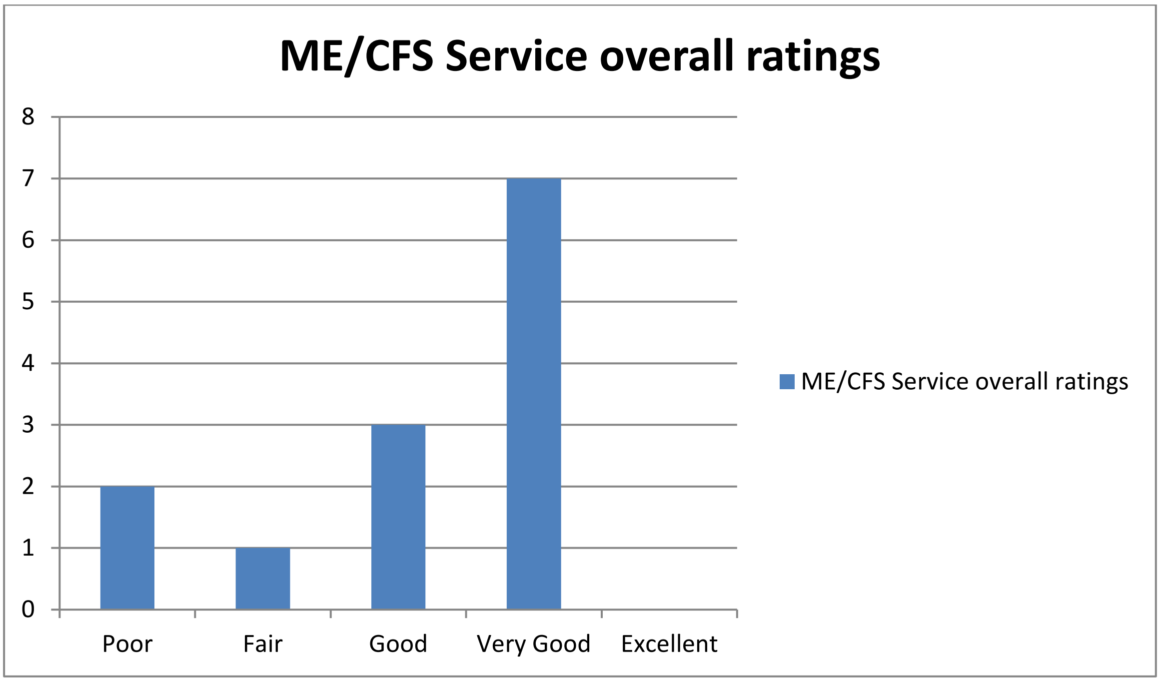
In terms of parents and carers introduction to the ME/CFS service it was seen to be good. The majority of parents and carers found the ME/CFS overall to be helpful with the exception of one or two. All reported the staff to be friendly and polite even where the service may not have met individual expectations and this should be shared with staff.

Communication

No parent/carer found the staffs explanation of their child's assessment and treatment poor with the majority rating the explanation as good. This continues in terms of the information and advice given. In terms of reassurance and confidence levels of parents and carers following the appointment with the ME/CFS Service levels were fair and good. From this it can be assumed parents and carers felt confident and reassured following their child's appointment in the ME/CFS service.

Service Provision

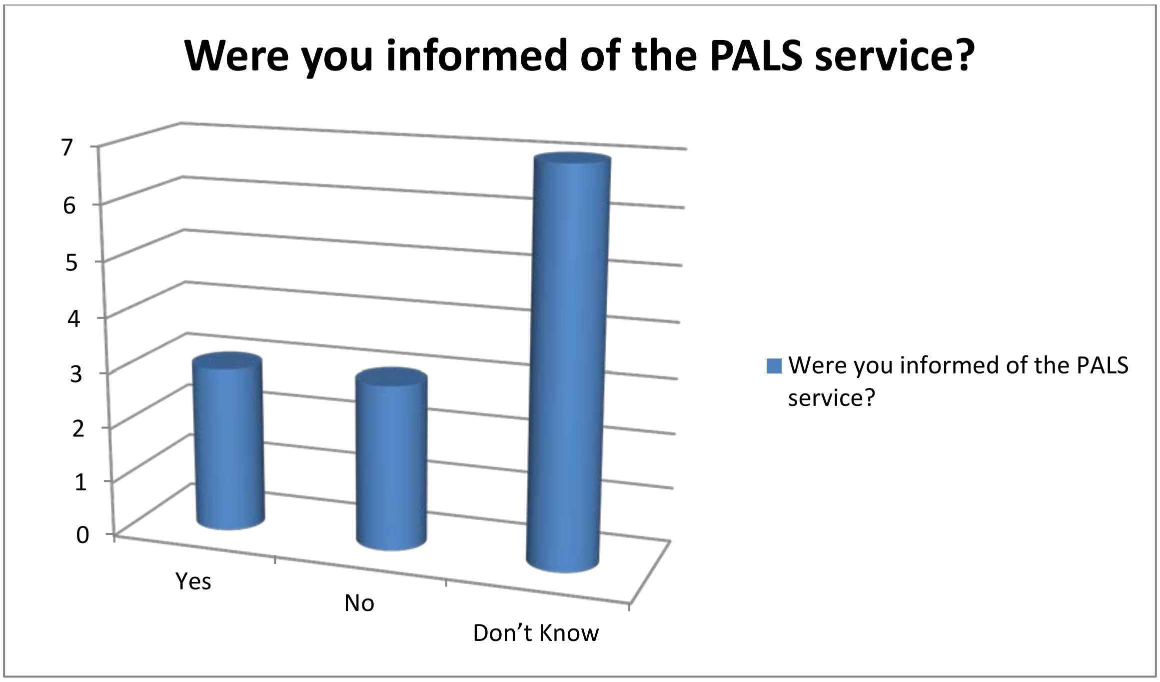
A question rating the ME/CFS service overall was asked –results are shown below:



One respondent did not complete the question

Signposting to other services

Has the ME/CFS service informed service users of the Patient Advice Liaison Service a service for service users to raise concerns and to complement a service. Known as PALS it sits under the umbrella term of Service User Engagement.



The results would potentially indicate routine informing of service users/parents/carers is not happening as well as it could be. However, it cannot be said that in terms of the don't know responders it is challenging to determine if the information was or was not given. Also the question should be asked that where a yes is reported was this information only given at this point in time due to a service user/parent/carer wishing to make a complaint or to compliment the ME/CFS service.

Conclusion

Overall the ME/CFS service is meeting the needs of those who responded in terms of service users and parents/carers. In terms of whether activity management plans and psychological intervention/therapy are useful the results indicate they are and therefore are beneficial to service users. Therefore a recommendation is for all service users to be offered an activity management plan and psychological therapy and intervention in accordance with evidence based practice.

For your information and out of interest some examples of Service User Comments received.

Very happy with the current service

Extremely disappointed with the lack of support I received for my daughter

Service was very good at the beginning then appointments cancelled and heard nothing since

We have been really impressed by the support we have received especially from Louise Halliday

We were all in a dark place before our first appointment with Jenny Miles, we were so relieved when we came away I can't thank the CFS Service enough for getting us all back on track and fulfilling our lives

Item 7 Appendix 3

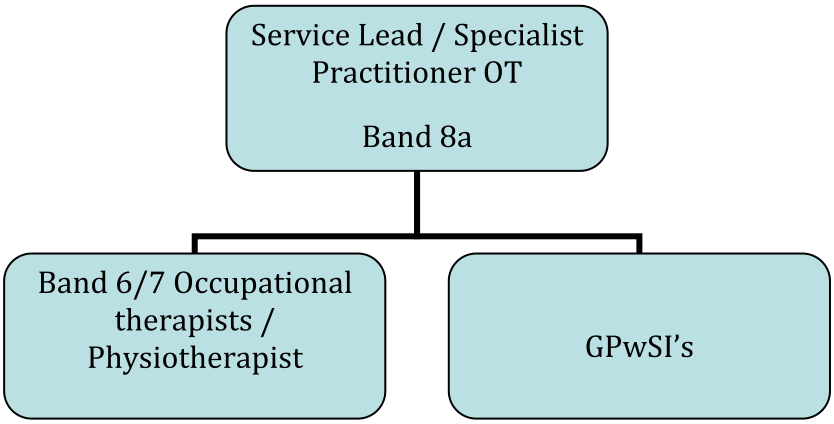
ME/CFS HOSC Paper – March 2017

Background

The ME/CFS Service is a specialist NHS service that seeks to meet the needs of people who have a diagnosis of Myalgic Encephalomyelitis (ME) or Chronic Fatigue Syndrome (CFS).

The service offers an outpatient service throughout Norfolk and Suffolk. Provision is outpatient based with a domiciliary service available for those who are unable to attend. In some cases telephone consultations are used.

Structure of the Service



The ME/CFS team is led by a Specialist OT. This individual is responsible for managing the service operationally including budgetary and governance accountability. This individual is supported by a Band 7 Occupational Therapist and both share the role of triaging all new referrals to the service.

The team then further comprises a number of therapists (occupational therapists and a physiotherapist) each carrying an individual caseload.

Finally the team is supported by 2 GPwSI's (GP's with Special Interest) who support the confirmation of diagnosis for those patients referred where this is not clear.

Staffing Levels - Whole Time Equivalents (current)

Band 6	4.53
Vacancy (Band 7)	0.2
Band 7	0.64
Band 8a	0.51
Total	**5.87**

In addition to this are 2 GPwSI's who provide sessional work seeing an average of 12 referrals a month.

Where does the service operate from?

The service currently provides ME/CFS clinics from the following locations:

- Lowestoft (Kirkley Mill Health Centre)
- Halesworth – Patrick Stead Hospital Outpatients
- Great Yarmouth (Nelson Medical Centre)
- Stowmarket (Stow Lodge Health Centre)
- Norwich (Bowthorpe Health Centre)
- King Lynn (Medical Centre)

Who can receive the service?

Patients of all ages are accepted for assessment, confirmation of the diagnosis, and advice and support to the patient and referrer in managing the case. Referrals are only accepted from GPs and Paediatricians, other hospital based medical practitioners and occupational health doctors.

Patients under the age of 16 can be referred by their GP, however the patient must have had input from a paediatrician before referral.

How are referrals processed?

Referrals which are inappropriate or do not contain the required information on the referral form are returned to the referrer.

Once a fully completed referral form has been received the patient is sent a Pre-Clinic Questionnaire (PCQ). The PCQ should be returned to the ME/CFS Service within one month.

If, after one month, the PCQ has not been returned the patient is reminded that the PCQ needs to be returned before an appointment can be offered.

If, after three more weeks, the PCQ has not been returned the patient will be discharged without being assessed. A letter explaining the situation is sent to the referrer and a copy sent to the patient.

Once the PCQ is returned the referral is triaged.

Triage

Referrals are initially triaged by the Band 7/8a OT's with 3 potential outcomes:

1. A diagnosis is clear – these patients will be sent an appointment with a therapist at the clinic of their choice.
2. Where diagnosis is unclear an appointment is made with a GPwSI to confirm diagnosis.
3. It is clear at this point that the patient does not have ME/CFS so are discharged back to the referrer.

Therapy Support

The team can offer a wide range of therapy support focusing on working with patients to find strategies that will help them achieve improvement in their condition and establish and maintain a quality of life. Generally patients receive 5 appointments over an 18 month period but this is very much tailored to the need of the individual.

N.B - Patients continue to be managed by their own GPs, with the guidance and support of the ME/CFS Team.

Additionally, the ME/CFS Specialist Team will provide education and support for clinicians involved in treating patients with this condition.

Referral rates

	Norfolk	*Suffolk*	*GYW*	*Total*
2014/15	330	256	180	766
2015/16	412	316	224	952
2016/17 (excl. March 17)	440	254	175	869
Overall Total	**1182**	**826**	**579**	**2587**

Above shows the number of referrals received across Norfolk and Suffolk over the last 3 years.

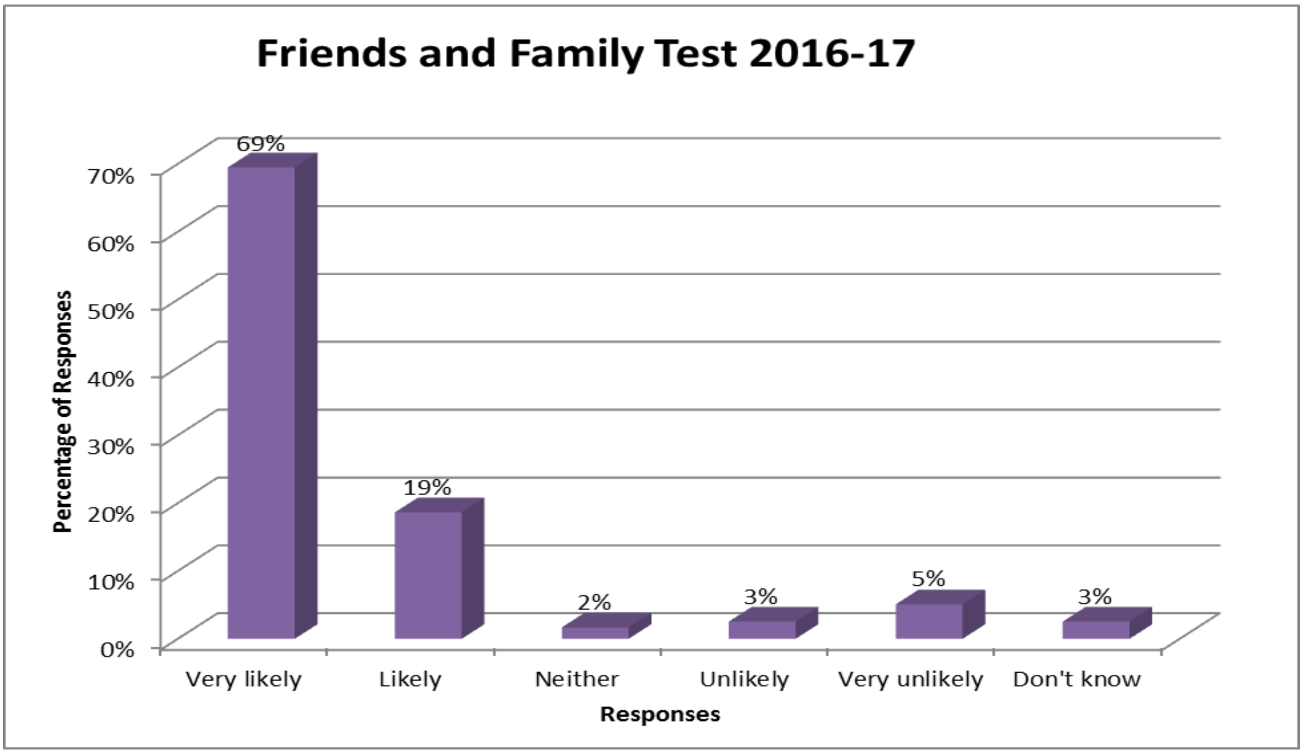
Patient Surveys / Feedback

Below is a collection of information and feedback for the ME/CFS Service.

Friends and Family Test

This shows a summary of responses covering the period of January 2016 to February 2017.

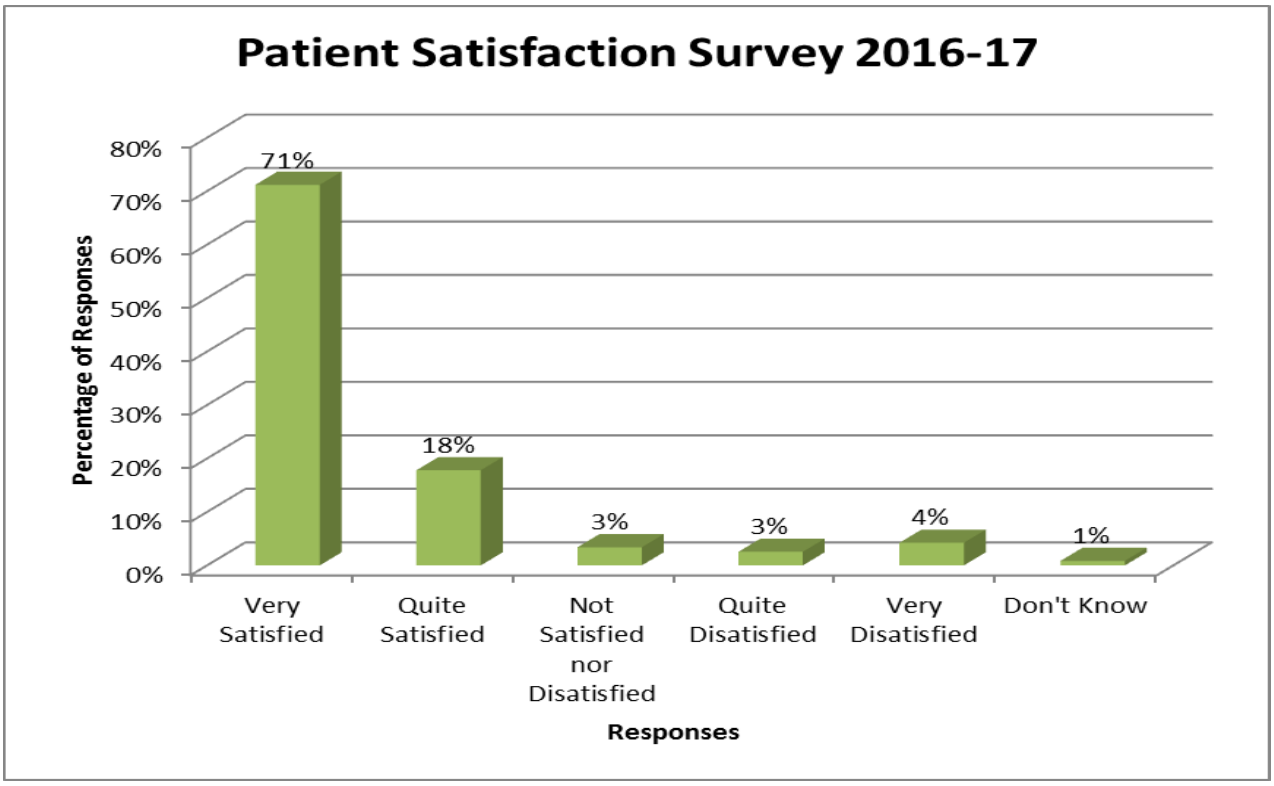
Friends and Family Test						
Very likely	Likely	Neither	Unlikely	Very unlikely	Don't know	Total
69%	19%	2%	3%	5%	3%	100%
82	22	2	3	6	3	118



