

SCRUTINY REVIEW ON HIGH INTENSITY USERS

11 FEBRUARY 2008

ISSUES PAPER

1. INTRODUCTION

- 1.1 The purpose of this paper is to bring together all of the significant evidence received in the course of the review and highlight what appear to be the key issues for discussion at the concluding meeting of the review. The aim of this is to assist the Panel in reaching conclusions and recommendations.

Definition

- 1.2 The term “high intensity user” has been used to describe patients who have several - at least three - emergency hospital admissions in a year. These repeated admissions cost the NHS more than £2 billion per year. Several reports and research findings have highlighted the fact that there is strong evidence that interventions in the community can reduce these emergency admissions, as well as lengths of hospital stay, leading to improved care and the potential for savings to be made by the NHS. In particular, studies in the US on hospital usage have categorised 19 chronic illnesses as “ambulatory care sensitive”. For these conditions, timely and effective outpatient care can help to reduce the risks of hospitalisation by preventing the onset of an illness or a condition, controlling an acute episodic illness or condition or managing a chronic disease or condition.
- 1.3 High intensity users tend to have one or more long term conditions (LTCs) plus complex social circumstances and/or additional mental health problems including anxiety and depression. Older people are most likely to be living with a LTC but there is also a link with social and economic deprivation. Not all patients with one or more LTCs become high intensity service users. Those that do tend to make additional demands on Accident and Emergency (A&E) and out of hours services and/or suffer from LTCs that have traditionally been managed by the NHS in isolation from social services (e.g. COPD, diabetes, heart failure). People with LTCs are the most intensive users of the most expensive services. This includes not only primary and specific acute services but also social care, community services and urgent and emergency care.
- 1.4 It was noted that Haringey Teaching Primary Care Trust (TPCT) now generally refers to this category of patients as “very high intensity users (vhiu)” and defines them as: “people who are likely to be users of multiple services and have frequent attendances or admissions to hospital because they have long term conditions”. They make no distinction between people who just present at A&E and those who are actually admitted to hospital. “Ambulatory care sensitive” (high impact users with primary care sensitive conditions) is not a piece of terminology that is used locally.

Strategic Responses and Models of Care

- 1.5 Strategic responses to high intensity users are typically based on what is known as the “Chronic Care Model”, which identifies the essential elements of a health care system that encourages high quality chronic disease (or long term condition) care. These elements are:
- The use of community resources and policies to keep patients well, involved and active.
 - The development of a health care organisation that prioritises chronic care.
 - Self-management support. This aims to give patients have a central role in determining their care and one that fosters a sense of responsibility for their own health.
 - Delivery system design that assures the delivery of effective, efficient clinical care and self-management support.
 - Decision support to ensure integration of protocols and guidelines and the promotion of clinical care that is consistent with scientific evidence and patient preferences.
 - Availability of clinical information such as:
 - Means of identifying subpopulations for proactive care
 - Reminder systems to support compliance
 - Feedback to health professionals providing information on chronic illness measures such as hypertension or lipid levels
 - Registries for planning individual patient care and conducting population based care.

The Pyramid of Care

- 1.6 The vast majority of patients with LTCs (70 – 80%) should be able, with appropriate support, to care for themselves and therefore only need minimal input from health and social services. They represent the bottom layer of what is referred to as the “pyramid of care”. In the middle layer are “high risk patients”, who are people who need more active disease and care management from professionals. Finally, in the top level, are the patients with highly complex needs. These patients are usually aged over 65, and represent a tiny proportion of the population, but account for a large number of emergency admissions to hospital. It is from this group that the high intensity users will most likely be drawn.
- 1.7 The NHS and Social Care Long Term Conditions Model uses a similar model to categorise that the care that people require as follows:
- Level 1 (bottom layer): Supported self care. This involves helping people and their carers to develop the knowledge, skills and confidence to care for themselves effectively.
 - Level 2 (high risk patients): Disease specific care management. This involves providing people with responsive specialist services using multi disciplinary teams and disease specific protocols and pathways.
 - Level 3 (patients with highly complex needs): Case management. This involves identifying the most vulnerable people and using a case management approach to anticipate, co-ordinate and join up health and social care.

