

**GREAT YARMOUTH AND WAVENEY JOINT HEALTH SCRUTINY COMMITTEE
MINUTES OF THE MEETING HELD ON 26 October 2018**

Present:

Stephen Burroughes	Suffolk County Council
Emma Flaxman-Taylor	Great Yarmouth Borough Council
Nigel Legg (Chairman)	South Norfolk District Council
Jane Murray	Waveney District Council
Richard Price	Norfolk County Council
Keith Robinson	Suffolk County Council

Also Present:

Cath Byford	Director of Commissioning and Deputy Chief Officer, NHS Great Yarmouth & Waveney CCG
Nick Wright	Deputy Director of Adult Services, East Coast Community Healthcare
Jo Wiggins	ME/CFS Service Lead, East Coast Community Healthcare
Luke Croager	Out of Hospital Hub Manager – Waveney, East Coast Community Healthcare
Debbie Coe	Out of Hospital Hub Manager – Lowestoft, East Coast Community Healthcare
Lorraine Rollo	NHS GY&W CCG
Dr Patrick Thompson PhD	Member of the Public (attending for item 6 regarding Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS))
Richard Chilvers	Member of the public
Beverley James	Member of the public (and an ME/CFS service user)
Robert Boardley	Member of the public
Barbara Robinson	Member of the public and Norfolk and Suffolk ME and CFS Patient Carer Group and Service Development and Implementation Working Group
Maureen Orr	Democratic Support and Scrutiny Team Manager, Norfolk County Council
Paul Banjo	Democratic Services, Suffolk County Council
Tim Shaw	Committee Officer, Norfolk County Council

1. Welcome to new Members

The Chairman welcomed Mrs Emma Flaxman-Taylor and Mr Keith Robinson to their first meeting of the Committee.

2. Apologies for Absence

There were no apologies for absence.

3 Minutes

- 3.1 The minutes of the previous meeting held on 13 July 2018 were confirmed as a correct record and signed by the Chairman.

4 Public Participation Session- Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS)

- 4.1 With the permission of the Chairman, Beverley James, a member of the public (and an ME/CFS service user) spoke about the difficulties that she had experienced in getting the help that she needed for her condition of ME since she was diagnosed in 2009. She said that the limited help that she had received had come from her GP and a nurse practitioner and that this fell far short of what was available elsewhere in the country.

- 4.2 With the permission of the Chairman, Dr Patrick Thompson PhD, a member of the public, spoke about the difficulties that sufferers from ME/CFS had in getting the kind of support that they needed. He said that although WHO and NICE had defined what was meant by ME/CFS they were silent as to whether the condition should be treated by a "consultant led" service. He said that it would be helpful if patients were able to have direct access to one of the two GPs in the Great Yarmouth and Waveney area with a specialist interest in the subject and for data to be kept as to how long patients had to wait for an initial assessment. He also said that an explanation should be given as to why it was appropriate for the existing Carer and User Group to be disbanded.

- 4.3 With the permission of the Chairman, Barbara Robinson, a member of the public, spoke about the issues which she had raised with the Great Yarmouth and Waveney CCG on a number of occasions before today's meeting and to which she had received a response by letter yesterday. She said that it was important for her and for other patient carer representatives to be seen by the public to be working in a transparent and open manner. Barbara Robinson said that she and other patient representatives would be happy to take up an opportunity to meet with senior members of the Great Yarmouth and Waveney CCG commissioning team to talk about the needs of patients but were concerned that the CCG had indicated that responding to further written questions would be an inappropriate use of their staffing resource.

- 4.4 The Chairman thanked the members of the public for their comments and asked the speakers from the CCG if they would like to respond when the Joint

Committee considered the issue further at item 6 on the agenda.

5 Declarations of Interest

- 5.1** Stephen Burroughes declared an “other interest” in relation to his councillor role at Suffolk Coastal District Council, where he was a member of one of the planning/development related ‘shadow’ teams set up in preparation for the new East Suffolk Council next year, from the merger of Suffolk Coastal and Waveney District Councils.
- 5.2** Emma Flaxman-Taylor declared an “other interest” because she was a member of the JPH Board of Governors.
- 5.3** Richard Price declared an “other interest” because his wife suffered with ME and he was the Deputy Leader of North Norfolk District Council.