Patient Satisfaction Survey

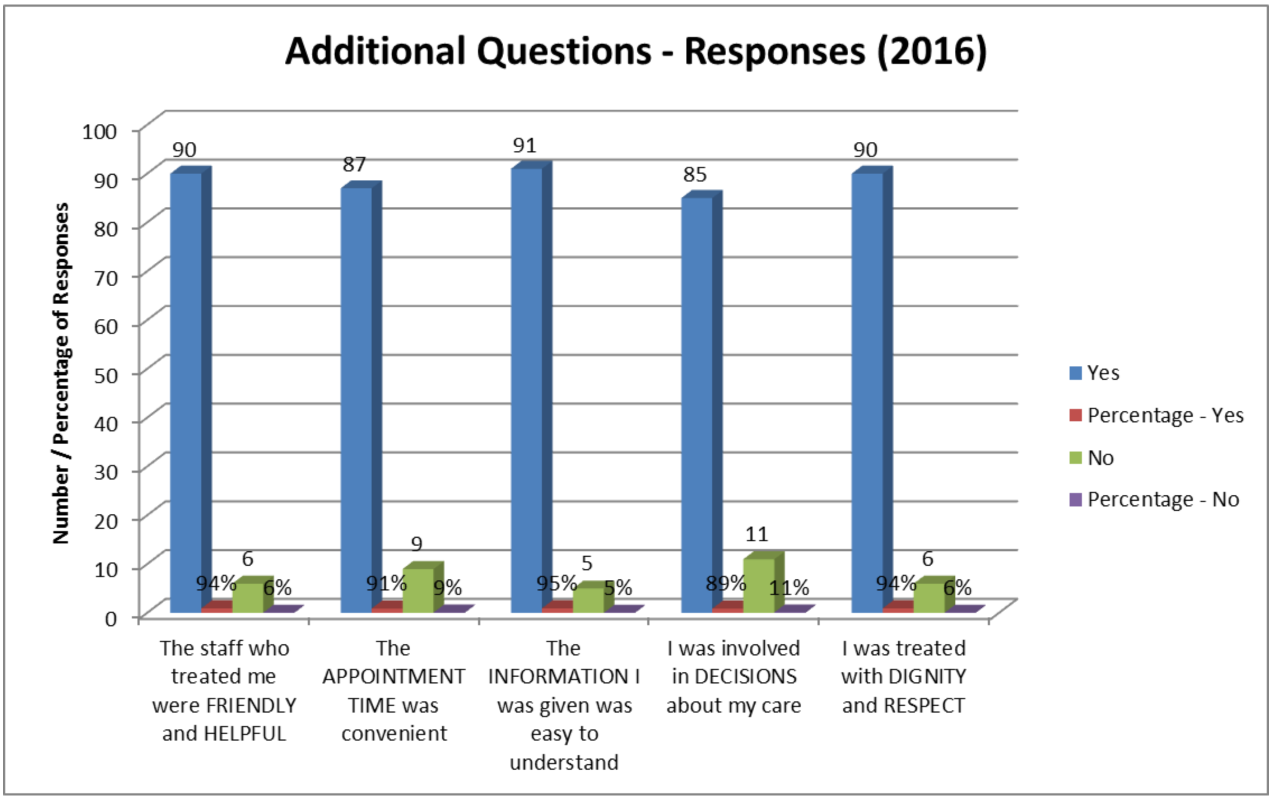
This shows a summary of responses covering the period of January 2016 to February 2017.

Patient Satisfaction Survey						
Very Satisfied	Quite Satisfied	Not Satisfied nor Disatisfied	Quite Disatisfied	Very Disatisfied	Don't Know	Total
71%	18%	3%	3%	4%	1%	100%
84	21	4	3	5	1	118



In addition to the above we routinely ask further questions and the results (covering the same period) are shared below:

	Yes	Percentage	No	Percentage
The staff who treated me were FRIENDLY and HELPFUL	90	94%	6	6%
The APPOINTMENT TIME was convenient	87	91%	9	9%
The INFORMATION I was given was easy to understand	91	95%	5	5%
I was involved in DECISIONS about my care	85	89%	11	11%
I was treated with DIGNITY and RESPECT	90	94%	6	6%



Below shows the comments also received. It should be noted that all responses are anonymous so where any negative feedback is provided this is fed back directly to the team and addressed through team meetings as a whole service.

Comments
Was a long time for the appointment but understand that it's very difficult to get an appointment any quicker.
Prompt appointment and the person I saw was friendly and I felt at ease. She also explained ME/CFS so I could understand it.

I have passed on my concerns in detail to the patient liaison service about my appointment and the clinician.
Pleasant staff, seen quickly.
First time I have seen specialist doctor for CFS/ME, she was very good, answered my questions, was very knowledgeable.
I have managed this condition for 25 years. I was surprised the Nurse did not have the information for Sjögren's syndrome.
Fantastic consultant, lots of questions answered.
Polite staff, nice environment, on time, etc.
Staff were very helpful.
The staff have been amazing. I've been suffering with M.E since 2009 and until I used this service I felt so alone and that no one understood. This service has helped change that and given me light at the end of a very long tunnel.
The visit was very helpful getting a confirmed diagnosis was very good and getting advice/help given was very helpful.
Far too early, I have only had one appointment.
I was seen on time, I was given practical and helpful advice and made to feel that I had a valid reason for seeking help.
I was taken seriously and given time with responding to questions.
I was treated with consideration, kindness and repsect. I was allowed to linger for lunch ad a rest break before the drive back home and was helped with this and locating toilet facilities. I felt cared for and helped in all respects.
The Dr was fantastic and had thoroughly prepared for my appointment, fully aware of history and events leading to the appointment as well as the results of all investigations. She involved me in making a positive plan going forward to support my recovery.
The DR was very patient, she really took the time to listen and was very helpful.
Made to travel over an hour (which makes me ill) for a very unprofessional, miserable women who never once smiled to see me for 10 minutes and tell me to go google things. Asks me some questions every time. No help.
Thorough, understanding and clear. Early days yet, but I am beginning to get the information to help me manage the condition.
The doctor treated me with respect and although I was not diagnosed with CF, she did not dismiss my tiredness. I felt very comfortable talking to her. However, the occupational health nurse also rang me beforehand, seemed uncaring and dismissive.
Very understanding, helped me with new stage of illness.
Well informed.
The person I saw was very loud, hard to understand at points, although she did explain everything well and I am happy with the outcome.
The appointment was on time, with excellent care and knowledge used throughout.
Doctor was understanding and took the time to help me.
I had a very helpful and informative appointment with ******. She was very understanding and offered me some very helpful advice.

The care given has been really good. *********** has been really good in trying to help me understand how I can help improve my CFS. However, it is a working progress and with additional stresses it hasn’t always been easy to implement everything yet and I know I t will take time, but I am very grateful for the care I've received.
Got a diagnosis, felt like the doctor listened to me and was sympathetic.
All the staff have been very helpful and informative, keen to understand and do all they can to assist me.
My appointment was with Dr ********** and she was extremely helpful/knowledgeable which enabled me to feel reassured and heard.
I found the staff at the clinic very helpful and friendly. I was a little disappointed with the long wait to see one specialist. (5 months).
If you suffer ME/CFS the GPWSI can help you manage your illness.
Although I have had this illness for many years, it is nice to have someone who understands and can offer a different view on how to handle things differently. ****** listened and understood which was a big help to me.
I wish I had been referred earlier. This was the first time that I had felt understood. The doctor just seemed to know all about me. She convinced me that I'm not mad, just not treated well for a long time.
Dr was kind, listened to what I had to say, didn't talk down to me. Made me feel relaxed and was able to talk to her with ease.
Seen by a friendly, informed, caring consultant.
Physio easy to talk to, was helpful, friendly, approachable and encouraging.
I received an appointment very quickly, with a very helpful doctor who was able to give me lots of information and answer questions.
Based on 1 interview with specialist me/cfs doctor after 2 years of illness. Felt listened to and understood, though there seems to be very little that can be done to improve things.
Very helpful and informative service/team.
Courteous, listened to me and made me feel at ease.
The doctor was nice and was clear in what she said to me and in my diagnosis.
The gap I saw took the time to explain my condition in a way that I understood and didn’t try to fob me off. She was very friendly and was able to answer my questions and provide advice to help me manage my condition in the future.
I was quite nervous about the appointment as I has seen many doctors and felt I was getting nowhere. Louise Halliday made me feel so relaxed and gave me the time and listened. First class.
I was given information and graded exercise therapy to help with me/cfs but there is no therapist in the service to carry this out.
********* listened to everything that was said. She was compassionate and gave excellent advice which made ******* responsive to treatment like a light in a dark tunnel, thank you.
********** was very understanding and caring and explained a lot about my illness.
Waited 1 hour and 15 mins for Dr to arrive. She had an issue but was more interested in explaining her problems than listening to mine.
Relaxed and clean environment, friendly staff. I was given a very clear description of my condition. Staff listened to what I had to say. I felt understood at last.
I was listened to. The doctor had obviously read the information about me. She knew what she was talking about. She explained her reasons for her opinion. She was supportive. She treated me like a human being.

Pleasant enough consultant, but I felt slightly talked over/interrupted when trying to explain things. Other than that, I feel somewhat assured I'll get further help.
Feel as though I have now been listened to however still ongoing with use of service so unable to give a full and correct response to how satisfied I am of the service.
Would have been better to not have to have another app to get actual energy management help. Also she said I would have 4 days work recommendation in writing - Didn't get this.
The doctor I was very efficient and informative.
The information I gave during my appointment was miss-understood (Yes this happens sometimes) An email from me informing you of this was sent which I received an acknowledgement on 07/07/2016. I am still waiting for anything more than an acknowledgement.
It was a very positive experience.
Only had one appointment, but I was very pleased how it went.
Lots of information and guidance given.
I felt this was just a tick box exercise, no help offered yet.
To be completely satisfied I would have liked to have seen a consultant rather than an OT.
Lovely, understanding nurses/doctors who deal with ME/CFS, really brilliant referral and letter. Shame it took so long to get the referral though, 3 months!
Lovely lady, helpful staff and easy to find and park.
The appointments I had (both over the phone and at the clinic in Great Yarmouth) were useful. I felt I was in good hands the whole time.
At long last someone listened and I was not dismissed.
Referral time was fast. Contacted by phone prior to appointment for assistance. Listened to at appointment, no assumptions made.
I did not have to wait long for an appointment and found the service friendly, helpful and flexable when I needed to change my appointment. The OT I saw was also friendly, patient, knowledgeable, clear and supportive.
Very pleased with the support given by this team. The advice and guidance has been invalube to me and certainly has has a significant impact on helping me manage this.
I was given a clear understanding of my illness and measures to help control it.
I have never before been treated with so little respect and dignity, compassion or humanity. I felt violated and humiliated. There may also have been data protection breached.
Doctor was friendly and knowledgeable.
Dr was very good. Listened to what I had to say, She gave me a diagnosis and explained it and changes very clearly. Refered me to other services as well.
The doctor I saw was very clear and obviously knew what she was talking about. I felt confident about seeing her and would recommend her.
It Is worth going to point out that we need other treatments to be developed for our symptoms. But basically you will come away no further forward.
Help staff. Attractive building. Free parking. Excellent facilities.
Dr was a professional, knowledgeable Dr who simplified and explained my condition, and treated me like an individual. I'm in the right place now!
Very happy with medical appointment with Doctor. I had to wait ages at the reception desk on arrival.

The doctor I saw had read my notes before hand and was supportive and direct. I felt I was listened to which was very reassuring.
Extremely efficient service, fast diagnosis from seeing GP to being seen. Thank you to the GP for your friendly and informative consultation,
Very informative, being looked after well.
The only disappointment was the length of time it took to received an appointment, following the referral.
Because they understand my problem and needs.
Very attentive to detail. Listened with compassion and showed comprehensive understanding of CFS
Good length of time to discuss situation, empathetic positive course of action recommended
Lovely doctor. Explained everything well and next stages of treatment.
Haven't had any treatment yet. It was my first visit.
Everything was fine but when report came back it said I was a smoker, which I clearly said I weren't.
Specialist Occupation Therapist was talking to me like I was thick, as soon as I explained I had hearing aid in and told her I couldn't hear what she was saying as she had her back facing me. Tried to explain have done diary and was basically told to be quiet as she had alot to get through during our appointment. It's a shame as could be helpful to have CBT but will not be returning to this clinic. Lady was rude.
Typos and some incorrect data on letter after appointment which I am requesting corrected letter
Firstly I was believe and listened to. I was treated with respect and dignity.
Very supportive and informative medical practitioner. Answered a lot of questions for me. Was able to actively support my symptom management & understood my diagnosis and its presenting symptoms.
My doctor was very war, reassuring, helpful & informative
Although my referral was delayed (due to GP service incompetence), my specialist appt with the doctor was arranged closer to home for me and the doctor took time to discuss my illness and for that I was very grateful. Information received was very useful.
It has helped to equip me to cope with my condition and has provided information to other health professionals to help understand my illness
The doctor had read the information I submitted before the appointment, gave me plenty of time to explain my symptoms and asked follow up questions, explained clearly her diagnosis and recommendations to my GP. It was a helpful and positive experience.
I was listened to and the recording is a fair assessment of what was discussed. Appointment came through quickly and on the day met my expectations.
For me it was such a relief to have a diagnosis after approx 4 years of feeling so awfully unwell. The therapist was excellent in showing me empathy and kindness and explaining the condition to me in great detail with patience. I am very grateful for that, thank you.
Dr I saw was very supportive (Even though there was a 5 month wait to be seen!)
OT very understanding and kind. ME research requires more funding, so many people’s lives are devastated by this illness.
1. Seems to be only support for people in Norfolk with CFS 2. Apart from a slight wait and a trip to Great Yarmouth the consultant was very attentive, supportive and friendly.
I don't know anyone else that would need this service. I'm very satisfied, I have waited 24 years for a diagnosis and now, thanks to your team I have one.

Receptionist very helpful when I have telephoned. Consultant I saw discussed my symptoms and what was wrong with me. Everything was explained. Very positive experience and knew exactly what was going to happen.
I am happy with the service I received and am grateful for being given a cancellation appointment. However, I am less satisfied with the speed that I received diagnosis and medication.
Prompt appointment, professional, knowledgeable, pleasant staff, efficient.
The OT was lovely, explained in full detail made me feel like I wasn't going mad. Lovely lady and very helpful.
Looked after brilliantly, answered all questions and put mind at ease. Extremely helpful, a credit to the NHS
Quite a long wait to be seen but very happy once I was 'in the system'
The help and support I have received have been critical to my understanding of this illness and my day to day management of the condition and hopefully gradual improvement.
Appointment was fairly quick, on time and convenient. The doctor was great. Took her time and explained everything.
The consultant was very friendly and patient with me and the questions that I had. She made sure that I understood what she was saying and what was going to happen.
Very thorough and clear. Fabulous doctor.

ME/CFS – Complaints Report 2014 – 2017

Below are the details of formal complaints over the last 3 years including outcomes and actions taken.