- 1.8 Providing effective care at levels 1 and 2 may help to slow down or prevent patients at the lower levels needing higher levels of care in the future.

Government Policy

- 1.9 It is a government priority to improve care for people with long term conditions by moving away from reactive hospital based care towards a systematic, patient-centred approach. This is based on several relevant reports such as the Royal Commission on Long Term Care (1999), Independence, Well-Being and Choice (2005), Commissioning a Patient Led NHS (2005) and Our Health, Our Care, Our Say (2006), as well as National Service Frameworks, such as the ones for older people, coronary heart disease and long term neurological conditions. These emphasise the fact that the majority of patients prefer to be treated close to their own homes.
- 1.10 'National Standards, Local Action' (2004), set the following national target for Long Term Conditions (LTCs):
- “To improve outcomes for people with LTCs by offering a personalised care plan for vulnerable people most at risk; and to reduce emergency bed days by 5% by 2008 (From the 2003/2004 baseline), through improved care planning in primary care and community settings for people with LTCs.”
- 1.11 Haringey is currently meeting this target.

Community Matrons

- 1.12 Community Matrons (CMs) are perhaps the most significant part of the government's strategy for addressing the needs of high intensity users. The NHS Improvement Plan (2004) introduced their role. They are expected to be experienced, skilled nurses who use case management techniques to work with patients who are high intensity users.
- 1.13 The objectives of case management undertaken by CMs are to:
- Help to prevent unnecessary admissions to hospital
 - Reduce the length of stay of necessary hospital admissions
 - Improve outcomes for patients
 - Integrate all elements of care
 - Improve patients' ability to function and their quality of life
 - Help patients and their families plan for the future
 - Increase choice for patients
 - Enable patients to remain in their homes and communities
 - Improve end of life care
- 1.14 The principle of this particular model of care is that there is one person who acts as both provider and procurer of care and takes responsibility for ensuring all health and social care needs are met, so that the patient's condition stays as stable as possible and well being is increased. The CM has a key function as a co-ordinator of care, within the

framework of the Single Assessment Process. They develop a care plan in conjunction with the patient that identifies needs and offers solutions as to how they can best manage their long term condition, including any possible deterioration. The role of community matrons (CMs) is intended to include:

- Using data to actively seek out patients who will benefit
- Combining high level assessment of the physical, mental and social care needs of patients
- Reviewing and prescribing medication
- Providing clinical care and health promoting interventions
- Co-ordinating inputs from all other agencies, ensuring all patient's needs are met
- Teaching and educating patients and their carers about warning signs of complications or crisis
- Providing information so patients and families can make choices about current and future care needs
- Being highly visible to patients and their families and carers and being seen by them as being in charge of their care
- Being seen by colleagues across all agencies as having the key role for patients with high intensity needs.

- 1.15 A target was set by the government for 3,000 CMs to be in post in England by March 2008 but this was amended by the government after only 1,470 had been recruited by December 2006. This was to allow PCTs to put staff from other disciplines in case manager posts, such as social workers. The target number was subsequently reduced to 2,500 but only 1,600 were in post by the end of March 2007.
- 1.16 The Healthcare Commission's State of Healthcare report recently revealed 41% PCTs failed to hit the targets for recruiting CMs and case managers in 2006/7 and only a third met the target for the number of people with long-term conditions under the care of a CM. As a result of this, the report stated that 60,000 people who needed this support were not getting it. This was worse than the year before, when 39 per cent of PCTs hit the target for patients being managed by community matrons or case managers.
- 1.17 The target for Haringey was to have 21 CMs in post by March 2008. Haringey currently has 13 posts, with 11 being currently filled. Some of these roles have been designed specifically as CM posts whilst others have developed from existing specialist nurse posts, who were already working in this way. In addition, there was also a target for 950 high intensity users to be receiving a service from CMs this year. This has been met, with 959 residents having benefited from the service.

