

**MINUTES OF THE SCRUTINY REVIEW - HIGH INTENSITY USERS
TUESDAY, 20 NOVEMBER 2007**

Councillors *Hoban, *Lister, *Mallett and *Winskill (Chair)

* Member present

LC17. APOLOGIES FOR ABSENCE (IF ANY)

None.

LC18. URGENT BUSINESS

None.

LC19. DECLARATIONS OF INTEREST

None.

LC20. MINUTES

AGREED:

That the minutes of the meeting of 30 October be approved.

LC21. PROGRESS WITH REVIEW

It was noted that City University had been in contact and it was hoped that they would attend to next meeting on 18 December to provide independent expert input.

Preliminary consideration of evidence by the Panel to date suggested that there was an issue with information gathering and sharing. In addition, interventions were not always proven to be effective and there were a lack of resources for support groups. The complexity of many of the issues being considered by the review was a challenge for the Panel.

The Panel noted that the Alzheimer's Association and Age Concern had not been able to attend the meeting and agreed that they would be invited to come along to the next meeting on 18 December instead.

It was agreed that future meetings of the Panel would begin at 18:00 hrs in order to assist in enabling Members to attend all of the meeting.

LC22. EVIDENCE FROM USER GROUPS AND ADVOCATES

The Panel received evidence from Samantha Greaves, Comfort Rainier and Vivienne Mensah from Barnet, Enfield and Haringey Sickle Cell Support Group. Ms. Greaves reported that she had previously been admitted to hospital approximately every six weeks during the winter. Many of these admissions had been by ambulance. She was frequently in pain. There had been a great improvement in service when the North Middlesex hospital had introduced its outreach service where nurses went out to

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visit patients who were experiencing problems. However, she no longer used the outreach service. She had changed her diet and now did not use the drugs that were previously administered to her by the nurses. She had done this because she did not like the side effects of them. Since making these changes, she had not been admitted to hospital for 3 years.

Sickle cell was a condition that caused the red blood cells to become misshapen. The cells became clogged around the joints, preventing oxygen flow and causing pain and organ failure. When people had crises, these were normally dealt with by administering painkillers and blood thinning drugs. Blood transfusions could also be required. The condition was hereditary. Free blood screening was available. The prevalence of the condition was become greater due to mixed race relationships.

Ms. Mensah reported that her 15 year old son had the condition. Although a Haringey resident, she received her services from Hackney as she had built up relationships with health professionals through them. Her son had to receive blood transfusions regularly which entailed her driving to the hospital regularly. Hackney were now thinking along similar lines to health professionals in Haringey and looking at providing an outreach service.

Ms. Greaves felt that the service could be improved further if there was a greater availability of nurses. At present, patients were only able to have two visits in 24 hours and had to wait till a nurse was available. The nurses were very busy and were not available overnight. The nurses were often required to administer opiates to help control pain and these could only be given by appropriately qualified professionals. She had previously needed large doses of opiates but had weaned herself as she did not like the side effects or the feeling of being constantly high. She now used complimentary medicines and these had enabled her to stay out of hospital for three years.

The support group had been set up in 1985 and was the first in the country. It was a voluntary group and received no funding. They were currently trying to register as a charity. They had over 800 members and helped to signpost services and increase awareness of sickle cell disease. In particular, there was a need to increase awareness amongst health and social care professionals and especially the fact that cold weather could trigger it off. They had good links with the medical team at the George Marsh Centre. They were trying to get into schools to increase awareness amongst young people.

The Panel thanked the members of the support group for their attendance.

LC23. DESMOND AND THE EXPERT PATIENT PROGRAMME

Marina Chrysou and Sue Tokley from Haringey TPCT gave a presentation about the Expert Patients scheme. This was a generic course open to all people with long term conditions. Referrals came from a wide range of sources including self referral, community matrons and other health professionals. The programme was piloted in 2004. It was not aimed at any particular conditions nor was it specifically intended for very high intensity users. The emphasis was on self management and the long term consequences of conditions. It was led by volunteer lay people who had a long term condition themselves. It aimed to address a range of issues including loss of confidence, stress management, relaxation and living with pain. It promoted physical

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activity and a problem solving approach. Its overall objectives were to help people become more self sufficient and overcome the symptom cycle. The group structure provided a means of support for people as well as social benefits. The sessions all took place in community settings.

7 courses had been run last year, including one aimed at Turkish speaking people as part of the Race for Health programme. There had also been a course aimed at people with communication impairments. Referrals for the scheme were steadily increasing and good links with the Mental Health Trust's team of psychologists had been developed. Mental health users constituted the largest group of those referred (1/3). This was due partly to the fact that mental health professionals had a good understanding of the approach that was used. Other conditions that participants had included chronic pain (25%), arthritis (21%), diabetes (17.5%), COPD and angina.