First received	Description (Policies)	Outcome code	Outcome	Action taken (Investigation)	Closed
28/04/14	Care provided to pt. and staff attitude not satisfactory.	Complaint NOT upheld	Letter of explanation to patient and zero tolerance statement re. patient's abusive behaviour.	I would like to apologise that your original appointment had to be cancelled with therapist for the most valid of reasons. However, your lack of understanding of this situation was clearly evident. I would also like to apologise that your previous records were not obtained. Although this does not alleviate the details of your complaint, to avoid this situation happening in the future, all medical notes will, in future, be requested on receipt of the initial referral to the service. In this way, we are able to demonstrate to you a willingness to learn from your complaint and to improve our service to patients. In the interests of clarity, we wish to inform you that you are able to ask your GP to re-refer you into the ME/CFS service if you feel this would be of benefit to you.	29/05/14
11/11/14	Patient has had incorrect communications resulting in a wasted clinic visit.	Complaint upheld	Administrative error. Pt is correct in her complaint. Letter of apology sent	* To discuss with all therapy staff (OT, PT) that if they are typing their own appointment letters then they need to check that the letters are correct and tally with system 1 diary before letter is sending, or to ask member of the admin team to check this for them. * As part of system one review to look at automatically generating letters " Check most carefully the dates stated on the letter and that these match with our electronic appointments system. " Alternatively, they are able to request that the administration staff check the details of the letter with the system, prior to these being posted out to our patients.	25/11/14

05/12/14	Patient complaint that the therapist is not trying to help with her problems and had lied about a referral to her GP for a wheelchair/crutches.	Complaint NOT upheld	Letter of explanation sent	1. The therapists should now ask their patients if they require a copy of any onward referrals that are made on their behalf and if the patients so request, copies of these should be sent to the patient. 2. I understand that you prefer not to have contact with therapist in the future and arrangements have been made for you to remain on an alternative caseload. You have indicated that you are happy with this proposal.	30/12/14
06/02/15	Complaint about the attitude of ME/CFS OT	Complaint partially upheld	Letter of explanation sent and partially upheld. Further letter received and second letter of explanation sent.	Team to explain importance of diary sheets to patients - discussed in staff meeting. Team to ensure they are explaining to patients that they will receive 4-6 appointments and then be discharged back to care of GP. For therapist to receive a period of shadowing from her clinical supervisor to monitor her clinical practice. To discuss with team members the importance of explaining the benefits/importance of the diary sheets to patients. To discuss with team the importance of explaining to patients at the outset of their treatment that they will receive 4-6 appointments and then be discharged back to the care of their GP.	27/04/15
09/03/16	Patient was late attending 2 hr. appointment at Stow Lodge but thought she had flexible arrival time. Clinician had marked her DNA and left as pt. over half an hour.	Complaint upheld	Letter of apology	* All staff will be instructed that if any special arrangements are made with their patients regarding appointments, this must be clearly logged on SystmOne.* All staff will be reminded to clarify with their patients the ECCA telephone number and ensure this is clearly shown on all correspondence. * All staff will be instructed to ensure that all messages from their patients, given to ECCA on their pagers, emails or SystmOne tasks are always acted upon promptly and should patients wish to receive a return call, this is done as soon as possible.	21/03/16

10/03/16	Patient was sent an incorrect appointment letter which resulted in a wasted journey and a delay in being seen by a therapist.	Complaint upheld	Letter of apology and reimbursement sent.	* The administrative staff will no longer make decisions on which clinics the patients will be attend. Each Specialist Occupational Therapist decides which location each patient should attend and this is recorded on that patient's electronic clinical record. This will ensure no such errors occur in the future. * Reimbursement made for wasted travel expenses.	11/04/16
05/10/16	Treatment and care provided	Complaint partially upheld	Letter of explanation & apology	* During a Team meeting with all ME/CFS therapists held on the 25th October 2016, which was formally minuted, all staff were reminded that if they are not following the normal format of appointments or assessments, they need to effectively communicate this to the patients. * A follow up Email was then sent on the 25th October 2016 to all therapists to ensure full understanding and compliance.	08/11/16
05/10/16	Pt referred to ME/CFS service by her GP in error and attitude of ME/CFS service GPwSI dismissive and unhelpful.	Complaint partially upheld	Letter of explanation and apology	* The ME/CFS Referral form will be changed to improve the information requested from GPs making referrals to the service.	22/11/16

Nick Wright
Deputy Director of Adult Service
East Coast Community Healthcare CIC
March 2017

ME/CFS service survey
Jan/Feb 2014

east coast
community healthcare

Introduction:

Nearly 1000 users of the ME/CFS Service were sent a questionnaire asking the following questions about the service provided. Some answers could be answered with free text and do not appear on this analysis page. (Please see the tab labelled "Comment data")

It is not recommended that you print the All data sheet. The All data tab has been set to print only 1 of the 43 pages it would

of 202 total responses

Name (see Quantifiable data tab below)	Are you aware that we have a Website?	Patient Liaison Feedback form useful in the future ?
% yes	13%	84%
% no	87%	16%
% n/a (newly diagnosed - no service yet received)		

	Are you happy with the ME/CFS service being provided to you?	Interested in Group Therapy	Interested in Acupuncture	Interested in Graded Exercise Therapy	Interested in Cognitive Behavioural Therapy
% yes	72%	37%	56%	46%	41%
% no	27%	63%	44%	54%	59%
% n/a (newly diagnosed - no service yet received)	1%				

	Would attend large group meeting to look at the future of the current service?	If yes, would you be able to come to Bury St Edmunds for this ?	
% yes	52%	55%	(of total interested in meeting)
% no	48%	45%	(of total interested in meeting)

Report compiled by Wendy Moore, Patient Liaison Officer

ME/CFS service survey
Jan/Feb 2014

Are you happy with the ME/CFS service being provided to you	Coments on ME/CFS service	Additional services requested	What you would like to see happen at this meeting ?	Any other comments you would like to make ?
y				Very happy with care I've had over last 5 years
y			Good chat with like-minded people	
y				
y			Group therapy meeting to be put in place every 6-8 weeks for patients	Groups can discuss how the illness effects them and others around them (lack of understanding). Dealing with depression that comes along for some with the illness. More support networks needed locally.
y	Not happy it is so far away, but do have appointments via phone	Relaxation		Can be very isolating and lonely. Not a lot going on in Suffolk as far as I am aware
y			Emphasis on more local group meetings	This service is the only place I get help and support, and I would not like to see it discontinued
y				The accessibility and professionalism of the service provided has been very helpful.
nothing offered as yet as new diagnosis		Newly diagnosed - do not know what would help	n/a	Difficult to answer as newly diagnosed but help available advice would be appreciated as new to service
n	no different from past with just ot	more information	more support	no
y	Would prefer appointments less frequently but for longer	Nutrition information. Pacing information	Proposal for extended service for housebound. More staff.	Problems with family and friends understanding. Take different family member each time. Make service available for familiiy member support.
y	Wish there was somewhere local to go. Not been contacted for a long while	Self help advice eg nutrition.		Web use not good as have vision and concentration problems so cannot access online forums.

Yes	N/A	************ is absolutely fantastic	Information to be provided in laymen's terms, no jargon. Suitable breaks. Discuss current provision and possible future developments	Difficult to read black on white, perhaps use pale green or pale blue with black writing, part of ME symptoms. When first diagnosed given a video, as these are now redundant, would be useful to have this information on DVD or CD to enable patients to print out it they wished. If meeting is to go ahead, invite patients to inform of any special dietary needs etc.
y		no	Checking everyone has the info and help they need	Getting a diagnosis isthe hardest stage
n	no recent visit	To help make government aware	To help make government aware	More public awareness
Very happy	Would like more frequent appointments	Diet	Increasing public awareness. Possibility of introducing adverts	Has been treated very well
y		Conselling to cope with the illness. Access to the recovery info from The Optimum Health Clinic which specialises in recovery from ME/CFS	n/a	
Yes. OT has been excellent		Willing to try anything	Make people aware of service offered	Meeting others with condition has been really beneficial
Rubbish. It was okay to begin with.	Passed from pillar-to-post. Originally seeing an OT in one area, but this changed to a different location	Website have been a big help, particularly AFME	Helping with the day-to-day management of condition	Info about websites and forums should be given to patients
y		Found previous acupuncture treatment helpful	opinions /ideas listened to	excellent service
y			include consideration of different ability levels	appreciate the service
y		Finds relaxation tapes helpful		The OT that he sees has been very helpful
n	Prefered old system where there were direct lines to the Ots	Advice about diet and suppliments	Discussion of new studies and research. Opportunity to meet other patients valuable	The new systems, going through messaging service, makes patients feel more isolated
y		pain management	don't know	longer face to face appointments desirable
y	more advice would be nice on alternative remedies		Don't know	
y			Resolve problems	no
y		n	More awareness to GPs of service provided	GPs brickwall - think ME does not exist

n	Has not been of any benefit. Has only had 2 meetings in 2 years	n	Not sure	Patients need more contact. Ots should call patients every couple of months just to check they are okay
y	More awareness of info available	More accessible service. More services. Kinesiology.	Clear referral process and outline of support available.	Organised support from medical profession gives kudos to illness.
y			secure funding	********** is brilliant
n	Used to have *********************. Contacted them as and when but when diagonsed with another condition received letter to say taken off system and referred to Stowmarket. They said there was nothing they could do and recommended private treatment (massage) which was not suitable.	Ogoing studies	Better service for patients	
y			Promote need for the service. More publicity. Understanding of condition for GPs	no
y		More info provided more contact	Future of service assured and more widely available. To make GPs aware of service	Research to get answers abouut causes.
y	Wished you had been prescribed the Gabapentin before because it has helped so much with the pain. I do now have a life. The pain stopped me going out for years. I had seen many doctors over the years and none ever prescribed this for me.	Forward comments to the DH on the use of specialist white full spectrum lights to be hired to provided on the NHS to patients suffering with SAD.	N/A	Happy with the service being provided, but is not getting anywear. Had ME 30 years. Was referred, but the clinician said she could only provide 2 to 6 sessions on the NHS - should be on-going to help with the pain.
n	attitiude of staff. Inconsistency of information	n	Consistent information given about treatment	n
y		n	Meeting other people and see how they cope	
n	Until September I was happy, but the last time I saw someone was September, when my therapist went on maternity leave.	Placebo? Saw programme and amased on how they worked on some pateints	Nothing really to add	Nothing else.
y	N/A	n		Found ************* very helpful. Regular relaxations have helped a lot
y		n		OT support very useful
y		Not really sure. I would try anything.	I would like to listen to aother people and how or what have been helpful to them, is anything at all	

y and n	Happy with the OT support, unhappy with location. Would fond it easier to have a clinic in Ipswich or Woodbridge. Currently husband has to take annual leave to drive me to Sowmarket.	Reflexology. One-to-one counselling		
n	The service is extremely limited. OT always tries her best but she has nothing to offer.			
		I had a few weeks of CBT with wellbeing service, but found limited benefit due to primary focus of being depression repeatedly having to score mood. I needed help to change my behaviour and improve my CFS. This was frustrating.		
y	Very happy with service provided and people should be able to access it for as long as they need it.	Dietary help for weight management etc. Massage therapy. Meditation groups.	Ensure continued service and that doctors do understand symptoms, and to be more knowledgeable about how to help and not make you feel like you are making it up.	Your service is invaluable to ME sufferers. Please continue.
y				The service I get is very good and I would struggle without it. It is a very good support network and very professional.
n	Feel a bit forgotten sometimes, especially by GP.			Wish there were services available in Norwich.
n	Very good OT in Stowmarket and supportive - would like more support / appointments please.			
y		Am willing to try anything that can help.		I am very happy with the service. It has helped me a great deal to understand ME/CFS better and how to pace to reserve any energy I do have. My whole attitude has changed and I accept my limitations but cope well with how my illness affects me.
y		Am having CBT from MIND at the moment.	My mind is not in a good state at moment, so thinking of anything along these lines is not easy.	Sorry I am not computer minded, but I'm sure the website is of great help to people.
y				
y		n		Coping quite well - happy with the service as it is

y	Happy with ********	n		People with ME not able to travel a long way to a meeting
y	Could be improved	Cheap swimmiing pool entry		OT advisor very helpful but I can't afford swim, jacuzzi or acupuncture which helped me.
y		Dietary guidance	Confirmation that service will continue	
n	Good to meet people who understand but need to support prsctices that actually make a difference	Lightning technique - NLP changed me in 3 days to positive move in right direction. Support to learn meditation properly. Alexander technique for pain.	To know if resources can be found to offer alternatives and changes needed	
n	Was happy with regular phone calls but the service no longer available as have had them for several years	Pacing advice, EFT, relaxation.		The techniques used by the Optimum Health Clinic in London are excellent - would be good if taught by NHS
y				
y			Meet other ME people	
y	Being able to see the advisor more often would be helpful	n	n/a	More regular appointments with ME advisor/chat sessions as ME is an isolating illness. More support sessions e.g. massage/swimming/exercise etc, maybe in groups
n	Feel no better with suggestions tp control my condition	n	Free acupuncture	More helpful advice and support
y	Really appreciate the time and support	Guarantee that support will continue as long as neededed		I rely on the service and it worries me that it might not be available long-term
n	Would like 6-monthly appointment with medical professional to discuss progress	Dietary guidance and domicilliary visits	More resources to allow domicilliary visits	Severely affected patients cannot attend appointments without relapsing further.
y		Massage, reflexology, anything that deals with sensory overlaod and confusion	More information on holistic options	Would rether try natural options rather than taking medications that seem to exacerbate condition
y			A cure	Totally fed up with the medical profession's lack of knowledge of ME
n				
n	The service has stopped due to limited resources	Lightning Process	Physical treatments	I would like to see more clinical trials incorporated into the ME/CFS service

n	It took 7 months to get to clinic for a quick assessment and visit to the OT,by which time I had read everything I could, joined ME assoc, tried acupuncture, nutritional therapy graded exercise, pacing etc. GP gave no advice. Present OT helpful but far too late. Info & support CRUCIAL	Regular support & information from the beginning prior to assessment	Discuss the REAL needs of those with CFS and make decisions to improve support	This is a debilitating condition which causes loss of 'normal' existence, isolation, loss of self. clear information and regular groups to share issues etc. really important. This could save money in the end because of reduction in depression etc. Would like feedback on the result of the survey.
y		n		
y		n		
y		n	n/a	
Yes	n/a	Medication. Yoga		Need to take other conditions into account. I have bipolar, and on an 'up' it is not easy to take things at a steady pace
Yes, once diagnosed		Being able to communicate with other people with ME	How services could be improved	I think Patient feedback is important, to help you improve services offered
				Have found acupuncture very helpful for pain control, but no longer available at JPUH pain clinic
y				Would prefer group meeting to be in Lowestoft
y			How far forward CFS/ME has come	At this meeting, if any groups (self help) will be represented. Stands maybe? Drug sponsors. A display on how big an area is covered and who runs the service. Let those who cannot attend know the outcome of the meeting
Yes and No. Shame we have to lose our ME/CFS nurse after a while			That sufferers still get the help needed	Wish there was more on offer in Ipswich/Felixstowe. I do attend a group in Felixstowe which is good. Thankyou for all your help and support

n	Sporadic appointments, on a few occassions sessions were cancelled due to staffing problems, and I had to wait weeks for another one. Also have to travel from Norwich to Lowestoft for a session, and I was worn out when I got there.	Massage. Relaxation sessions. Swimming in very warm pools		You need more staff, plus doctors who understand this illness, to talk to. How about giving the worse patients aquiet place to go away from all the noise of the world, like a sanatorium. I could have done with a retreat like this 20 years ago when no one understood the illness.
y		n		Shame it's not an on-going service
y				
y				
y, very			To be updated on ME/CFS	Need to raise awareness of ME/CFS, not enough know about the illness. Thank you for chance to provide feedback, and for the work you do. I would not have been able to manage without it
n	No contact, no response to emails. Telephone appointments not kept. Generally ignored when desperately seeking help and advice	Advice on medication for managing symptoms. Advice when experiencing a new or unusual symptom, when to seek medical intervention. Knowledge about causes of symptoms	Service users views to be respected, even if they are different to NICE treatment guidelines	More on what service could offer. Relaxation classess in service users own area. Nutritional advice and related tests
y		Have tried acupuncture, but it did not help		Have found face-to-face meetings have helped a lot. Pacing is best for me. OT has been very helpful with advice and support
y, invalauble help and advice from OT		Mctimoney Therapy. Attached information		
y			Not sure	The aditional services (q.4) would be invaluable to me. Please contact me if you are going to be offering them in future. These will help my recovery. My OT has been invaluable, I really appreciate her help and time.
n	Not much in the way of pro-active language. Just a general chat for 15 minutes every 6 months	Advice on diet, nutrition and management of stressful situations/events	Positivity! Advice and chance to share tips etc	
y		What is CBT. How can acupuncture help?		

y		Massage therapy	Strengthening of awareness of what could be available	Regular blood tests etc to make sure nothing else is going on as well as ME
n	Always grateful when OT phones for my appointments, but would be really nice to see her in person. Have been twice when husband has taken me, but is too far for me to drive	All would be good to try, but not always possible to go out. Would make the effort though.		I'm trying meditationand following the eli diet, both of which I found on Facebook ME groups. These groups have stopped me feeling so alone. OT always helpful and kind, but a phone call isn't enough when you feel so ill
n	Acupunture should be available on the NHS		Maybe invite local MP?	Perhaps have comprehensive feedback compiled to see where patients have obtained some degree of success or cure for their condition
y		Reflexology		
n	When OT went on maternityl feel I have been forgotten. I'm sure I was to expect another meeting with someone at St James Medical Centre, King's Lynn	Regular meetings in King's Lynn	Advice, latest research, able to meet other sufferers	You mention in the letter to follow a link to the Survey Monkey - you failed to state this link so we are all having to pay postage to get the questionnaire to you
y				I am very pleased with the therapy I am receiving at the present time
y		Hydrotherapy		
n	Leaflets don't help, people can do research by themselves. Another leaflet is insulting. However, the CFS service pack is good - put it online	Physiotherapy		CFS/ME social network: to share tips and experiences (or forum with NHS professionals). Faster diagnosis. List of GPs with CFS/ME experience, to help support sufferers. NHS funding for CBT and physiotherapy. GPs need to go on a CFS course so misdiagnosis rates decrease (no more wasting anti-depressant pills.
y	However, more links with local services like social services, DWP, GPs etc. Is a chronic illness so any support needs to be ongoing	Welfare rights support (benefits). Access to social services. Ongoing treatment.		Service needs to have links to hospital's mental services, because when crisis happens and patient ends up in A&E nobody has a clue about ME/CFS and its chronic nature.
y	My OT has changed. I understand that this happens from time to time, but it's nice to build a relationship			

y		n		Answered y to Q3 but I don't get any benefit from appointments. Hassle to get there and just answer questions about how I feel
			Patient input regarding the future of service, and more info disseminated to GPs	Unable to use internet or travel far due to symptoms. These limitations need to be considered when asking for patient input
y				
y	The service I receive from OT is exceptional, but I am not aware of any other service other than CBT from her		To have a better understanding of what is happening and what services are available	
y			Forward planning. New treatments or other people's issues heard	
y and n	GPs don't want to know, as they don't know much about ME. This gets to you sometimes when you need help	Somewhere you can call if you need help	More info and help	Just wish there was more info to hand
y			More info on services available	I would like more help with task management and everyday issues that my illness causes.
n	I was happy with the advice about pacing and relaxation, but the service provided is very limited, i.e. pacing and relaxation	Diet advice. Tailoring advice and help to the individual, depending on the scope of their particular symptoms		Widen boundaries to beyond pacing and relaxation, including complementary therapies, diet advice, and maybe look at the Lightening Process or Reverse Therapy. More holistic approach needed, not everyone responds to pacing and relaxation.
y				
n	Old OT helped smooth the pathway for me visiting consultants as I get flustered. Since she left I don't feel fully supported. I had built up a rapport with her, and she helped me greatly	Medication support to unhelpful practitioners. Anxiety management. Help with form filling, especially for DLA and PIP. Meditation classes, relaxation techniques	More one-to-one support	More info and support to patients dealing with numerous appointments with healthcare professionals, and with form filling and dealing with people's attitudes to CFS. Some people don't feel this is an actual condition
y		n		I have found the service helpful & supportive and I hope it continues.
y		Mickle Therapy		
y, it's vital				Vital to keep services locally. Unable to travel to Bury St Edmunds.
y				

y		Can only cope with one thing at a time.		Really grateful for clinic as it has been very helpful, and that there is one in Norwich as I find travelling very exhausting.
y		Introduction and support in deep relaxation technique.		Has been a great help to me, in dealing with disabling and mysterious condition. Thank you!
y		Comedy as therapy	To discuss ideas that can be implemented	Great service, please keep it up.
y		Sleep therapy		Not sure if other therapies would help, but think trying them is a good idea.
y		Dietary advice	Discussion of possible treatments, stategies, and updates regarding research	Need advice about pressure at work, targets making it difficult to pace
y				People still do not understand ME and think it is just an excuse to be lazy. Can more be done about this?
y		n		
y, excellent		Reiki and massage, meditation	Increased awareness of ME	Keep up the good work.
y		Massage	Extra funding to enhance the service	A very big thank you to all involved with my treatment. I am given support from a professional and empathetic team.
				I would probably be more likely to attend a local meeting, re question 5, if there were to be any.
y and n	Individual staff excellent and supportive. Gap between appointments and location of them less good. Changing venue also stressful.	Meditation therapy	An honest appraisal of service, meeting needs of users discussed and locations.	I appreciate this is a scarce resource run by very committed individuals but this is a very lonely illness, so appointments at right frequency plus access to support (maybe via web resources) is critical.
n	We are in desperate need of a consultant. To have severe symptoms for a decade, and not having seen a consultant for many years is extremely depressing		For patients to explain any concerns	Thank you for the opportunity to provide feedback.