“Healthcare for London – A Framework for Action”

- 1.18 The models of care outlined in the recent report by Lord Darzi entitled “Healthcare for London – A Framework for Action” are currently being consulted on by the NHS across the capital. If approved, they will provide a blueprint for the London wide development of services. The report refers explicitly to the need to improve community care to reduce emergency admissions.

- 1.19 It argues that, in order to cover the needs of just those patients with diabetes, congestive heart failure and asthma and reduce the need for urgent care appointments and emergency admissions, there should be much greater use of systematic appointments with community healthcare professionals. The model of care that he proposes would require over 800,000 GP appointments and 1.6 million nurse appointments. He estimates that this will require 175 more GPs and 350 more specialist nurses. This increase will be offset by a reduction in urgent care appointments and emergency admissions. Haringey currently has 211 GPs and is scheduled to have 208 (3 fewer) by 2011/12. However, it currently has 13 CMs and is projected to have 21 by 2011/12.
- 1.20 In addition to this, Lord Darzi recommends the following:
- The designation of a consultant/nurse and community lead for each long term condition in each PCT area.
 - Better integrated health and social care to be developed by requiring PCTs to work with local authorities to develop joint action plans for the management of long term disease.
 - Greater use of “assistive” technology
 - More support from community pharmacies
 - The development of London wide care pathways for long term conditions
- 1.21 It is envisaged that the re-direction of resources from hospital to community based care required will be achieved by the commissioning process. However, investment in improved health and social care services to support patients outside of hospital will need to be made before any reduction in urgent care appointments and emergency admissions can be achieved and it is unclear as yet how it is intended that this can be achieved.

2. IDENTIFYING THE HIGH INTENSITY USERS

Introduction

- 2.1 Identifying accurately patients who are most at risk of emergency admission is important in order to ensure that services are directed at those whose need is greatest and vulnerable people do not fall through the net. Accurate and up to date information is crucial to this.
- 2.2 The TPCT currently uses a combination of predictive data, including the Patients at Risk of Re-hospitalisation (PARR) software tools, plus referrals to identify high intensity users. They feel that this is the most effective way to identify appropriate patients for the service. CM referrals have come from:
 - PARR (40%)
 - GPs (36%)
 - Admission prevention (17%)
 - Other (7%)

PARR

- 2.3 The PARR predictive case finding IT tools were commissioned by the Department of Health and the NHS from a consortium of the King's Fund, New York University and Health Dialog Analytic Services. These software tools are available for use free of charge within the NHS in England.
- 2.4 The TPCT currently gets monthly reports from PARR1 and PARR2, which both use Hospital Episode Statistics (HES) data to produce a 'risk score' showing a patient's likelihood of admission within the next 12 months. Risk scores range from 0 – 100, with 100 being the highest risk. The PARR tools use an emergency hospital admission as a 'triggering event' and then apply an algorithm based on diagnostic information from this most recent admission plus information from previous admissions and out patients/day case attendances. The admissions and attendances can be anywhere in the country.
- 2.5 PARR1 focuses on admissions for specific 'reference conditions', for which improved management can often help prevent future hospital admissions. These conditions represent around 20-25% of all emergency medical admissions and include conditions such as congestive heart disease, COPD and diabetes. PARR2 uses any emergency admission as a trigger and is not limited to admissions for a 'reference condition'. Because it focuses on a larger number of patients, it produces risk scores for more patients than PARR1 but has a slightly lower rate of predictive accuracy for comparable risk score bandings. However, due to the higher number of patients found, PCTs are able to use a higher risk threshold cut off point than for PARR1 in order to find a comparable number of patients. Particular attention is paid to patients with risk level of more than 50%. However, there are limitations to the usefulness of PARR data, as in some cases, patients have moved on or changed circumstances by the time that figures come to light.