6 Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS)

- 6.1** The Joint Committee received a suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager at Norfolk County Council, to an update report from Great Yarmouth and Waveney CCG on the work to improve the current Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS) service for Norfolk and Suffolk.
- 6.2** The Committee received evidence from Cath Byford, Director of Commissioning and Deputy Chief Officer, NHS Great Yarmouth & Waveney CCG, Nick Wright, Deputy Director of Adult Services, East Coast Community Healthcare and Jo Wiggins, ME/CFS Service Lead, East Coast Community Healthcare.
- 6.3** In the course of discussion the following key points were noted:
- Cath Byford said that while there would always be fluctuations in caseload numbers for any clinical service, and a degree of rounding up or down of caseload figures was not atypical, she was able to confirm that the active caseload for ME/CFS at any given point in time was usually in the region of 1,500 to 1,600 cases.
 - The number of active cases had doubled since 2009.
 - The caseload numbers found in the report included those with Mild/Moderate/Severe needs.
 - The speakers said that patients had access to the ME/CFS service in a variety of ways such as by a clinic appointment, email, telephone or domiciliary visit. Access was determined by patient choice and based on individual circumstances and needs.
 - All patients who were assessed as requiring support were offered an individualised follow up plan. A flexible approach was taken to the delivery of patient follow ups that met with their individual needs.
 - All patients were offered a minimum of six appointments. The average period of intervention was 18 months.
 - Where the need for medication was considered appropriate, the assessment service advised the patients’ own GP.
 - Where patients had other health conditions or developed further problems as a result of ME/CFS then they were signposted to the most appropriate

service. Where patients were severely affected by ME/CFS and unable to get into an assessment clinic, home visits were available.

- Members said that many GPs remained unfamiliar with the ME/CFS condition.
- The speakers said that this was partly due to there being no specific medication to treat ME/ CFS, although the clinical staff at the GY&W CCG could advise GPs on medications that they knew from past experience had worked well for this group of patients.
- The speakers said that there was a 'ring-fenced' and protected education and training budget specifically for the clinical team working within the ME/CFS service.
- All diagnosis of children was made by a paediatrician as per the current referral protocol.
- Members were of the view that information should be collected and recorded about ME/CFS in a way that it could be used in dashboard performance data.
- The speakers from the GY&W CCG said that the Norfolk and Suffolk commissioning organisations were confident that by bringing contracts together and robustly monitoring delivery against the service specification that this would ensure an improved service over and above that which was provided in the past.
- The speakers said that GY&W CCG would review the Change Audit format and seek an objective review of the current specification ahead of the anticipated publication of new NICE guidance in 2020. The review would include observation, interviews, meetings and discussions with stakeholders, and documental data gathering and information analysis.
- It was pointed out that in addition to the service provided by East Coast Community Healthcare (ECCH), NHS Ipswich and East Suffolk and NHS West Suffolk CCGs (IES and WS) also invested in the service by using some of the money from the Individual Funding Request budget to meet the needs of people with moderate and severe ME/CFS.
- Members asked for a breakdown of the numbers of ME/CFS patients within each CCG area covered by the ECCH service and the amount of funding provided by each of the CCGs for the ECCH service.
- The locations from where the ME/CFS Service provided clinical services in Norfolk and Suffolk were set out in the report. Members were concerned that these locations did not include a base in North Norfolk.
- Members suggested that the GY&W CCG (as the co-ordinating commissioner for Norfolk and Waveney) and ECCH should consider working together to identify a possible location for a base for the ME/CFS service within the North Norfolk area and keep the Joint Committee informed of developments.
- Members also spoke about the importance of improved communication with GPs. It was suggested that GY&W CCG should look to provide a short briefing note for GPs to raise awareness of ME/CFS and the public services that were available and for this to be updated on a regular basis.
- Members also asked for more of a breakdown of where the funding received by the ECCH was spent (i.e. how much was spent in each CCG area).
- Members asked if the data collected could include information about where patients came from and where the money was spent in terms of

staffing costs and overheads, travel etc.

- The speakers said that the plan was for the Norfolk and Waveney CCGs to have a joint contract in place from 1 December 2018 with a view to the other CCGs joining by 1 April, 2019.

6.4 The Joint Committee **noted** the information presented by the GY&W CCG and asked for additional information on the following issues:

- The numbers of ME/CFS patients within each CCG area covered by the ECCH service and the amount of funding provided by each of the CCGs for the ECCH service.
- A breakdown of where the funding received by ECCH was spent (i.e. how much spent in each of the CCG areas it covered).
- To be kept informed of any developments regarding the possibility of a new base for the ME/CFS service within the North Norfolk area.

It was noted during the discussion of this item that the information requested of the GY&W CCG that was not commercially sensitive would be included in the Joint Committee's next Information Bulletin. Where commercially sensitive financial information had to be provided to Members then this would be done in the strictest of confidence.

6.5 The Joint Committee **agreed** the following recommendations:

- That GY&W CCG (as co-ordinating commissioner for Norfolk and Waveney) and ECCH should consider providing a base for the ME/CFS service within the North Norfolk area.
- That GY&W CCG should look to provide a short briefing note for GPs to raise awareness of ME/CFS and the services that were available. The briefing should be regularly updated to cover relevant developments.