n	I have found my initial diagnosis appointment useful because I now have a letter explaining my condition that I can show to my university/work. However, I did not find the OT appointmentuseful as suggestions made were mostly unfeasable and did not tell me anything I didn.t already know.	Relaxation therapy like massage and guided meditation. It is really hard to travel to therapy as I find going on the bus etc really tiring. Something close to home would be great (in Holt, or a taxi provided).	Listen to the needs of people with ME for more effective therapy on and research on the NHS.	I find it very frustrating that there is no good consultant for ME in Norfolk and Suffolk. I also feel that the service is very limited. It took me 4 hours round trip to travel by bus to an OT appointment, where I was told to go to Thursford Christmas Spectacular, which I am not interested in! When I asked for some guided meditation MP3s the OT didn't know where to get any. She taught me a simple breathing exercise and that was all. I would really like some support in my own town (Holt) and useful things like counselling and holistic / relaxation therapies like massage, aromatherapy, gentle yoga, guided meditation, mindfullness courses etc.
y		Massage therapy	Plan the future timetable and likelihood of full recovery	Still awaiting follow-up appointment.
y, excellent from diagnosis		Support with adjustments with gaining support / empathy from employer, concerned about culture of organisation.	Secure funding and expand service locally.	Alarmiingly I am employed by ECCH CIC and no adjustments made and albeit they fund your service, I am however unsupported as an employee within the same organisation! Advocate for change necessary.
y		n		Prefer 1:1 appointments
y				I am very happy with the service I get from East Coast.
y				
y				
n	The OT is very very good. I did think referral was to a doctor specialising in ME and a physiotherapist.	Medical expertise for treatment. Physiotherapy.	Aim for the above (number 4).	Was very disappointed after many medical tests / months of waiting to find no medical / doctor support / physiotherapist.
y and n	The service is unable to provide CDs or cassettes with relaxation techniques etc. There is plenty of advice on how to download these, but I don't have access to the internet for downloading purposes. Otherwise the service is very helpful.			My therapists have been very helpful.
y				

y				
y			Meeting like-minded people and free legal advice on occupational issues related to ME	Just a big thank you to the Ots for their help.
y				
y and n	I have a mixed opinion. I think it's good there is someone to talk to but I think I personally would be happier with more face-to-face appontments and feel funding and or help with therapies would help.	Hydrotherapy, as this could help with pain etc.	More therapies and exercise / group meetings.	I think more is needed instead of just phone conversations, such as therapies mentioned in Question 4, although having someone to talk to does help.
y	But - one Dr in local clinic ignorant of condition	For real lows, patient is dangeous to self and others. Help for carers	To help make government aware. Husband is happy to speak to help others.	no
n	Daughter has not been seen for over a year. The professionals made her uncomfortable. Has to rely on sporadic phone contact	Moving overseas so not interested in further treatment options	Unsure	ME association has been very useful. Have found help on internet. The staff working for service need to keep up-to-date with current research. Was sent another patient's details in error
y		n		Very helpful service.
y	not seen physician for some time ? If still available		no	
n	not enough support, more difficult now as have to contact Yarmouth (used to be done through local hospital), have to explain yourself twice, very tiring, OT keps changing, not consistent.	massage, pain management	The future of the service	Hard for OT's to support when they change & don't know you, DNA- appts; miss sometimes due to difficulty of condition & travel issues; feel it unfair to be taken off the list due to this, ? Home visits possible, more research into condition, would like to remain anonymous to service on feedback please
y/n	Not enough support or info	n		Lot of family & friend
Yes				
Yes				Due to other medical problems I have it has been difficult to help me, but ********** has been very good.

Yes		ALL the staff i have met at Lowestoft, Yarmouth, Halesworth and James Pagent over the last 15 years approx have been exceptional with my care. ********* in particular has been very impressive. I generally avoid conversation and interacting with others at every opportunity as too tiring emotionally and physically which even family members. However, I've been lucky that my Ipswich GP and all your staff who have dealt with my care have been very easy to talk to face to face. I find the meetings tiring but worth every ounce of effort no matter what distance my husband has to drive to get me there. I think he finds the sessions as relaxed and informative as I do. The paperwork received has been very easy to understand and has made digesting how to deal with this illness easier. AN EXCELLENT ORGANISATION all round. THANKYOU SO MUCH.	For the service to continue functioning as brilliantly as it has so far.	see previous comments. I did attend a group session in the early days of my illness which was one day a week at James Pagent for a few weeks. It was very informative and made me feel that I was no longer going crazy. The only drawback to this meeting (I was not so anti social at the time) was that I thought that my long suffering husband who had taken time off work to drive me there would have also benefited from the session or a similar one for partners to give them more of an insight into the illness and how to help. I've been lucky that my husband is very laid back and accepting but others may struggle to understand or cope.
Yes				
Yes				
Yes		I have received excellent support and it would be extremely assuring to know that this support is to continue		
Yes				
No	Meetings have gone from 3 months to 1 year!		To actualy know what service is provided.	

No	as far as I can ascertain the only service available is a pared down version of the service available in 2006 when I saw Dr Gerken. At best it is part-time with some very hard-working and sympathetic OTs. At worst it is a low-level service that is beholden to everything that NICE pushes e.g. CBT and GET which has been no help to me whatsoever and has been found to be of little use to most people with M.E./CFS. We need a proper service based on a bio-medical model	We do NOT want CBT/GET offered in a local NHS service. CBT/GET are not genuinely evidence-based treatments for ME patients. We want a full biomedical service based upon the Carruthers et al International Consensus Criteria/Primer documents. We have been telling you this for many many years	I might if I could get there but realistically how many people with M.E./CFS do you think would be able to attend and remain at such a meeting. If I did manage to attend I would like to see an open and honest discussion about provision of a service based on a bio-medical model that moves away from the Psycho-social model and all the flim-flam of Wessley and his ilk and the idea that people with M.E. /CFS of such things as aberrant illness beliefs, the idea that CBT could provide anything more than a way of coping with a chronic health condition and the idea that GET could be beneficial	Please stop peddling the same script and see if the service you are going to provide (the service you have been promising to provide for many many years) is based around a proper scientific bio-medical model. We don't need any more therapy -- group, individual or otherwise. We are all sick of being sick and sick of being treated as if some sort of tinkering with our psychology will help. It won't.
No	No effective treatment (not your fault, but inevitably makes the service rather pointless for me).	Quack-busters. The most important thing you could do is go after those making exaggerated claims about the efficacy of treatments for CFS (acupuncture, CBT, GET). If treatments are only able to lead to minor improvements to subjective self-report measures in non-blinded trials, while leading to no improvement in more objective outcomes (employment, actometer data, etc), then they are worthless quackery, and their promotion to patients is abusive and manipulative.	Debate the use of resources. Should money be given directly to patients so that they can choose how to improve their own quality of life, or should it be used to pay for interventions which seem to be no more effective than placebo?	It is important the patients have access to reliable information about the efficacy of treatments before they decide whether to spend their time and effort upon them. Anyone working in this are should be calling for the full release of results for the outcome measures laid out in the PACE trial's protocol, and working to ensure that all future non-blinded research includes objective measures of activity as one of their outcome measures. Patients should not have to put up with quackery just because they have been diagnosed with CFS.
Yes			Discuss alternative treatment options	
Yes				

No	I cannot comment on patients with fatigue states, but the service is wholly inappropriate for people with ICD-10 G93.3 Myalgic Encephalomyelitis.	Full biomedical testing (in published studies 40% of patients are found to have other diseases). Appropriate supplementation, taking into account the poor absorption of nutrients from the gut in many patients. Investigation of the reasons for the inflammation in most patients. Identification of pathogens. Cardio-pulmonary exercise testing on at least two consecutive days. This is a small selection of factors to consider.	I would like to see a proper biomedical service on the lines of that provided by Dr Terry Mitchell until his retirement. Three consultants agreed to take over his role between them - I would like to see that implemented.	NICE CG53 and the PACE Trial do not apply to Myalgic Encephalomyelitis. The Guideline Development Group for CG53 made this clear, and Prof Peter White, Principal Investigator for PACE, stated publically that there were no patients with Myalgic Encephalomyelitis in the study. I am appalled that people in the the ECCH area who are desperately ill with severe or very severe ME but totally or almost totally without medical care. Priority needs to be given to remedying this state of affairs. People suffer horribly and die from ME. See www.stonebird.co.uk and http://www.hfme.org/mesymptoms.htm.
Yes			Talk to other people with similar problems as I don't know anyone with me/cfs	
No	No service for severely affected	Home visits for severely affected Referral to endocrinologist and other medical specialists not just psychiatric treatment unless patients need cbt to help them cope.	Don't want meeting like that	
No	I was treated by a lady called ********** who was unprofessional and patronizing	Physiotherapy, massage or pain management		Physiotherapy or massage or pain management would be very helpful
No	I have only had one appointment in the year since diagnosis as I live in King's Lynn. Also I have mental health issues and I'm not sure conventional treatment can help me..		Open discussion regarding the service provided and future improvements to access for people living in King's Lynn area.	The nurse I saw for my one appointment was excellent and I really appreciated her understanding.
No	diagnosed, had cbt, then left to my own devices	nutrition advice, benefit advice, follow up consultations, opportunity to take part in research.	You are asking M.E sufferers to attend a meeting in Bury St Edmunds.....really? When just getting out of bed can be a challenge! I'd like to see a good shake up of the system. I don't even know what help is available.	What is the point? Does anyone actually listen?

No	no consultant. no expert dr who does home visits. OTs who don't get extreme ME - I'm tube fed - & seem to think everyone can do rehab. when ********** there I was very ill, initially told still must wait a year to see him. prior to this I'd been refused as he was to busy as the PCT would only fund him part time over four counties.	Yes a knowledgeable consultant who will use experimental drugs eg immunivir in the very sick, as ************ did. Home visits from expert Dr & ongoing support/liasing with GP & better trained OTs. Access to email counselling.	Action to get a medical consultant NOW. & NNUH be made to care for ME Inc. inpatient.	
Yes				
Yes			Discussion of the future of the service. Unfortunately I can't get to Bury St Edmunds but I would like to help shape the service	Link in with MIND's Peer support network http://www.suffolkmind.org.uk/peer-support-network-psn.asp. Work with support groups like Beccles. Provide meeting places and administrative help. Expert patient programme. Use the benefit of patients ability to support one another alongside expert input from OTs and GPs/nurses. Maintain contact with patients who are managing or have recovered.
Yes			Chat to others with m.e to know I am not on my own or going mad ,	
No	service good, but took years to be diagnosed	reflexology		

No	Promise-"It is the intention of all three PCTs that the development of services for ME/CFS will be a true partnership venture with patient and carers working with the PCTs to create a world class service\u2019Where are you responsibilities to carers reflected here? Address what you should be doing before considering additional.The service being delivered is contrary to that agreed and outlined in the service spec. It is purely a NICE spec. It will fail to meet what we understand of the new service spec. In 2009, we were promised a consultant led biomedical service (with proscribing rights re instated). The service is not working towards the agreed service as recommended in 2009 by Joint Health Scrutiny and as was promised to the approximately 8,000 potential local patients. Ongoing care is not being addressed and this results in a dangerously high level of unmet need, particularly for the severely affected. This is a failure of duty of care for the new Clinical Commissioning Groups . Patients/ carers have been engaged fully with the official process and been petitioning in earnest for 9 years to see us going backwards not forwards. Local needs are being treated with contempt. Health Scrutiny recommendation is being ignored. Pledges made have been repeatedly broken. GET is potentially dangerous. CBT is an expensive palliative and not cost effective, We were promised and demand a proper service.	GET is potentially dangerous. Although the service should have regard to NICE locally, Patient and Carer Group Reps have indicted local patient wishes, back up by a detailed, comprehensive patient survey, to for a consultant led biomedical specialist service, NOT a bio psychosocial one which is indicated here.	Deliver AGREED to a biomedical, consultant led service. Acknowledge the detailed Needs Assessment delivered by Norfolk in 2012. Meet unmet need, particularly for the severely Affected, deliver ongoing care as you are failing both currently.	The repeated formal complaints made to the Service Provider about the nature of the service and the psychological approach adopted by GPwSI have not been addressed. The consultant replacement has not been actioned. The managers of the service have failed to action promises of dialogue and liaison with the working group reps. The group were not informed of this survey and should have been. Have the commissioning teams who process the Service Spec been informed? The OTs are regarded well by patients generally. Patients are particularly grateful for the service the OTs provide particularly with respect of support for benefit difficulties and for their telephone service. This can may life bearable at least.
Yes			Regular meetings arranged locally	

No	I think it might be more effective if it was more intense/regular included CBT and developed some sort of personal plan with the individual patients. (I understand financial constraints this is purely a wish list!)		All attendees to have a voice. A positive action plan outlined.	The service has been invaluable just by being there. But sometimes it feels that that is all it does. Although I'm glad it is there I'm sure it could be improved. I'm bemused that CBT combined with careful and supported GET isn't offered. PS I didnt know about the website until I received the questionaire and looked it up Thank You
Yes				
Yes		Non CBT, One-to-one Counselling	Large sounds daunting for those with ME/CFS !!! Sharing of up-to-date research/information. Not a moan session !!!	I found the one to one contact with the OT invaluable.
Yes				
No	There does not seem to be much help or support especially for children with M.E. The only advice is to pace which is not very easy for a child to do.	I think giving children a course of CBT could maybe help them to manage the illness better. Also small group therapy of children of a similar age could help them to feel they are not alone and help them to open up and talk about there're feelings.		
No	I would like more frequent contact			
Yes				I was very happy with my initial consultation with the specialist doctor, ********* and have had further chats with the specialist physios. I have arranged an in person appointment with the physio for March, so she can assess and advise me further. I am hoping to soon arrange a trial run of doing a few hours a week at work to see how I get on. Thanks for all your help.
Yes				
No	lack of support to limited input			
Yes				Its early days yet for my use of the service, hence I have no strong views.
Yes				

No	I just find that in the appointments, I regularly have the same conversations and find the only method suggested to me is rest, which in my career path is very difficult even in quiet times. I also find that talking for an hour takes all of my energy and i'm exhausted for the rest of the day so could probably benefit from alternative approaches to talking therapies.	Relaxation sessions	Discussion about the current service and suggestions from the service users about how to improve the service.	
Yes				I am now being seen by the pain clinic at King's Lynn Hospital. I am having a session of Acupuncture as well as other treatments. I was very pleased with all the help ******* gave me. Thank You.
Yes				More alternative therapies available
No	The only advice offered to me by the occupational therapy department have been things I already know and to be honest are things that just help me to get through each day. I have not been offered anything practical that might actually help me to feel better. I want to live my life not just get through. To be honest the best advice was given to me by my son's pediatric diabetes consultant and to me that seems wrong - the ME/CFS service should be offering more to help in the long term- especially those of us who want to keep working and supporting family away from benefits.	I have ticked no to CBT simply because I have been trained to deliver CBT so it is something I use everyday for myself as well as teaching my clients to use it so this would not be a useful thing for me to be offered - having said that this would be extremely useful to those that do not have the experience I do with it.	I would like to see those of us dealing with ME/CFS on a day to day basis being able to have a say in what we feel the service should be delivering. It is all very well having people that maybe read a book or did a training course on it to say what they think, but to have insight from people who are living with it can really make a difference. I know there are budgets involved in delivering different healthcare services so lets spend the budget on a service that will really make a difference to people's lives.	Thanks for asking me for my thoughts on the current service provision for ME/CFS.
Yes				
Yes				In addition to the amazing help you gave me, I would like to commend the programmes being run at The Rowan Centre, Leiston.
Yes		I have always been an individual with my treatment so group therapy isnt for while it may well be for others. I dont know enough about acupuncture to comment.		