- 2.6 A third tool has been developed which combines secondary care data with community based data, such as GP electronic records and social care data. This third tool will have the added power of being able to predict the risk of hospital admission for those patients who have not yet experienced a recent emergency admission. The ability to identify emerging risk enables organisations to plan early interventions to minimise or prevent emergency admissions. This tool is not yet in use in Haringey.
- 2.7 The Panel's expert adviser reported that current NHS information systems are designed to react to rather than prevent ill health. They do not easily enable identification of current or potential high intensity users. The PARR formula is a reaction to these current deficiencies in routine data collection and the accuracy of its predictions can be variable. Systems are not joined up and much essential information, such as District Nursing notes, tends to be manual rather than electronic and therefore cannot be interrogated. They normally give information on episodes of care or incidence of a single disease and not people. In addition, data from A&E on patients who have attended is not always accurate as hospitals use a different coding system that is based on a description of the condition. In some cases, conditions are not always immediately obvious and therefore the coding may not be accurate. In addition, NHS IT systems are also not currently compatible with those used by social services departments. However, efforts are being made locally to enable A&E staff to have read only access to Adult Services data. This would assist A&E staff by flagging up potential issues.
- 2.8 Data from IT software systems are not the only source of referrals as CMs also liaise with GPs. All GP practices now hold disease registers and these can be referred to as well. Information on exactly how many people have been diagnosed as having particular conditions should therefore be readily available. In all cases, CMs make the final decision on who they can work with after consulting with the GP and finding out more information. If the patient has more than one long-term condition, lives in Haringey, consents to contact with a community matron and is not already in nursing or residential care, the CM will carry out an assessment. From this they decide if there is a role for the CM in helping to co-ordinate their care and to help them to manage their condition better. If they do not take them on, they will inform the GP and consider if there is another service that it would be appropriate to refer them to, including social or voluntary sector services.

3. HOW THE TPCT ADDRESSES THE NEEDS OF HIGH INTENSITY USERS

Community Matrons (CMs)

- 3.1 The Panel noted information from the TPCT that 650 patients are currently in touch with the CMs. The more prevalent long term conditions are the most common such as COPD, heart disease and diabetes. There are also a number of people with mental health problems and a significant number have cognitive or memory impairments, which may reflect the number of older people on the caseload. In addition, a significant number have a mental health problem, which might lead to them being high users of services and reflects the link between mental health problems and poor physical health.
- 3.2 The overall approach adopted by CMs within the Borough is based on a pilot project that was undertaken in Haringey and known as TeamHealth. This provided telephone support to people with heart disease, heart failure and/or diabetes. An evaluation of this project was undertaken, including a randomised controlled trial and patient and practitioner satisfaction surveys. The learning from this was used to support development of the current CM programme. Haringey currently has two sorts of CM: generic and specialised.
- 3.3 There are currently 6 generic CM posts who are working actively with 125 people. Their role has been developed using information on what has been successful in other such projects and described in the Kings Fund report of December 2005: *'What Works in Case Management of High Risk Populations – Identification of Key Components to Improve Effectiveness'*. They do not only work with people who have more than one long-term condition and are high intensity users of services but also those people who are likely to become so. All the generic community matrons link to a commissioning collaborative, and are based within a community nursing team for their locality. They have close working links with and make referrals to a variety of health, social care and voluntary services.
- 3.4 Additionally, there are a range of specialist nurses who also support the management of high intensity users and act as specialist CMs. Although these are specialist nurse posts, they work to the CM criteria e.g. working with people who have HIV, with people who require palliative care and within the continuing care team.

Monitoring and Evaluation of CMs

- 3.5 The effectiveness of the CM role in reducing hospital admissions over time is currently being evaluated by the TPCT. The Practice Based Commissioning Collaboratives will then consider how best to commission services for high intensity users in the future.
- 3.6 The Panel noted the view of the TPCT that reasons for hospital admission are multi-factorial. A percentage of patients will have had a high number of admissions as they are nearing the end of their life. There may also be some others who refuse to change their behaviour and their way of managing their health. The CMs are also using proxy measures to evaluate the service, such as service user feedback, numbers of medication reviews, individual admissions avoided and GP feedback.