7 Out-of-hospital services

7.1 The Joint Committee received a suggested approach from Maureen Orr, Democratic Support and Scrutiny Team Manager at Norfolk County Council, to an update report from Great Yarmouth and Waveney Clinical Commissioning Group (GY&W CCG) and East Coast Community Healthcare (ECCH) on progress of the out-of-hospital services across Great Yarmouth and Waveney in the past year, including development of the new service in South Waveney.

7.2 The Committee received evidence from Cath Byford, Director of Commissioning and Deputy Chief Officer, NHS Great Yarmouth & Waveney CCG, Nick Wright, Deputy Director of Adult Services, East Coast Community Healthcare, Luke Croager, Out of Hospital Hub Manager for Waveney, East Coast Community Healthcare and Debbie Coe, Out of Hospital Hub Manager for Lowestoft, East Coast Community Healthcare.

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

- The Joint Committee was updated on the progress with the expansion of Out of Hospital Team (OHT) services by East Coast Community Healthcare (ECCH) into the South Waveney area.

- The speakers said that OHT services in the South Waveney area were now fully operational. In reply to questions, the speakers said that the OHT team serving the South Waveney locality had the right skills mix to meet the needs of the population and deliver out of hospital services that were equitable with those provided elsewhere in the Great Yarmouth and Waveney area.
- OHT services were run by teams of senior professionals and support staff operating from bases at Beccles Hospital and from two other bases across the Great Yarmouth and Waveney locality at Kirkley Mill Health Centre in Lowestoft and at the Herbert Matthes Block on the Northgate Hospital site in Great Yarmouth.
- Case load figures for each team were as set out in the report, as were the locations used for reablement beds with care in the Great Yarmouth and Waveney area and details regarding the 22 intermediate care beds available at Beccles Hospital.
- The Joint Committee was informed of the work that had gone into making significant upgrades and improvements to the facilities at Beccles Hospital, including a dementia friendly design.
- It was pointed out that average length of stay in the intermediate care beds at Beccles hospital was for 18.5 days, which was lower than the average length of stay for intermediate care beds elsewhere.

7.4 The Joint Committee agreed:

- That Great Yarmouth and Waveney (GY&W) CCG and East Coast Community Healthcare (ECCH) should be asked to consider carrying out an audit of the effect of length of stay at Beccles hospital on the condition of patients over the age of 80 (for comparison with the data in relation to acute hospital length of stay that could be found at page 41, paragraph 9 of the agenda papers).
- That Members should be informed of the amount of money that the CCG spent on commissioning beds in private care homes. (A ball-park figure of approximately £400,000 per annum was given at the meeting but this had to be confirmed).
- That GY&W CCG should look to investigate a concern raised by a Member of the Joint Committee about a GP practice in the North Lowestoft area that it was alleged had not carrying out a blood test required by the James Paget Hospital.
- That the Joint Committee should receive an update on healthcare services in the Halesworth area via its next Information Bulletin (see the Forward Work Programme item at minute 9 below.)

8 Information Only Items

8.1 The Joint Committee noted information on the following subjects:

- a) Blood testing services in Great Yarmouth and Waveney**
- b) Norfolk and Suffolk NHS Foundation Trust progress in Great Yarmouth and Waveney**
- c) Norfolk and Waveney Sustainability Transformation Plan –update**
- d) Health provision for the Woods Meadow development, Oulton**

9 Forward Work Programme

- 9.1 The Joint Committee **agreed** the forward work programme as set out in the report subject to the following updates:

1 February 2019

Agenda items:-

- *Mental Health Services in Great Yarmouth and Waveney – update following CQC reinspection of NSFT during 2018* - removed from the agenda as NSFT is scheduled to attend both the Norfolk and Suffolk health scrutiny committees in January 2019 and issues can be raised at those meetings.
- *Great Yarmouth and Waveney NHS Community Services* – added to the agenda. The Joint Committee will examine details of the new service to be provided in the GY&W CCG area from April 2019.

Information Bulletin items:-

- ME/CFS – a progress update and including the information set out under item 6 above.
- GP and general healthcare provision in the Halesworth area

Visits to services

- A Member visit to the primary and community services at the Shrublands site, Gorleston, to be arranged.
- Waveney Members of the Joint Committee to be invited to any visits arranged in the Great Yarmouth & Waveney area as a result of Norfolk Health Overview and Scrutiny Committee's 18 Oct 2018 resolution to visit community palliative & end of life care services across the Norfolk and Waveney Sustainability Transformation Partnership area.

10 Urgent Business

- 10.1 There were no items of urgent business.

The meeting concluded at 12.50 pm.

CHAIRMAN



If you need this document in large print, audio, Braille, alternative format or in a different language please contact us on 18001 0344 800 8020 (text relay) and we will do our best to help.

T:\Democratic Services\Committee Team\Committees\Great Yarmouth and Waveney Joint Health Committee\Minutes\110513 Mins