Yes				Messages do not always get through.
Yes			what things could be added to the service and discussing better links with the GP	I have found the service very useful and supportive - thank you.
Yes		Relaxation techniques?	Not sure what to expect but maybe something a little more local to where I live as I have to rely on telephone consultations as not very often able to drive to Halesworth.	I do want to say that the service and care I have received has been a real life saver thank you.
Yes			Open discussion with the patients as we all have tried different things that may work for another.	So far, an excellent service that has helped me to no end. Hopefully this year I will be able to return to work thanks mostly to help from ************.
Yes		Benefit seminar this area is now becoming a minefield	Discussions centred around long term effects of this illness side effects. Benefits system. Gp attitudes and medication. Thankyou	Excellent and well maintained service

No	No The 2009 Patient Survey of over 200 patients clearly stated what patients want. http://nandsme.blogspot.co.uk/p/patient-survey.html Four years later this is still not being delivered. Patients said they want: 1) A biomedical consultant to lead the service 2) A team of healthcare professionals who have the skills and expertise to care for people of all ages, of all levels of severity and complexity 3) Ongoing care for all with reviews between 1 month and 6 months depending on severity and need 4) Treatment and management to consist of self management - pacing and activity management and pharmacological treatment 5) Support for patients and carers including liaison with employers, education services, voluntary services, DWP and JCP 6) Information to facilitate informed choice regarding treatment options 7) Access to aids and equipment 8) Onward referral to other services e.g. pain clinic 9) GP training to ensure prompt recognition of ME/CFS and prompt referral 10) Respondents were significantly more satisfied with the service delivered by the therapists, but no action has been taken to improve the service delivered by the GPwSI	This question ignores the outcome of the patient survey of 2009 which found CBT and GET to be the least helpful and most harmful interventions and ignores the Needs Assessment finalised in 2012, which does not recommend GET and only recommends CBT to help patients to cope with their ME and CFS. The patients survey found the most helpful and least harmful interventions were pacing, rest, relaxation and meditation, Also medication for symptoms, massage and dietary changes were worth considering. Why have these options not been included in the survey?	Please note that patients with severe ME, such as myself, are rarely able to travel, or in my case stay upright during a meeting. Questions raised as to why further surveys are being held when the results and recommendations of the previous survey are being ignored.	In the letter from ************** of 27th Jan 2014 three different options were given regaring the response to this survey: 1. "By telephone on the above direct line number when I can take the answers to the questions..." Please note the only telephone number given was to the Community Services call centre - not a direct line to Geraldine Adams, or anyone else. 2. "Follow the link to the Survey Monkey" No Url/Link was given, Why not? I had to get the online survey details through waiting in line to talk to the Community Services call centre. 3. "Complete the questions below and return it to me at the address given above" - No SAE was enclosed. No end date for the survey is given. Why not? The online version of the survey not ask for contact details so the service can get back to patients who wish to attend a meeting. Have East Coast contacted the user groups who worked with Commissioners on the Needs Assessment and Service Specification both of which are mentioned on the service user website http://nandsme.blogspot.co.uk/ regarding this survey? If not why not? Finally although the governance of the service is questionable, as in my comments to this survey. I have nothing but praise for the staff of the ME/CFS service who are always reliable, supportive and straightforward. The ongoing support of therapists such as Louise Halliday and Jo Wiggins, with whom I have had the most contact is invaluable. Perhaps you should give some attention to their advice and recommendations.
Yes				The service has been a godsend for me - to have a confirmed diagnosis is a relief. Thank you

Yes		personal contact	a guarantee that the service will continue, even if the format changes	I hope the service continues, and will not be axed as a result of cutbacks, to me the service is important and valuable
y	n/a	n	Discussions on how people coping	ME site on Facebook interesting
n	Treatment has not made much difference. Frustating. Diagnosis stage difficult. A lack of interest shown even by staff	Good diet. ME association	Discussion on the need for more research	Lack of funding shows. Appointments were in a poor environment. Small, warm room that just added to the stress. OT themselves seemed stressed, their workload high
y			Any improvements to service	
Very happy		Massage	Provide info about HR and employment. Discuss possibility of a helpline	More info needs to be provided for family, to help them understand. Perhaps they could attend the meeting?
y	n/a	n	New avenues	What happened re. research - blood tests and questionnaire at JPUH

Joint Health Overview & Scrutiny Committee, 4 April 2017 - Norfolk & Suffolk ME & CFS Service
Report of Patient Experience Submitted by the Norfolk & Suffolk ME & CFS Patient / Carer Group

Service Development Implementation Group and Patient / Carer Group

In December 2012, the new ME & CFS biomedical service specification was signed off. The NHS Norfolk Full Public Health Needs Assessment for ME & CFS[i] informed the development of the new specification. Norfolk Commissioning were taking the lead in the Service Development process, and established the Service Development Implementation Group (SDIG) in 2013 to progress the implementation of the new specification. The Terms of Reference describe the purpose of the SDIG:

> *"to enable service users and carers to work in partnership with commissioners to develop and implement biomedical services for people with ME or CFS in Norfolk and Suffolk".*

The NHS are represented in the SDIG by Nicola Brunning & Jon Reynolds (IESCCG & WSCCG), Rachel Leeds & Catherine Griffiths (GY&W CCG), and Julie Endersby (Norfolk CCGs).

Patients and carers are represented by the Patient / Carer Group. As required by the SDIG Terms of Reference the Patient / Carer Group has patient and carer representatives from the Norfolk, Suffolk and Gt Yarmouth & Waveney geographical areas.

Included are Committee members of ME Support Norfolk (MESN)[ii], John Sayer (Patient) and Dan Ward (Carer). MESN is a large support group covering Norfolk & Suffolk who arrange monthly meetings, issue regular newsletters and provide invaluable assistance with benefit claims. MESN has regularly delivered a wealth of feedback to Service Development meetings from patients regarding the local service.

Our members from the Gt Yarmouth & Waveney area are the founders of Blue Ribbon Awareness for ME (BRAME[iii]), Tanya Harrison (Patient) and Christine Harrison (Carer) who work at a regional and national level including with the House of Lords and the All Party Parliamentary Group on ME. This provides the Service Development process with an invaluable regional and national context.

In Suffolk, one of our members advises health & social care commissioning in her personal capacity as a Carer (Barbara Robinson), and also in a professional capacity as a specialist in "education other than at school" service. These interests are represented at the APPG for ME level and also as an Associate Lecturer at the University of Suffolk. Barbara coordinates Suffolk Youth & Parent Support Group set up by Suffolk County Council in 1997. The patient representative for Suffolk is Dawn Whitaker. To keep local people informed about Service Development and to encourage interaction with the process a website was set up in 2009[iv], including email contact details. Facebook and Twitter social media accounts have also been established as additional conduits for feedback from local patients and carers, along with links to local support groups.

The approach of the Patient / Carer Group has been guided by:

- The NHS Norfolk Full Public Health Needs Assessment[v]
- What local people have told us they want from the service[vi]
- The approach taken by Dr Mitchell, NHS Clinical Champion for ME & CFS in the Eastern region and previous clinical consultant lead of the ME & CFS Service
- The approach recommended by the International Consensus Primer[vii] for Medical Practitioners for ME, co-authored by Dr Mitchell
- Reference to NICE Guidance where appropriate

Report of Patient Experience

This feedback is from patients living in Norfolk and Suffolk. The 'Can You See M.E.?' graphic contains quotes from patients who have emailed our group through the website, telephoned our group, passed on comments via support groups, commented in the Providers', East Coast Community Health (ECCH) Patient Change Audits and our Patient Survey. The other feedback comprises:

1. **Social Media**
   These comments are all the posts received via Facebook between Friday 17th March and Monday 20th March 2017 in response to a request for feedback regarding specialist ME & CFS Services and GP care. The comments have been given letters so that it is clear where a patient has made more than one comment. Personal information or anything relating to other issues has been removed

2. **Reduction in level of service provision**
   A quote from a letter sent to patients by ECCH in March 2017 has been included along with reports from patients via ME Support Norfolk regarding the effect on waiting times and number of sessions delivered

3. **Patients as Teachers**
   In the autumn of 2016 ECCH set up a 'Patients as Teachers' Forum. ECCH stated in the invitations:

   > *We will be holding a forum to get feedback on your experiences, your ideas to improve the service….. We will then explore ways to improve our service to you. After we have done this, we will write to each patient carer and/or relative who attended to tell you the outcome of your suggestions*

   There were no attendees for 2 of the 5 events (Norwich & Halesworth). One of our group members attended the forum in Stowmarket in October 2016 and took notes of the points raised, which are available on request. There were 7 patients / carers present. There has been no further contact so far, although the Service has promised an 'improvement and action plan' by the end of March 2017, 6 months after the forum met. The approach appears to focus on activity by ECCH rather than improving outcomes for patients.

4. **Patient Change Audits and additional feedback**

   As part of the Service Development process our group has had the opportunity to review the last two available Patient Change Audits carried out by ECCH. These audits include comments from patients. In addition, statistical data has been made available for the past 5 years. A copy of our groups analysis of the latest Patient Change Audit can be found at Appendix 1. The report of patient experience also includes three short illustrative case studies from Suffolk, along with further feedback from local patients and a few short quotes from our 2009 Patient Survey[viii].

Complaints by the Patient / Carer Group

In 2005 Gt Yarmouth and Waveney PCT, without consulting patients, made a significant variation to the ME & CFS Service by changing it from consultant led to therapy led. This has resulted in longstanding inequalities of care, especially for the 25% of patients severely affected by ME & CFS, who in the absence of a consultant, have very little, if any specialist care. Our Patient / Carer Group took our complaints firstly to the PCT but when this proved fruitless, to the Joint Committee. We were supported in this process by Norfolk LINk.

The whole Service Development process began on the recommendation of the Joint Committee in 2009[ix]. In addition to the longstanding failure to deliver equality of care to all patients with ME & CFS, there are also grounds for complaint regarding the failure of the Service Development process to deliver an acceptable Consultant led service within a reasonable time frame. Part of the delay has been beyond Commissioners control, such as the change from PCT's to CCG's.

However, despite the considerable commitment and effort of Ian Ayres at Norfolk Commissioning, and then Jon Reynolds at Suffolk Commissioning, there has been significant resistance to change both at East Coast Community Health and Gt Yarmouth & Waveney PCT, now CCG, which has hampered progress. Neither ECCH, nor Gt Yarmouth & Waveney CCG appear to have a culture which is conducive to partnerships with Patients and Carers designing, developing and implementing service change.

Formal complaints were made by our group on 21 July 2013 to ECCH, to all the 7 CCG's on 18 October 2013 and to Suffolk Commissioning in February 2014. Suffolk LINk also made a complaint to the Provider on our behalf in January 2013. Complaints have also been recorded regarding the service in each of the annual ECCH Quality Accounts which are available online. Anonymous negative comments have not been actioned or processed as complaints by ECCH, even when there is a clear pattern of dissatisfaction. An example of this occurred during 2015 when repeated complaints from patients raised concerns regarding a particular member of staff. These anonymous complaints were passed on to the Provider at SDIG meetings, yet ECCH did not act.

Although we raised concerns about the current service at every Service Development meeting we did not formalise these as complaints apart from those already mentioned above. This was because we wanted to work constructively to focus on delivering a new service to address the inequalities of care, rather than utilize scarce resources processing complaints. In addition, patients, carers and patient groups locally held off formalising complaints through Norfolk & Suffolk Healthwatch teams as it was felt that the wider, national survey of ME Service Experiences through the Healthwatch Trafford Survey would be more powerful way of registering general complaint /dissatisfaction. However, we are now in the process of formalising a complaint via Norfolk & Suffolk Healthwatch.

Finally, repeated feedback from patients and carers indicates that they are reluctant to formalise complaints, preferring anonymous feedback through our group, other support groups, surveys, the APPG for ME, Patient Change Audits and social media etc. The reasons they have told us they do not wish to complain formally include:

- They do not wish to jeopardise any limited care or support from the service they receive and / or precipitate a breakdown in the relationship with their GP
- Complaining takes a lot of effort and people with ME and CFS often have very low energy levels. Those most in need of specialist care, the severely affected, are those least able to complain about lack of provision
- There is a perception that complaints will not result in meaningful change in the NHS, especially as ME & CFS are poorly understood, and virtually all patients report insensitive comments by Health Professionals indicating a fundamental lack of understanding of ME & CFS

Joint Health Overview & Scrutiny Committee, 4 April 2017 - Norfolk & Suffolk ME & CFS Service
Report of Patient Experience Submitted by the Norfolk & Suffolk ME & CFS Patient / Carer Group

Can you see M.E.?

I have struggled to receive any help or information from my GP, or any other health professional

I have never had a GP ask how I am. I have never had a GP offer voluntarily to find access to services.

I've fallen into a black hole, invisible to health professionals & society

I cannot travel to see the doctor [GPwSI] because I am too unwell but I'm told he does not do home visits or telephone consultations

As an elderly person with ME how will I be treated with respect in the future?

I asked to see a doctor or consultant who specializes in ME and was informed that there was none

I now suffer pretty much in silence

My ME was deemed too complicated. I was discharged due to the fact there was no consultant

My GP just shrugs his shoulders and says ME, what's that--as a caustic throwaway line.

It's almost criminal. Because my long term serious illness is called ME why is it treated different to MS is beyond me?

If you are bedridden with ME/CFS you are unable in this area to access the specialist ME services

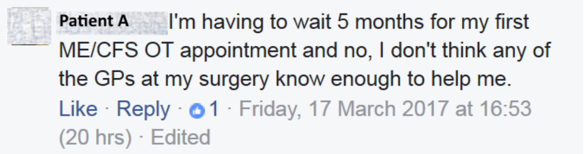
As my health has significantly worsened over the last 5 months, I am very keen to find a specialist that I can work with on a way forward

After short intervals of 'so called care' it's been a case of 'you're on your own'. GP's have no time or understanding or interest in the isolation

I believe my condition would improve with a proper structured programme in place…I feel like a prisoner in my own body left to rot by the NHS

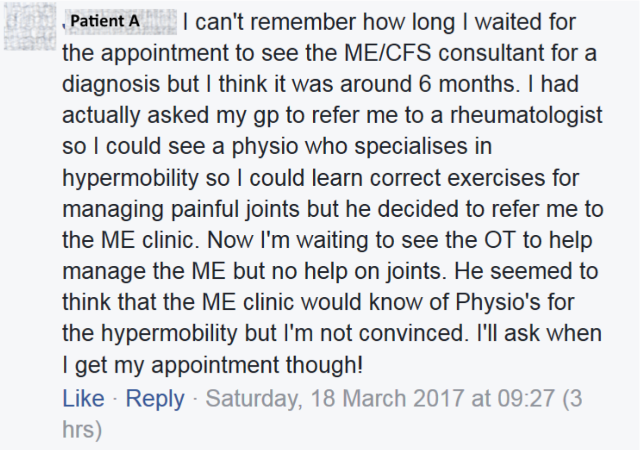
Joint Health Overview & Scrutiny Committee, 4 April 2017 - Norfolk & Suffolk ME & CFS Service Report of Patient Experience Submitted by the Norfolk & Suffolk ME & CFS Patient / Carer Group

Social Media: Dereham and Area – March 2017



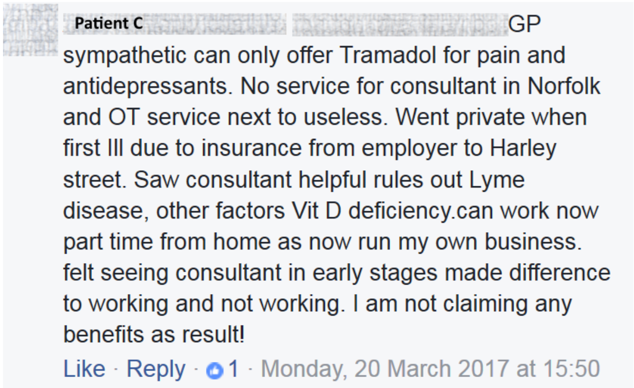
Patient A [redacted] I'm having to wait 5 months for my first ME/CFS OT appointment and no, I don't think any of the GPs at my surgery know enough to help me.

Like · Reply · 1 · Friday, 17 March 2017 at 16:53 (20 hrs) · Edited



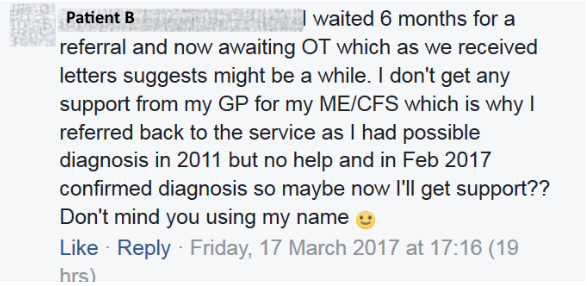
Patient A [redacted] I can't remember how long I waited for the appointment to see the ME/CFS consultant for a diagnosis but I think it was around 6 months. I had actually asked my gp to refer me to a rheumatologist so I could see a physio who specialises in hypermobility so I could learn correct exercises for managing painful joints but he decided to refer me to the ME clinic. Now I'm waiting to see the OT to help manage the ME but no help on joints. He seemed to think that the ME clinic would know of Physio's for the hypermobility but I'm not convinced. I'll ask when I get my appointment though!

Like · Reply · Saturday, 18 March 2017 at 09:27 (3 hrs)



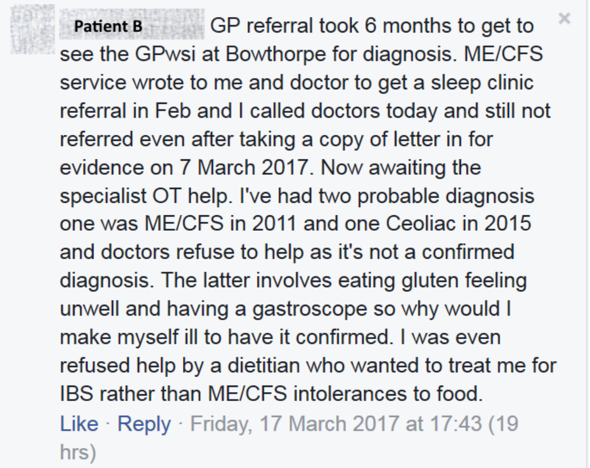
Patient C [redacted] GP sympathetic can only offer Tramadol for pain and antidepressants. No service for consultant in Norfolk and OT service next to useless. Went private when first Ill due to insurance from employer to Harley street. Saw consultant helpful rules out Lyme disease, other factors Vit D deficiency.can work now part time from home as now run my own business. felt seeing consultant in early stages made difference to working and not working. I am not claiming any benefits as result!