- 3.7 The Panel also noted wider evidence that the CM role has not been proven to have a significant effect on hospital admissions. The National Primary Care Research and Development Centre (NPCRDC) analysed the nine pilot schemes conducted in England between 2003 and 2005. The NPCRDC's evaluation found that, while the model made positive improvements to patient care and reduced GP workload, it did not reduce hospital admissions. The author of the report commented that it was unrealistic to have expected them to do so. The US model, where admissions were cut, was accompanied by an intensive home-care system. The patients did not stop getting ill but were instead cared for at home instead of being sent to hospital. The study also showed that the UK pilot schemes suffered from a lack of effective IT systems and poor integration between the pilots and local hospitals. Out-of-hours and primary care services were also not set up to prevent hospital admissions.
- 3.8 However, the role is currently in its infancy and may need longer-term evaluation before its effectiveness can be assessed accurately. Other evidence shows that the approach is effective and that patients are benefiting from it by being alive and well, still living at home and avoiding hospital. Many PCT boards are also pleased with local evidence showing that community matrons have more than covered their costs in emergency admissions saved. There is also strong evidence that they improve quality of life. There is always likely to be sufficient demand to fill hospital beds so significant savings are unlikely to be made. In addition, many studies on their effectiveness are based on the US experience, which was not comparable to the UK due to structural differences. Finally, if no distinction is made between conditions which are sensitive to primary care interventions and those that are not, CMs may be intervening with patients for whom a reduction in hospital admissions may not be a realistic goal.
- 3.9 The Panel also noted the evidence from the GP who gave evidence as part of the review that there is some element of risk in not admitting patients to hospital who are suffering from an episode of illness. Healthcare professionals may therefore vary in their willingness to take on board such an element of risk, especially if they have incomplete information on the patient concerned.

Future Development of Services for High Intensity Users

- 3.10 The Panel noted evidence from the TPCT that CMs form only one part of their strategic approach and that, on their own, they cannot manage all high intensity users within Haringey. The TPCT's recent Primary Care Strategy presented their future plans for supporting people with long term conditions, which included:
- The development of care pathways that support effective prevention, management in primary care and ensure clarity and coordination between different elements of service provision. A diabetes care pathway has already been developed and, in addition, a model of diabetes care is being developed to deliver improved outcomes. This model will involve improving and bringing together care within primary care and will help the TPCT in developing its overall model for long-term conditions.
 - Locality services for long term conditions to be developed with the primary care commissioning collaboratives. These will bring together a range of clinical inputs such as GPs with a special interest in a certain condition, nurse practitioners, dietetics,

physiotherapy, foot health, psychological support as well as a route into a range of community and self care support services.

- Intermediate Care and Rehabilitation strategy (rehab strategy). The TPCT are working on a rehab strategy together with the Council which it hopes to consult upon soon. This aims to provide care as far as possible in people's homes and to provide a single point of entry into services, integrating health and social care teams including community matrons.
- Improved access to support for self care including the Expert Patient Programme for people who have recently been diagnosed with a long term condition and the DESMOND programme which promotes a structured self management approach for people with diabetes. The Panel received specific evidence about both of these schemes.

Expert Patients Programme (EPP)

- 3.11 This is 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 is not aimed at any particular conditions nor is it specifically intended for high intensity users. The emphasis is on self management and the long term consequences of conditions. It is led by volunteer lay people who have a long term condition themselves. It aims to address a range of issues including loss of confidence, stress management, relaxation and living with pain. It promotes physical activity and a problem solving approach. Its overall objectives are to help people become more self sufficient and overcome the symptom cycle. The group structure provides a means of support for people as well as social benefits. The sessions all take place in community settings.
- 3.12 The EPP scheme is now in its fourth year of operation. Last year, 80 patients took part in the scheme and 76% completed it. 7 courses were run, including one aimed at Turkish speaking people as part of the Race for Health programme. There was also a course aimed a people with communication impairments. Three generic courses are planned for this year plus one each for Turkish people and people with Aphasia. In addition, a specific course is planned for people from the Greek and Greek Cypriot community with cardiac conditions who have a low take up rate of cardiac rehabilitation. Referrals for the scheme are steadily increasing and good links to the Mental Health Trust's team of psychologists have been developed. Mental health users constitute the largest group of those referred (1/3). This is due partly to the fact that mental health professionals have a good understanding of the approach that was used. Other conditions that participants have had include chronic pain (25%), arthritis (21%), diabetes (17.5%), COPD and angina.
- 3.13 Encouragement is given to people on the courses to continue meeting and twice-yearly reunions are held. No data is kept on whether people who had completed the course were more likely to comply with their medication. Consideration is being given to franchising the programme to appropriate support groups so that they could run them themselves. The intention is to increase the number of courses are run next year and a