Evaluation of the course had shown that patients had felt that they had benefited from an increased level of physical activity, social benefits and increased confidence. Three generic courses were planned this year plus another course for Turkish people and one for people with Aphasia. In addition, a specific course was planned for people from the Greek and Greek Cypriot community with cardiac conditions who had a low take up rate of cardiac rehabilitation.

The scheme was now in its fourth year of operation. Last year, 80 patients took part in the scheme and 76% completed it. Encouragement was given to people on the courses to continue meeting and twice yearly reunions were held. No data was kept on whether people who had completed the course were more likely to comply with their medication. Consideration was being given to franchising the programme to appropriate support groups so that they could run them themselves. The intention was to increase the number of courses that were run next year.

A bid for expansion had been put in for next year. This was part of a four year plan and would mean that more courses could be run. However, whether or not additional money was forthcoming was dependent on other priorities.

Monitoring of take up was undertaken but there was a lack of information on how effective the courses were. Consideration could be given to assessing the effectiveness of the courses by looking at how well people were self managing before and after they had been on the course. This could include take up of exercise, diet, levels of confidence and how well they communicated with health professionals.

Ms Tokley reported that DESMOND was a 6-hour group education programme designed for all people who have newly diagnosed type II diabetes. It has been designed to support the person to become an expert in self-managing their condition. From December 2006 to October 2007, the TPCT had run 8 courses with 82 patients referred. The 6-hour course has been split into 2 sessions and 32 patients had completed both sessions.

Ms Tokley felt that the multidisciplinary working involved had increased the skills of those professionals who had been involved and they had been able to contribute to the development of DESMOND. In addition, it had influenced delivery of education in other group work as DESMOND resources and explanations had a wider relevance. It offered a different style of education that was patient led and patient centred. There was particular emphasis on communicating to patients that they are responsible for

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their condition. GPs had an important role prior to attendance on the course to ensure certainty of diagnosis and preparing the patient for a life of self-management. However, health professionals needed to consider how to work effectively with empowered patients.

The courses had met with mixed success in Haringey. The courses and the training to deliver them cost several thousand pounds as they were copyrighted and the scheme was set up first and foremost as a business. It cost £3000 to train people. In addition, of the 82 patients that had been referred but only 32 had completed the course.

There were currently only four educators trained. Two of these had since left the organisation and one was on maternity leave. Referrals were made from practice nurses and GP's but there were only 15 practices that were regularly referring patients. The number of attendees for the course had been low as a result of not being able to get GP's to refer or encouraging patients to attend and general staffing issues. The sessions were run on Monday mornings at Bounds Green Health Centre.

An action plan had been developed. The current budget was £27,000 per annum. It was hoped to train a further 10 people to deliver the DESMOND training by October 2007. By January 2007, it was hoped to start to roll out further programmes within a central location in each of the four GP collaboratives.

As part of the restructure of primary care dietetics, a band 7 team leader role with a clinical lead in diabetes to was to be created to co-ordinate the operational delivery. In addition, a member of staff would be working with each GP practice to identify all newly diagnosed type II diabetics and automatically invite them to attend a DESMOND programme within their locality. They would be responsible for booking patients and sending out resources, information, ensuring attendance and also supporting the team leader to timetable the programmes and educators.

It was envisaged that 2-4 rolling programmes could be run per month alternating between collaborative. Patients would be offered a choice as to where they would prefer to attend. There might be scope to run quarterly programmes for Turkish Speakers. Patients would be identified through a combination of case finding and community development approaches within their own community groups.

The Panel noted that there were a high number of diabetics within Haringey and that this was linked to ethnicity. Haringey was a partner in a successful bid with Islington PCT and the Whittington Hospital for Co-creating Health monies, which aimed to develop, better self-management for diabetics. Type II diabetes tended to affect older people although more younger people were now being affected by it. It was often difficult for people who were newly diagnosed to understand the condition. Type II was a major concern as it was growing and large numbers of people were considered to be at risk from developing it.

The Panel thanked Ms. Chrysou and Ms. Tokley for their assistance.

AGREED:

That the TPCT be asked to provide figures for the number of diabetics within the Borough.

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LC24. NEW ITEMS OF URGENT BUSINESS

None.

LC25. DATE OF NEXT MEETING.

Tuesday 18 December at 6.00pm.

Cllr David Winskill

Chair