Like · Reply · 1 · Monday, 20 March 2017 at 15:50



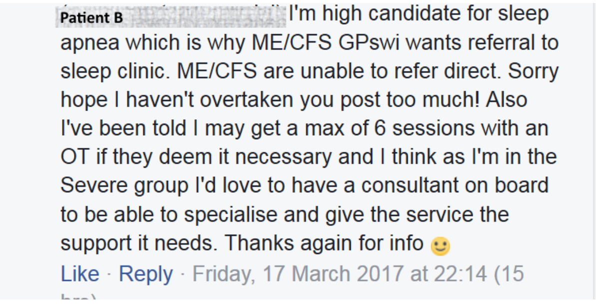
Patient B [redacted] I waited 6 months for a referral and now awaiting OT which as we received letters suggests might be a while. I don't get any support from my GP for my ME/CFS which is why I referred back to the service as I had possible diagnosis in 2011 but no help and in Feb 2017 confirmed diagnosis so maybe now I'll get support?? Don't mind you using my name 🙂

Like · Reply · Friday, 17 March 2017 at 17:16 (19 hrs)



Patient B [redacted] GP referral took 6 months to get to see the GPwsi at Bowthorpe for diagnosis. ME/CFS service wrote to me and doctor to get a sleep clinic referral in Feb and I called doctors today and still not referred even after taking a copy of letter in for evidence on 7 March 2017. Now awaiting the specialist OT help. I've had two probable diagnosis one was ME/CFS in 2011 and one Ceoliac in 2015 and doctors refuse to help as it's not a confirmed diagnosis. The latter involves eating gluten feeling unwell and having a gastroscope so why would I make myself ill to have it confirmed. I was even refused help by a dietitian who wanted to treat me for IBS rather than ME/CFS intolerances to food.

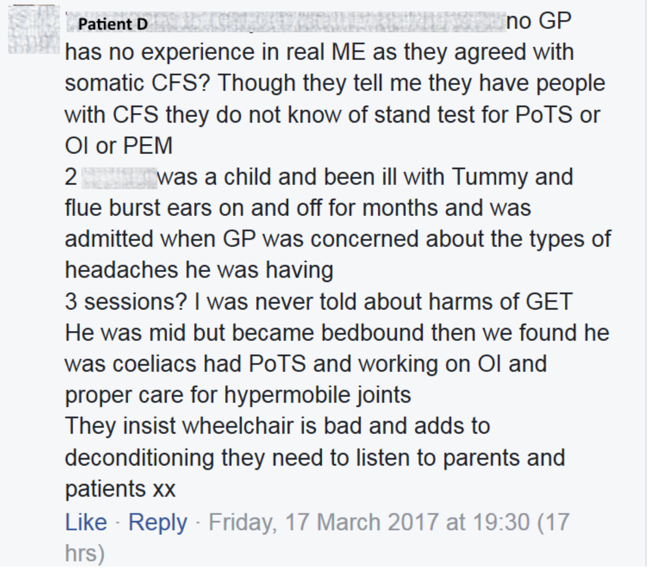
Like · Reply · Friday, 17 March 2017 at 17:43 (19 hrs)



Patient B [redacted] I'm high candidate for sleep apnea which is why ME/CFS GPswi wants referral to sleep clinic. ME/CFS are unable to refer direct. Sorry hope I haven't overtaken you post too much! Also I've been told I may get a max of 6 sessions with an OT if they deem it necessary and I think as I'm in the Severe group I'd love to have a consultant on board to be able to specialise and give the service the support it needs. Thanks again for info 🙂

Like · Reply · Friday, 17 March 2017 at 22:14 (15

Social Media: Bury St Edmunds and Area – March 2017



Patient D [redacted] no GP has no experience in real ME as they agreed with somatic CFS? Though they tell me they have people with CFS they do not know of stand test for PoTS or OI or PEM

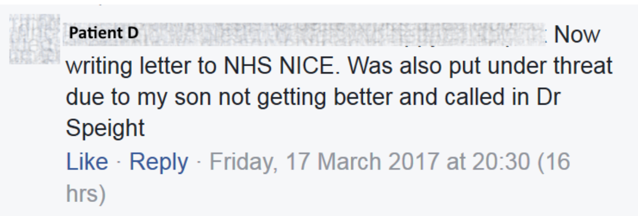
2 [redacted] was a child and been ill with Tummy and flue burst ears on and off for months and was admitted when GP was concerned about the types of headaches he was having

3 sessions? I was never told about harms of GET

He was mid but became bedbound then we found he was coeliacs had PoTS and working on OI and proper care for hypermobile joints

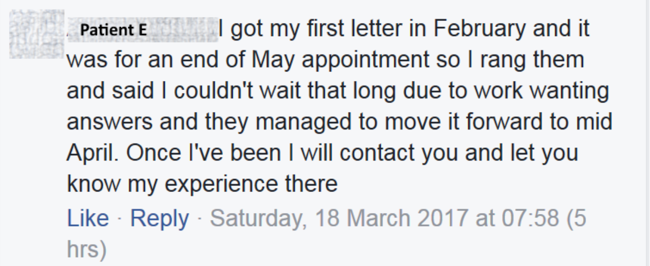
They insist wheelchair is bad and adds to deconditioning they need to listen to parents and patients xx

Like · Reply · Friday, 17 March 2017 at 19:30 (17 hrs)



Patient D [redacted] Now writing letter to NHS NICE. Was also put under threat due to my son not getting better and called in Dr Speight

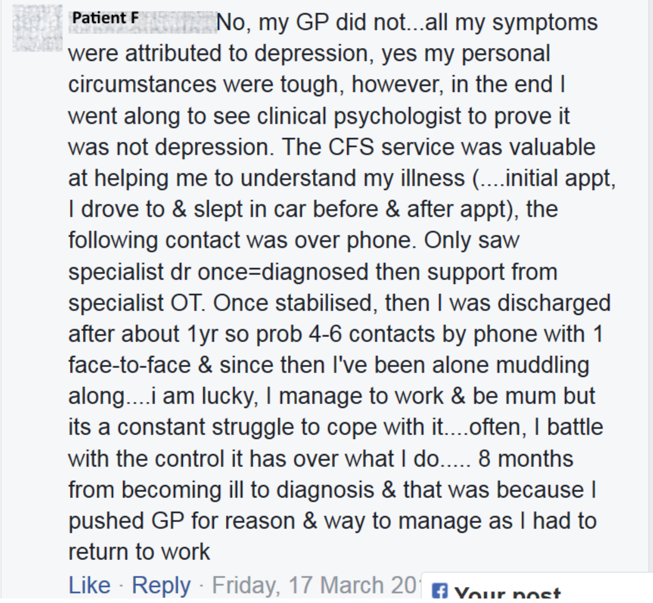
Like · Reply · Friday, 17 March 2017 at 20:30 (16 hrs)



Patient E [redacted] I got my first letter in February and it was for an end of May appointment so I rang them and said I couldn't wait that long due to work wanting answers and they managed to move it forward to mid April. Once I've been I will contact you and let you know my experience there

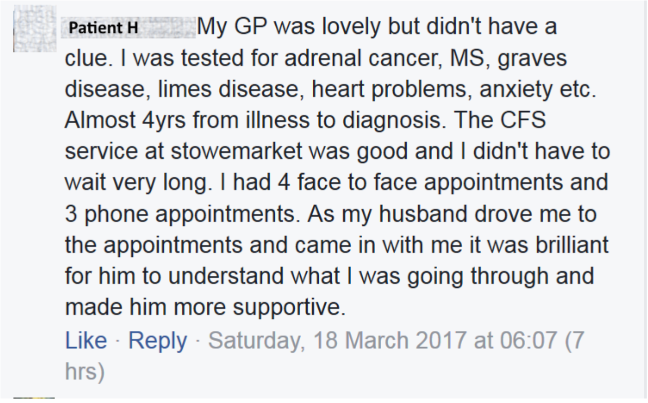
Like · Reply · Saturday, 18 March 2017 at 07:58 (5 hrs)

Social Media: Ipswich and Area – March 2017



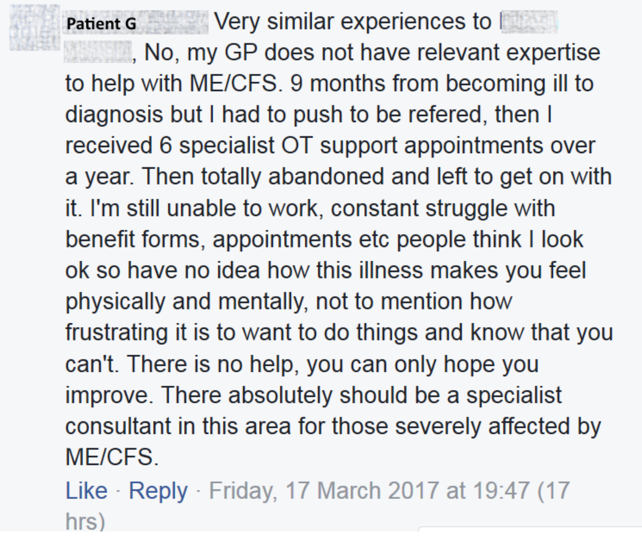
Patient F [redacted] No, my GP did not...all my symptoms were attributed to depression, yes my personal circumstances were tough, however, in the end I went along to see clinical psychologist to prove it was not depression. The CFS service was valuable at helping me to understand my illness (....initial appt, I drove to & slept in car before & after appt), the following contact was over phone. Only saw specialist dr once=diagnosed then support from specialist OT. Once stabilised, then I was discharged after about 1yr so prob 4-6 contacts by phone with 1 face-to-face & since then I've been alone muddling along....i am lucky, I manage to work & be mum but its a constant struggle to cope with it....often, I battle with the control it has over what I do..... 8 months from becoming ill to diagnosis & that was because I pushed GP for reason & way to manage as I had to return to work

Like · Reply · Friday, 17 March 20



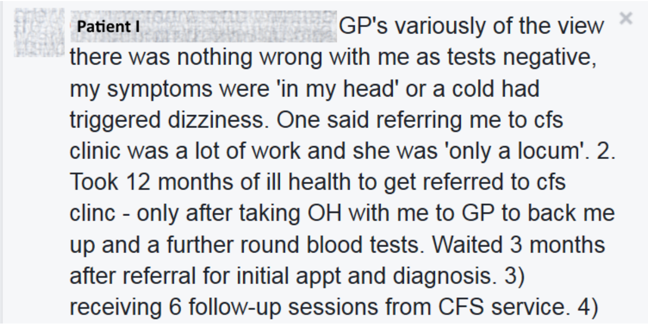
Patient H [redacted] My GP was lovely but didn't have a clue. I was tested for adrenal cancer, MS, graves disease, limes disease, heart problems, anxiety etc. Almost 4yrs from illness to diagnosis. The CFS service at stowemarket was good and I didn't have to wait very long. I had 4 face to face appointments and 3 phone appointments. As my husband drove me to the appointments and came in with me it was brilliant for him to understand what I was going through and made him more supportive.

Like · Reply · Saturday, 18 March 2017 at 06:07 (7 hrs)



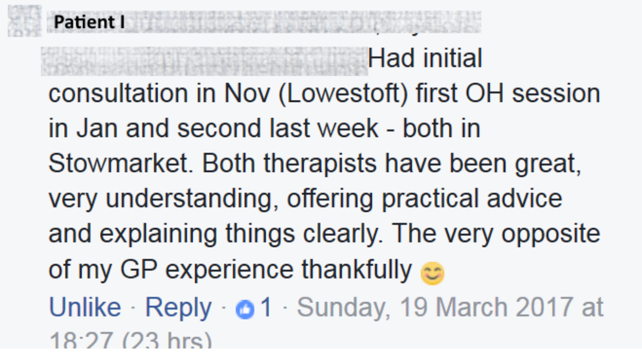
Patient G [redacted] Very similar experiences to [redacted], No, my GP does not have relevant expertise to help with ME/CFS. 9 months from becoming ill to diagnosis but I had to push to be refered, then I received 6 specialist OT support appointments over a year. Then totally abandoned and left to get on with it. I'm still unable to work, constant struggle with benefit forms, appointments etc people think I look ok so have no idea how this illness makes you feel physically and mentally, not to mention how frustrating it is to want to do things and know that you can't. There is no help, you can only hope you improve. There absolutely should be a specialist consultant in this area for those severely affected by ME/CFS.

Like · Reply · Friday, 17 March 2017 at 19:47 (17 hrs)



Patient I [redacted] GP's variously of the view there was nothing wrong with me as tests negative, my symptoms were 'in my head' or a cold had triggered dizziness. One said referring me to cfs clinic was a lot of work and she was 'only a locum'. 2. Took 12 months of ill health to get referred to cfs clinc - only after taking OH with me to GP to back me up and a further round blood tests. Waited 3 months after referral for initial appt and diagnosis. 3) receiving 6 follow-up sessions from CFS service. 4)

Patient I [redacted] Initial appointment and diagnosis was 100 mile round trip.. No way I could have done the journey on my own but thankfully my OH was able to take me. Follow up appointments much closer [redacted]



Patient I [redacted] Had initial consultation in Nov (Lowestoft) first OH session in Jan and second last week - both in Stowmarket. Both therapists have been great, very understanding, offering practical advice and explaining things clearly. The very opposite of my GP experience thankfully 😊

Unlike · Reply · 👍 1 · Sunday, 19 March 2017 at 18:27 (23 hrs)

2. Letter sent out to patients from the ME & CFS Service (March 2017)

> *'As a service, we have seen a significant increase in our referrals and unfortunately this has led to increasing waiting times between therapy appointments and for this we can only apologise.*
>
> *To try and minimise the need for cancellations and missed appointments as a result of the length of time between booking the appointment and the actual appointment date, we are now only booking appointments a month prior to your review date'*

We have had feedback from ME Support Norfolk recently that waiting times for appointments have increased and the number of sessions offered to patients are decreasing. The average wait time for both GPwSI and therapist appointments is recorded by the Service as increased to 12 weeks, although as you can see from the Facebook comments, patients are reporting longer. For the therapists, this is an increase from a wait time of 5 weeks last year.

3. ''Patients as Teachers'' Forum organised by ECCH held in Stowmarket in October 2016

The main issues for improvement identified by the 7 patients / carers participating in the forum were:

- **Problems with GP's** – fundamental and widespread lack of expertise and understanding and failure to deliver care plans recommended by NICE. This is a significant barrier to delivering ongoing care. It was explained by the lead therapist that the service sees its role to support GP's care for patients with ME and CFS
- **Level of care provided by the service** – there is no ongoing care, or care plan. Medication for symptom control is not prescribed or often recommended. There is very little care at all for the severely affected and a lack of specialist expertise for this patient group (about 25% of all patients). Patients describe falling into a 'black hole' of lack of care and understanding with comments from health professionals 'we all get tired sometimes'
- **Provision of Information about ME & CFS** – There is a great deal of information available online, but not enough information from the clinic – perhaps a knowledge bank could be provided. There is nothing about the Patients as Teachers initiative on the ECCH website.
- **Practical issues** – There should be greater use of electronic communication and telehealth. Digital recording of consultations should be offered to all patients due to cognitive problems. There should be somewhere to lie down in the consulting rooms & a fan/heater should also be provided. There are problems with the ECCH telephone system. Calls are not always returned. Patients are often not advised when discharged by the service.
- **Other issues** – Consideration needs to be given to the diagnostic criteria used as currently Post Exertional Malaise, which is considered to be a cardinal feature of ME is not assessed by the service. The questionnaires sent to patients are too long and overlap and need to be re-written. There needs to be more emphasis on functional outcomes which are important to patients. Further training is needed on Orthostatic Intolerance which is very common in ME and CFS, and the DWP descriptors for benefit claims.

4. Patient Change Audits – Annual survey of Patients by ECCH

These are especially important as the F&F test forms are sent out by ECCH after the first appointment and not at discharge so they do not reflect the whole journey through the service. This is what a patient said about this:

> ''*The problem is that this is before the service has done much more than initially listen. Fine, but it's not a good time to gather information*''

It is reassuring that data from ECCH indicates that patients report that the levels of improvements in symptoms and coping are relatively stable between 2012 and 2016. It is of concern that the 'got worse' responses are increasing, although for three of the 5 years there were less than 50 responses to the Patient Change Audits.

Comparison of positive comments between the two most recently available Change Audits are stable and centre around much appreciated support, validation, help with education authorities and benefit claims. Also appreciated are the recognition of the value of managing symptoms and adjusting to reduced activity levels.

There are definite themes around the negative comments for both years:

1. Lack of ongoing care (and GP care) and this is likely reflected in the high re-referral rates of 31%
2. Lack of care for the severely affected, especially surrounding symptom control and
3. Lack of care other than basic management

Selection of comments made by patients on the latest available Change Audits:

Level of care:

- *I would say that from my point of view the important thing would be being able to provide a good level of contact and support post diagnosis*
- *No-one helped me. Felt like I was just fobbed off. ME clinic appointments were so far apart and then cancelled -they were very unhelpful and to them I was just a number. I have learnt I'm on my own with this so manage the best I can*
- *This service is very good. Please lengthen the referrals as there is little support from people who have knowledge*
- *I remember coming out of the meeting with a distinct feeling that it was all my fault and I just needed to be more positive, and that there was nothing out there to help me and I should just get on with it.*
- *My husband was diagnosed and seen once or twice then left*
- *I feel I get no help and I find every day difficult, it's getting me down so much I take it out on loved ones,*
- *Good support but very limited. Only 6 sessions. I need someone to help long term*
- *I find I am not improving and am left to now get on with the illness as best I can. I am becoming more despondent about the future as I feel I may never recover*

Severely affected

- *The severely affected are neglected and forgotten about. It is time that the Health service appointed a specialist who will re-organise the ME service and make the severely affected their first priority*
- *There is zero help for ME/CFS sufferers, or no help for someone who is unwell as myself. There seems to be no one who can help or has complete knowledge to help me*

GP's

- *One [GP] told me to ignore all my symptoms, carry on as normal and symptoms would disappear*
- *I am very grateful to have the service but there is definite room for improvement and I am hugely relieved that it's going biomedical. I would particularly like to draw attention to: No offer of further tests to rule out alternative conditions… Very limited contact with a therapist not a GP. My GP not brought up to date re ME/CFS. No real improvements*

Other

- *A complete waste of time and NHS funding in my opinion*
- *[I found] the person who I was seeing to be the most unmotivated and miserable person I've come across in my life. I personally stopped going as found it to be of no benefit whatsoever.* [It is possible that this comment concerns the member of staff that our group raised concerns about in the Service Development meetings]

A more detailed analysis of the most recent Patient Change Audit can be found at Appendix 1.

5. Suffolk Case Studies

Suffolk CCG Commissioning have been interested, compassionate, supportive and proactive. Thank you.

However, the following 3 cases illustrate a fundamental and critical lack of coordination between agencies and services throughout Suffolk. This is despite the existence of the "Multi Agency Hub" MASH, effectively resulting in breaches of;

1. Disability legislation
2. The 2014 Care Act and
3. The 2012 Health and Social Care Act

Case 1 Suffolk
Patient A has experienced "unexplained " ill health for 40 years, post glandular fever. There was a GP referral to the service circa 2006 for an appointment with a GPwSI. The appointment was one hour with 3 hours travelling to and from Lowestoft which precipitated a severe relapse. Diagnosis was confirmed and the only following contact was information via post. No further contact from the service or notification of discharge.

Case 2 Suffolk
Patient B was diagnosed with ME in 1997 at Ipswich Hospital by Paediatrician. There was inappropriate management and advice resulting in severe ME from 2001. The patient was referred to ME Service in 2006- 2007. The patient received one OT domiciliary visit with no contact or follow up. However, the service did deliverer supporting medical reports for the DWP.

Case 3 Suffolk
Patient C was diagnosed as severely affected in 2006. During the past 11 years, there has been no oversight, guidance or input from the ME Service, despite the fact there is a high level of need both for the patient and wider family. The GP input was totally inadequate in progressing and advising leading to a multiple at risk situation for multiple family members. This was a "Multi Agency Hub case" involving both Suffolk Adult and Children's Social Services.

The resolution of situation finally dealt with by local advocates, voluntary and specialist charity input. This case study was requested by Suffolk Commissioning as part of their Due Diligence approach. The case was submitted to the All Party Parliamentary Group (APPG) Inquiry in 2016 and was incorporated into the APPG draft report and flagged up at the Parliamentary Select Committee debate in 2016. The case was also offered to the University of Suffolk Social workers training event in May 2016.

Historically MPs have shown complete disinterest and lack of compassion, although more interest has been shown recently. One MP made an inaccurate and damaging speech to Parliament whilst in a ministerial health post. Another local MP was also later in a junior health minister post at the time of Case 3. A third, in addition to being an MP, is also a practicing qualified doctor locally within the service area.

6. Selection of feedback from patients taken to Service Development Meetings

February 2015 (Anon) *I was pleased when I got the referral to Nsmecfs service, but disappointed at what they had to offer. ie nothing had changed in the eight years since I had had CBT. I have now been ill for 13 years and feel very distressed at the lack of understanding and real help.*

June 2015 (Aldeburgh) **-** *Very limited contact with a therapist not a GP. My GP not brought up to date re ME/CFS. No real improvements…. A neighbour sadly has another serious neurological illness. The difference between her care and support and people around here with ME is completely opposite. ME sufferers have nothing*

2015 Anon – (Bury St Edmunds) *Most conditions which are as devastating, or even those which are not, have medical support, follow up, ongoing support, advisory groups, gentle exercise groups, group support sessions run by the professionals etc. This goes a long way to encourage and enable the patients to stay positive and focussed in working towards their own improvement and wellbeing. Cost is obviously a factor, but intervention and support would save more money at a later time.*

April 2016 (Stowmarket) *I strongly feel that the lack of ongoing support is a huge weakness…. In the absence of a treatment or cure I do feel that ongoing support is crucial and limiting contact in such an inflexible way is a significant weakness.*

7. Patient / Carer Group 2009 Patient Survey[x]

Over 200 local patients responded and

- 92% of respondents rated the provision of a biomedical consultant lead as very important or important

- Only 33% felt that their GP had the relevant expertise to be responsible for their ongoing care
- 81% of respondents were either moderately (54%) or severely affected (27%) – unlikely to be able to work and restricted in all activities of daily living and likely to be in need of ongoing support and care

Comments include:
'How can one have such a debilitating condition that totally rules life and yet have no help or treatment to improve it?'

'If you are bedridden with ME/CFS you are unable to access specialist ME services'

'A larger budget for more specialist education (including GP's)'

Feasibility Assessment for the Implementation of a Consultant led ME & CFS Service for Norfolk & Suffolk

In the autumn of 2016 a feasibility assessment was undertaken by a world class and widely respected consultant who has published peer reviewed research in the field of ME and CFS. This consultant concluded that implementation could be achieved cost neutrally on an incremental basis.

ECCH however, are of the view that this cannot be achieved cost neutrally although they do not appear to be impartial in the matter. In addition, Gt Yarmouth & Waveney CCG are of the view that the consultant who led the review has a conflict of interest, although this is not a concern shared by the other 6 CCG's. At the last Joint Committee meeting the Gt Yarmouth & Waveney CCG representative stated that:

> *"We don't have concerns about the existing service. We have not been made aware of any complaints by the current patients regarding service"*

Given the longstanding and well established complaints regarding the service, this statement is a matter of great concern to our group. We have been informed that all the CCG's remain committed to service development. We await with interest the outcome of further deliberations by the CCG's.

Conclusion

Seven years after the deep concern expressed by the Joint Committee at their meeting on 12 November 2009 at the level of service provision[xi], there has been little improvement, other than opening clinics in new locations. Specialist service provision has deteriorated, especially for the severely affected, for whom there is no consultant level expertise and domiciliary care has reduced from 20% in 2010 to less than 5% now. Patient views regarding what is needed from the service and primary care has been clearly established over many years and from many different sources, as can be seen from this document. Delivery on the promises made by the NHS to people with ME and CFS in our area remains elusive and in the meantime, many, if not most, patients remain consigned to a 'black hole' of lack of care.

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[i] Needs Assessment for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Services in Norfolk and Suffolk
https://drive.google.com/file/d/0B1KcCpwxF0UHNkpLejk4NlZSTDg/view?usp=sharing

[ii] Website of ME Support Norfolk http://www.mesupportnorfolk.co.uk/

[iii] BRAME – Blue Ribbon Awareness for ME http://www.brame.org/

[iv] Norfolk & Suffolk ME & CFS Service Development http://nandsme.blogspot.co.uk/

[v] [v] Needs Assessment for Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Services in Norfolk and Suffolk
https://drive.google.com/file/d/0B1KcCpwxF0UHNkpLejk4NlZSTDg/view?usp=sharing

[vi] This includes our 2009 Patient Survey of over 200 local patients, and feedback via local support groups, our website and social media
Website: http://nandsme.blogspot.co.uk/ 2009 Patient Survey https://drive.google.com/file/d/0B2eUb8PoOndFbXpWUC15aFc5Tlk/view?usp=sharing

[vii] Myalgic Encephalomyelitis Adult & Paediatric: International Consensus Primer for Medical Practitioners
http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf

[viii] 2009 Patient Survey https://drive.google.com/file/d/0B2eUb8PoOndFbXpWUC15aFc5Tlk/view?usp=sharing

[ix] Joint Health Scrutiny Committee Meeting 12 November 2009 minutes
https://drive.google.com/file/d/0B1KcCpwxF0UHNDA3YTNmZGMtZjIwNS00MWQxLThlOWItZTQ2NGNjMjE3MWY5/view?usp=sharing

[x] 2009 Patient Survey https://drive.google.com/file/d/0B2eUb8PoOndFbXpWUC15aFc5Tlk/view?usp=sharing

[xi] Joint Health Scrutiny Committee Meeting 12 November 2009 minutes
https://drive.google.com/file/d/0B1KcCpwxF0UHNDA3YTNmZGMtZjIwNS00MWQxLThlOWItZTQ2NGNjMjE3MWY5/view?usp=sharing

Appendix 1
Joint Health Overview & Scrutiny Committee, 4 April 2017 - Norfolk & Suffolk ME & CFS Service
Report of Patient Experience Submitted by the Norfolk & Suffolk ME & CFS Patient / Carer Group

Patient Change Audit

This document consists of the Patient / Carer Group's analysis of the most recent Patient Change Audit tabled for discussion at the April 2016 Service Development meeting. We were unable to discuss the implications of the Change Audit with the Provider as there was no attendance from ECCH.

1. Introduction

1.1. Forty-five questionnaires returned of 162 issued. Response rate of 28%. Last year the response rate was 20%, 133 responses from 657 questionnaires issued. This is encouraging as the survey form is quite a bit longer this year. It is not clear over which period of referrals the Audit covers.

1.2. Thirty-two respondents commented with a total of 55 comments

1.3. Positive comments = 44% (last year there were twice as many positive comments as negative)

1.4. Negative comments = 56%

1.5. No one is asking for a service based on NICE or CBT/GET

2. Demographics

Severity	
Mild	38%
Moderate	38%
Severe	13%
Very Severe	7%
Not completed	4%

Staffing	
GPwSI p/t	4
OT f/t	4
OT p/t	3
Physio p/t	1

Patients saw	
GPwSI	38%
Therapist	33%
Both	29%

Referrals	
First Referral	69%
Re-Referral	31%

Comment

2.1 There is a high number of re-referrals, probably due to the lack of ongoing care

2.2 Does this mean that 38% of patients only had one contact with the service, i.e. with a GPwSI?

2.3 There is a lower level of severe/very severe patients than the expected 25%. (Our 2009 Patient Survey found that 27% of respondents were severely affected.) This may be due to difficulties accessing the service and/or completing the questionnaire. An electronic version of the survey may increase response rates for the severely affected

3 Qualitative Data

Q4 & 5 Did your HCP believe your ME or CFS to be	**GPwSI**	**Therapist**
A physical illness	44%	58%
A mixture of physical & psychological illness	56%	42%
Q6 & 7 How would you describe your HCP's report		
Excellent	31%	48%
Good	46%	32%
Average	23%	20%
Poor/ Very Poor	0%	0%
Q8 Functional Outcomes		
Improved	37%	
No Change	28%	
Deteriorated	35%	

Comment

3.1 This is the new data that the Patient / Carer Group requested be collected

3.2 The feedback indicated that some respondents found questions 4 and 5 confusing, not knowing if the question was referring to their own GP or therapist other than seen at the clinic. The question did initially say GPwSI but this appeared to have been changed by the Service. The question can be clarified next year.

3.3 The percentage of GPwSI & Therapists who believe ME & CFS to be a mixture of physical and psychological illness is disappointing, although not surprising. As the data from the ME Association demonstrated improved outcomes where health professionals believe ME & CFS to be physical illnesses, there is a clear training need

3.4 There appears to be a correlation between the approach of the HCP and satisfaction with reports. Our 2009 Patient Survey also found lower levels of satisfaction with GPwSI reports. It is likely that the reports, and therefore care, could be improved by:

3.4.1 training from a biomedical perspective
3.4.2 training on caring for the severely affected
3.4.3 using a more up to date diagnostic criteria
3.4.4 using updated descriptors for benefits purposes
3.4.5 more emphasis on functional outcomes
3.4.6 more emphasis on establishing all disabling symptoms, and consideration of medication
3.4.7 less emphasis on the 'standard assessments' e.g. the Chalder Fatigue Scale & HADS which may not be well understood or relevant, and revision of the PCQ
3.4.8 including a care plan and relapse plan
3.4.9 including a clear explanation of next steps and how many follow up sessions the patient can expect

3.5 It would be interesting to correlate the functional outcomes with the severity levels to assess if more could be done to improve functional outcomes overall. 38% of respondents are mildly affected and 37% reported improvement in functional outcomes, but it is not clear if there is a correlation between severity and outcomes. Research suggests that severity is a predictor of a poorer outcome, as is delayed diagnosis.

4 Change Audit

		2015	**2016**
Q1 Overall my illness has	Improved	56%	55%
	No Change	13%	7%
	Got worse	31%	38%
Q2 My symptoms are	Improved	53%	50%
	No Change	16%	11%
	Got Worse	31%	39%
Q3 I am able to do	Improved	50%	50%
	No Change	23%	11%
	Got Worse	27%	39%
Q4 I am able to cope with my illness	Improved	64%	68%
	No Change	15%	5%
	Got Worse	21%	27%
Q5 I am able to control the severity of my symptoms	Improved	58%	64%
	No Change	19%	11%
	Got Worse	23%	25%
Q6 My feelings about the future course of my illness	Improved	62%	52%
	No Change	11%	16%
	Got Worse	26%	32%

Comment

4.1 It is worrying that every 'got worse' outcome has increased since 2015. Only 20% of respondents are severely affected, so severity is probably not skewing the data. The reasons for this need to be explored – has there been a reduction in the number of follow up sessions or increase in inexperienced staff?

4.2 It would be interesting to know if there has been a reduction in the number of follow up sessions during the period under review which has resulted in poorer outcomes.

4.3 Respondents have reported an improvement in coping with illness and controlling severity of symptoms which is encouraging. 55% feel that their illness has 'improved' but this is not reflected in functional outcomes (section 3)

5 Thematic analysis of comments

Positive	Comment number	Total
Support, validation, help, understanding	3, 5, 7, 8, 10, 20, 22, 25, 30, 34, 42, 43	12
Support with employers, education authorities	11, 20, 26, 43	4
Help to adjust, cope & manage symptoms	6, 9, 13, 20, 32, 35, 36, 43	8
	Total	**24**
Negative		
Lack of ongoing care	2, 5, 21, 25, 30, 42	6
Lack of specialist care especially for severely affected	2, 11, 19, 38	4
Clinic didn't give help needed	8, 15, 24	3
Low mood / Depression	3, 14	2
Deteriorating	8, 33, 34, 38	4
Lack of specialist knowledge re meds for symptom control	8, 21	2
Hard to fill in form	3, 23	2
Difficulty in managing symptoms	18, 19, 23, 27, 33	5
Staff unhelpful	24	1
Lack of GP knowledge	25	1
Service limited in scope	42	1
	Total	**31**

5.1 Positive

Much the same as last year

1. Clearly some very good practice, support, validation and understanding remains much appreciated
2. Help with employers and educational authorities much appreciated
3. Recognition of the value of managing symptoms and adjusting to reduced activity levels
4. There were no negative comments around the approach of one specific HCP, unlike last year
5. There were no comments about travel / transport problems (something that was flagged last year)
6. What is new is the positive comments about the Suffolk Wellbeing Service

5.2 Negative

1. There are significantly more negative comments than positive (last year it was the other way round)
2. As with last year the lack of ongoing care remains a significant issue (and is reflected in the high re-referral levels)
3. Also difficulties surrounding symptom control – this could be addressed by training around medications for symptoms and more effective & thorough assessment of symptoms, possibly by using the Symptom Hierarchy Chart included within the International Consensus Criteria
4. There were more comments this year specifically surrounding lack of care for the severely affected and the lack of specialist knowledge beyond basic management

6 Action Points

6.1 As already agreed the service start to collect email addresses for electronic communication. This could be done at the PCQ stage
6.2 Clarify the wording for next year in questions 4 and 5 regarding the health professional patients saw
6.3 Ensure the survey is sent out after patients discharged, this should also be the case for the FFT
6.4 Consider an additional question to monitor how many follow up sessions patients are receiving
6.5 Upload Change Audit to Patient / Carer Website along with analysis
6.6 Implement the changes recommended in section 3.4
6.7 Explore why 'got worse' outcomes have increased across the board (section 4)
6.8 Review of PCQ & Functional Questionnaires, especially in relation to full range of symptoms
6.9 Last year an action point was to explore the possibility of extending the number or sessions for those who need it – has this been done as the lack of ongoing care continues to be raised as a significant problem
6.10 Consideration to be given to issuing the Change Audit to more patients to obtain more responses – last year it was issued to all patients for the year
6.11 Consideration to be given to updating KPI's based on the qualitative data as part of the process of 'transformation' of the ME & CFS Service and continuous improvement.

Comments from patients

No	Comment	Category
2	Need specialist to liaise with GP and other HCP's. ME Service needs reorganisation, lack of clinical leadership No ongoing care esp for severely affected	Service -ve (Ongoing care, severely affected, specialist leadership)
3	Contemplating suicide Therapist offers support & validation Form took 2 hours to fill in - exhausting	Staff +ve Depression Long time to fill in form
5	Service offers support and validation Important to offer ongoing care	Staff +ve Ongoing care
6	OT helped manage symptoms esp pain more effectively OT helped patient to adjust to reduced activity levels	Staff +ve
7	Therapist helpful & understanding	Staff +ve
8	Service supportive But have not affected progression of illness Erroneously discharged when very unwell Would like advice re meds for symptoms	Staff +ve -ve regarding progression Inappropriate discharge Lack of advice re meds for symptom control
9	Relaxation & pacing help management	Staff +ve
10	Ongoing support – phone call every 3 months valued	+ve re ongoing support offered
11	OT writing to college helpful Lack of support for severely affected	Staff +ve support ed auth Clinic -ve re severely affected
13	Service halted decline in health	Service +ve
14	Struggling with symptoms & depression	Service -ve re management
15	Two appointments cancelled by therapist	Service -ve
18	Struggling to manage symptom fluctuation esp pain	Service -ve re management
19	Severely affected, social isolation No specialist help for symptom control	Service -ve re management esp severely affected

20	Supportive & feel cared for by the service More positive outlook as a result Help with employer	Staff -ve support +ve affect on mood Staff +ve re employer
21	Ongoing care not adequate only 3 or 4 sessions a year Lack of specialist knowledge re symptoms & tests	Clinic -ve re ongoing care Lack specialist knowledge
22	Thanks to HCP for help & education	Staff +ve support
23	Diag 2005. Some v bad days, severe cognitive problems, hard to complete form. Difficulties managing symptoms	-ve symptom management
24	Felt fobbed off Clinic appointments long way apart then cancelled Staff very unhelpful	Staff -ve re support Lack of ongoing care
25	Clinic nearer to home appreciated Support & validation & helpful & realistic advice Importance of ongoing care Lack of knowledge from GP's	Clinic +ve Staff +ve GP's -ve
26	Support of HCP helped keep patient in work	Staff +ve
27	Struggling with fluctuating symptoms	-ve symptom management
30	Good service but lack of ongoing care	Service +ve Ongoing care -ve
32	Improved management but limited effect due to job (teacher)	Service +ve
33	Deteriorating Appointments with OT not helped	Service -ve
34	Deteriorating Care & support excellent	Staff +ve
35	Symptoms improving Learnt to manage illness since getting help	Service +ve
36	Attended stress / well being course	
37	Learning to live with it (unclear if service has helped)	
38	Deteriorating Researching causes and tests	Service -ve, lack of specialist support
42	Pacing & mindfulness helpful in adapting to illness Told good chance of recovery with positivity No offer of tests to rule out other conditions No info on current research knowledge No support outside NICE Guidance No mechanism for referral to research trials Very limited contact with therapist GP not updated	Staff +ve Staff -ve Service -ve
43	Value diagnosis Value management advice, improving Value support from HCP over the period of a year Value support with employer – phased return to work Value advice to refer to Wellbeing service	Staff +ve Service +ve

Great Yarmouth and Waveney Joint Health Scrutiny Committee
4 April 2017
Item no 8

Information Bulletin

The Information Bulletin is a document that is made available to the public with the published agenda papers. It can include update information requested by the Committee as well as information that a service considers should be made known to the Committee. The items are not intended for discussion at the Committee meeting.

If there are any matters arising from this information that warrant specific aspects being added to the forward work programme or future information items, Members are invited to make the relevant suggestion at the time that the forward work programme is discussed.

This Information Bulletin covers:-

(a) **Update on developments in primary care**:-
  - Development of the Shrublands centre
  - GP services for the Woods Meadow development, Sands Lane, Oulton

(b) **Delayed transfers of care** – update on the outcomes of the learning event held on 11 January 2017

(c) **Stroke information, advice and support service** – Stroke Association

(d) **Norfolk and Waveney STP** - response to Norfolk Health Overview and Scrutiny Committee's comments

Item (a)

NHS
Great Yarmouth
and Waveney
Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: Update on developments in primary care: Development of the Shrublands centre andGP services for the Woods Meadow development, Sands Lane, Oulton.

Shrublands:

The Shrublands project board continues to meet monthly in partnership with Norfolk County Council, Great Yarmouth Borough Council, NHS Property Services, and architects. The architects are in the process of developing plans and are in discussion with Great Yarmouth Borough Council planners, it is hoped that plans will be submitted in May 2017. There is a monthly stakeholder meeting where ideas are shared and relationships built.

There are various avenues being explored in relation to the financing of the whole build as well as assurance being sought from all interested parties that they are committed to the revenue costs in the future. There is a senior director of interested parties meeting on the 13th March for a due diligence workshop with architects and the CCG.

Woods Meadow development, Sands Lane, Oulton:

Bridge Road surgery were successful in obtaining Estates Transformation Technology Fund monies in September 2016.

They have been allocated monies from cohort two which is released in April 2017. At this time this money will allow for the development of plans, engagement etc. It is envisaged that there will be close working relationships with the practice, CCG, building developers and NHS Property services.

NHS England will support the CCG in the request for obtaining section 106 monies which will if successful contribute to the overall cost.

We will keep HOSC informed as we start to develop plans etc. as we enter April 2017.

Tracy McLean
Deputy Director of partnership and Strategy

Item (b)

NHS
Great Yarmouth
and Waveney
Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: Delayed transfers of care – Update

Delayed transfers of care (DTOC) rates at James Paget Hospital for the Great Yarmouth and Waveney system continue to be one of the best in the region. Below are the DTOC rates at JPUH for the past few months which demonstrate the effective processes in place to ensure timely discharge prior to patients registering as an official delayed transfer of care.

Month	DTOC Rate %
Oct-16	2.5%
Nov-16	2.2%
Dec-16	2.9%
Jan-17	2.4%

As referenced in the previous report, the system has performed extremely well and the CCG Chief Nurse has therefore been part of the DTOC Executive Central Team visits to other systems seeking to improve DTOC numbers and therefore reducing the number of patients remaining in hospital longer than they need.

The debrief meeting which was held on 11 January focussed on the Christmas/New Year period and not specifically delayed transfers of care. However, it did confirm that the system had robust plans in place to ensure continued quality and safe care for the population of Great Yarmouth and Waveney. A number of areas were identified to ensure future system resilience including implementing a discharge to assess model which will facilitate prompt discharge and reduce delays in hospital.

Currently a number of patients remain in hospital whilst they are assessed for long term support by social care or continuing health care. Discharge to assess is a model of care for patients who are clinically optimised and do not require an acute hospital bed, but may still require care services for a short period either within their own home (where appropriate) or another community setting. During this period an assessment for longer-term care and support is then undertaken in the most appropriate setting and at the right time for the person.

A local model is being developed with plans to implement from June 2017 which will ensure patients are discharged safely to an appropriate setting for their assessment for either a longer term social care package or continuing health care package removing the delays within hospital and ensuring the best outcome for the patient.
Emma Bray
Head of Clinical Commissioning

Item (c)

NHS
Great Yarmouth
and Waveney
Clinical Commissioning Group

Briefing for Great Yarmouth and Waveney Health Scrutiny Committee: Stroke Association

Background

The CCG previously commissioned a Stroke Information and Support Service through the Stroke Association at a cost of £43,428.

Commissioners had been working with the provider to deliver an effective service within resource. Actions have included;

- Change of office location
- Reduction in staff hours
- Stopping assessments of out of CCG area patients.
- Trying to stream line referral processes and integrate with JPUH team, rather than a stand-alone service.
- Development of a Stroke support group at JPUH.

In September 2015 the CCGs executive team agreed to continue the service at the existing cost for a further two years 2016/17 and 2017/18. However in November 2016 the contract had not been signed by the Stroke Association because they did not feel they could continue to provide the same level of service within available funds. The Stroke Association had asked for more funding to enable them to continue to provide the service or to redefine the referral criteria in order to provide a quality service to fewer patients. With this in mind, the continuation of the service beyond March 2017 needed to be reviewed.

The service was discussed through the normal commissioning process at the CCGs Clinical Executive Committee on 1 December where it was decided not to commission the service past 31 March 2017.

Are there plans to provide the service for this patient group in a different way?

Following a further meeting with the Stroke Association on Thursday 9 March NHS Great Yarmouth and Waveney CCG has committed to work with the association to find a way forward for stroke patients in the area.

The Stroke Association will now work with the CCG and the JPUH stroke team to develop comprehensive information and support discharge pack for patients which can be delivered by the Stroke team and the Early Supported Discharge team at the

James Paget University Hospital. A meeting to finalise this is scheduled for 14 March.

This will include information about local health and social care services, plus Stroke Association services which will continue to be available for patients in the Great Yarmouth and Waveney area. These services include the national helpline for patients and carers, the Stroke Association website and support for the network of three voluntary groups which are available in Belton, Lowestoft and Beccles.

It was also agreed that the organisations will work together to identify funding sources that could be available to the Stroke Association to provide additional services in the area.

The meeting helped to agree a constructive way forward for the CCG and the Stroke Association to continue to work together for the benefit of stroke survivors.

Rachel Leeds
Head of Clinical Commissioning

Item (d)

Norfolk and Waveney Sustainability Transformation Plan (STP) – response to Norfolk Health Overview and Scrutiny Committee’s (NHOSC) comments

Two of the Suffolk Members of Great Yarmouth and Waveney Joint Health Overview and Scrutiny Committee attended NHOSC on 8 December 2016, when the Norfolk and Waveney STP was presented and discussed. Following the meeting comments were sent to the Norfolk and Waveney STP lead on 12 January and a response was received on 3 February 2017. A copy of the response is attached.

Norfolk County Council

Dr Wendy Thomson CBE
County Hall
Martineau Lane
Norwich
NR1 2DH

Tel: 0344 800 8020
Wendy.thomson@norfolk.gov.uk

Councillor Michael Carttiss
Chairman of HOSC
Via email Michael.carttiss@norfolk.gov.uk

3 February 2017

Dear Michael

I am writing in response to the report of comments from Norfolk Health Overview and Scrutiny Committee regarding the Norfolk & Waveney Sustainability & Transformation Plan, dated January 12th. These comments related to the December 8th NHOSC meeting that I attended with Roisin Fallon-Williams.

Thank you for providing us with the opportunity to share and discuss progress with you and thank you also for the report of comments which I have shared with the STP Executive at a meeting on January 20th.

I know that you understand that our planning for how services will change over the next five years is at an early stage and securing feedback this early is very helpful as we further develop our plans as a system.

Key priorities over the next two to three months include completing a refresh of the Five Year financial plan, then detailed planning for each of the work streams to match the financial plan, identifying the resources to shape and deliver the proposals from within the system, establishing effective governance arrangements with a clear focus on clinical input and involving a wide range of stakeholders through robust communications and engagement plans. I believe that we will then be well placed to deliver on our aspirations.

In terms of the committee's specific comments:

1. *The STP should be developed alongside other Central and Local Government and NHS strategies (such as the Government's plans for 7 day working in all sectors of the NHS and the operating plans of the NHS which were not directly a part of the STP).*

Our STP is informed by a wide range of other strategies and we are engaging with all relevant partners at a senior level to ensure alignment with these. The NHS Two Year Operational Plans and the NHS Contracting Round were both concluded after the October 21st STP submission, and thus further refinement is now required.

NHS Two Year Operational plans were agreed over a longer timeframe to increase and cement the alignment to the longer-term objectives of the STP. We are now undertaking further work to review our STP in light of these Two Year Operational plans to maintain this alignment, in particular reviewing demand, activity and financial assumptions.

2. *Breaking down barriers in the provision of care is fundamental to success, particularly between GPs and hospitals, physical and mental health and between health and social care. This includes the barriers to the transfer of digital information between organisations.*

The revised governance arrangements for the STP bring together senior executives and clinicians across all sectors and settings to develop system-wide solutions to the challenges we face. For example the Clinical and Care Reference Group includes GPs, Medical Directors and social care leads and the Delivery Board includes workstream leads from a wide range of the constituent organisations as well as senior clinicians from primary and secondary care.

In terms of the barriers to the transfer of digital information, our Local Digital Roadmap "Connected Digital Norfolk & Waveney" has been published on the Healthwatch website - www.healthwatchnorfolk.co.uk/ingoodhealth. This document sets out the plans for NHS Paper Free at the Point of Care, and to improve digital interactions between primary and secondary care.

3. *It might take significantly longer than the 5 year timescale of the STP before the fundamental changes that the STP intended to bring about are viewed by the public as a success or a failure.*

The STP has to address system challenges in both the short, medium and longer term in line with the Nationally Mandated targets set out in Five Year Forward View and it will continue to evolve and flex in response to further changes over time.

We will set local milestones over the next five years years to deliver the Five Year Forward View and will track the pace of delivery and the degree of success in terms of patient and public satisfaction, achievement of National Targets, achievement of local milestones and financial sustainability. We will use these milestones to assess progress and adjust our approach accordingly, using strong input from our Stakeholder Board and the Clinical and Care Reference Group.

4. *There are questions around how acute services will be able to meet demand before the real improvements to the public's health materialise and the economic modelling that has been done around early intervention strategies.*

There are several approaches within the STP to deal with Acute Hospital demand for both Elective and Non Elective work in addition to the public health interventions. These include;

- A dedicated work stream focusing upon developing more out-of-hospital services to reduce Emergency and Urgent Care Demand including Integrated Multi-Disciplinary Health and Social Care Teams focussing upon patients with existing Long Term Conditions, and increasing Hear and Treat and See and Treat by the Ambulance Service to name a few.
- Increasing access to Primary Care Services and General Practice
- Early intervention through Case Management of vulnerable Groups
- Rapid Access to community services with a 2 hour response
- Earlier intervention by social care working within the integrated teams.

This will mean more patients will be treated in the community and closer to home, offering benefits to the patient and reducing demand on acute hospitals.

In addition, a further dedicated Demand Management workstream has now been established to address the current elective demand and meet the

Referral to Treatment challenges as an immediate priority. This will be achieved by offering more patient choice and the three acute hospitals working more efficiently together. Increasing capacity within Primary Care will also assist with this and plans are currently being drawn up for the GP Five Year Forward View.

5. *Providing greater public and in-patient access to therapies that tackle mental health issues at an early stage should be addressed as a strategic issue.*

The Five Year Forward View sets out the National targets for improving access to Mental Health Services, which we are well placed to meet. The Mental Health work stream includes a wide range of initiatives to improve access to therapies in primary and community care, urgent care and secondary care. These are being prioritised as early initiatives and work on many of these is already underway. We already have Transformation Funding for Early Intervention in Psychosis services, Integrated Perinatal Mental Health and improving access to Child and Adolescent Mental Health Services.

We have also bid in the latest round for Improving Access to Psychological Therapies targeted at patients with Long Term Conditions to improve compliance and reduce A&E attendances and a further bid for Integrated Mental Health Liaison Services.

6. *People with mental health problems do not have access to health services on a parity with the population as a whole, resulting in significantly shorter life expectancy and often inappropriate treatment. These inequalities should be addressed by integrating mental health with other services.*

The Mental Health workstream has proposed Parity of Esteem as one of its key priorities in line with the Five Year Forward View. This will include improving how mental health is treated across primary and secondary care; a focus on psychological therapies to support patients with long term conditions; improving psychiatric liaison with acute services and integrating mental health into perinatal services.

7. *The reference in the STP Workforce workstream to resilience training for staff should be explained so that its connection to the NHS Five Year Forward View is understood and it is not seen as referring to the whole workforce.*

The Workforce workstream is currently being scoped ahead of more detailed planning and to align to the Local Workforce Action Boards. The role and audience for resilience training will be clarified as part of the detailed planning work.

8. *The impact of the STP on third sector organisations should be recognised.*

We are working with partners from the third sector and have invited the Chief Executives of Community Action Norfolk and Momentum (Norfolk) and the Chair of Carers Council for Norfolk as members of the STP Stakeholder Board to represent the third sector and help identify and manage the impact of the STP.

I hope that this letter has helped to reassure you that the feedback and concerns of Norfolk Health Overview and Scrutiny Committee are being addressed. I look forward to sharing further progress with you in the coming months.

Yours sincerely

Wendy

Dr Wendy Thomson CBE
Managing Director

Date: 4 April 2017
Item no: 9

Great Yarmouth and Waveney Joint Health Scrutiny Committee

ACTION REQUIRED

Members are asked to suggest issues for the forward work programme that they would like to bring to the committee's attention. Members are also asked to consider the current forward work programme:-

- whether there are topics to be added or deleted, postponed or brought forward;
- to agree the briefings, scrutiny topics and dates below.

Forward Work Programme 2017-18

Meeting date & venue	Subjects
Thursday **6 July 2017** Riverside, Lowestoft	Services for children who have an Autistic Spectrum Disorder (ASD) – update from the CCG and Norfolk and Suffolk Children's Services on progress with services for children with autism *(a follow up to the meeting on 15 July 2016)* ***Information Bulletin item*** - *Update on changes to adult and dementia mental health services.*
Friday **20 October 2017** Riverside, Lowestoft (Tbc)	A&E performance at James Paget University Hospitals NHS Foundation Trust To examine:- • overall trend of A&E performance • an analysis of the effects of the Greyfriars Walk-in Centre and GP practice closure on JPUH A&E after the summer period, including analysis of visitor attendance at A&E as well as resident analysis
Friday **2 February 2018** Riverside, Lowestoft (Tbc)	
Friday **13 April 2018**	

Riverside, Lowestoft (Tbc)	
Friday **13 July 2018** Riverside, Lowestoft (Tbc)	

NOTE: These items are provisional only. The Joint Committee reserves the right to reschedule this draft timetable.

Items for consideration / scheduling:

None noted.

Great Yarmouth & Waveney Health Overview and Scrutiny Committee 4 April 2017

Glossary of Terms and Abbreviations

A&E	Accident And Emergency
ADASS	Association Of Directors Of Adult Social Services
AHRQ	Agency for Healthcare Research & Quality
APPG	All Party Parliamentary Group
APS	Admission Prevention Service
ASD	Autistic Spectrum Disorders
BMC	BioMedCentral (journal)
BMJ	British Medical Journal
BRAME	Blue Ribbon For Raising Awareness Of ME
CAMHS	Child And Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CCG	Clinical Commissioning Group
CDC	Centers for Disease Control and Prevention
CFS	Chronic Fatigue Syndrome
CI	Confidence interval
CICT	Community Integrated Care Team
CQC	Care Quality Commission
CSU	Commissioning Support Unit
DNA	Did Not Attend
DToC	Delayed Transfer Of Care
DWP	Department of Work and Pensions
ECCH	East Coast Community Healthcare
F&F	Friends and Family Test (an NHS patient satisfaction survey)
FTE	Full time equivalent
GET	Graded Exercise Therapy
GP	General Practitioner
GpwSI	General Practitioner With A Special Interest
GY&W	Great Yarmouth And Waveney
GY&WCCG	Great Yarmouth And Waveney clinical commissioning group
HCP	Health Care Professional / Practitioner
HNA	Health needs assessment
HSCIC	Health & Social Care Information Centre
IAPT	Improving Access To Psychological Therapies
ICC	International Consensus Criteria
IOM	Institute of Medicine
JPUH	James Paget University Hospital
KPI	Key Performance Indicator
LD	Learning Difficulties / Disability

LGA	Local Government Association
LINk	Local Involvement Network
MASH	Multi-agency safeguarding hub
ME	Myalgic Encephalomyelitis
MEA	Myalgic Encephalomyelitis Association
MESN	Myalgic Encephalomyelitis Support Network
MIND	National Association For Mental Health
NHOSC	Norfolk Health Overview and Scrutiny Committee
NICE	National Institute for Health and Care Excellence
NSFT	Norfolk and Suffolk NHS Foundation Trust (the mental health trust)
OHT	Out-of-hospital team
OI	Orthostatic intolerance
OT	Occupational Therapist / Therapy
PACE	Pacing, graded Activity and Cognitive behavioural therapy
PALS	Patient Advice and Liaison Service
PCT	Primary Care Trust
PEM	Post-exertional malaise
PT	Physiotherapist / physiotherapy
SDPG	Service Design Project Group
SENCO	Special Educational Needs Co-ordinator
SIDG	Service Development Implementation Group
STP	Sustainability & transformation plan
VAS	Visual analog scale
WHO	World Health Organisation
WTE	Whole time equivalent