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

- 3.14 Evaluation of the course has shown that patients feel that they have benefited from an increased level of physical activity, social benefits and increased confidence. Monitoring of take up is undertaken but there is a lack of information on how effective the courses are. 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.
- 3.15 A national evaluation of the pilot phase of the scheme concluded that it had increased patients' self-efficacy by a moderate amount, and had had a relatively smaller impact on the amount of energy people reported (energy was chosen as the health status outcome most relevant to people with a range of long-term conditions). However, there was no change in health services utilisation although overnight hospital stays and use of day case facilities were reduced.

DESMOND

- 3.16 DESMOND is a 6-hour group education programme designed for all people who have newly diagnosed type II diabetes. It aims to offer a style of education that is patient led and centred. There is particular emphasis on communicating to patients that they are responsible for managing their condition and DESMOND has been designed to support people in becoming an expert in self-managing their condition. GPs have an important role prior to attendance on the course to ensure certainty of diagnosis and preparing the patient for a life of self-management.
- 3.17 The courses have met with mixed success in Haringey. From December 2006 to October 2007, the TPCT ran 8 courses, with 82 patients referred. Of these, only 32 completed the course. The courses and the training to deliver them cost are expensive as DESMOND has been copyrighted and was set up, first and foremost, as a business. It costs £3000 to train one person.
- 3.18 There are currently only four educators who have been trained. Two of these have since left the organisation and one is on maternity leave. Referrals are made from practice nurses and GP's but there are only 15 practices that are regularly referring patients. The number of attendees for the course has been low as a result of not being able to get GP's to refer or encouraging patients to attend and general staffing issues.
- 3.19 An action plan to deliver DESMOND has nevertheless been developed. The current budget is £27,000 per annum. It is hoped to train a further 10 people to deliver the DESMOND training by October 2007. By January 2008, it is also hoped to start to roll out further programmes within a central location in each of the four GP collaboratives. It is envisaged that 2-4 rolling programmes could be run per month alternating between the collaboratives. There may be scope to run quarterly programmes for Turkish speakers. Patients will be identified through a combination of case finding and community development approaches within their own community groups.

4. HEALTH AND SOCIAL CARE PROVISION BY THE TPCT'S PARTNERS

Introduction

- 4.1 Local hospitals have developed their own systems for addressing the needs of high intensity users. There is a 1st Response team at the North Middlesex Hospital that refers cases to CMs. There is also a lead nurse at the Whittington Hospital, who also keep a “top 100” of their most prolific service users. In addition, social care plays an increasingly important role in meeting needs as it will be an essential part of any strategy that is aimed at keeping people out of hospital and caring for them closer to home.

North Middlesex University Hospital (NMUH)

- 4.2 NMUH has a First Response Team (FRT) who have proven to be effective in interventions to help avoid admissions and/or reduce their duration. They provide a highly visible, co-ordinated therapy and discharge service by means of early specialist assessment and intervention, internal/external networking and referrals, as well as fast track access to health and social care services. The main benefit of the service is the provision of integrated services for patients, allowing a concentration and continuity of care from admission to the discharge of patients. This incorporates promotion of care standards and the screening of medical and nursing interventions in order to assess for potential issues that might lead to a delayed discharge or readmission.
- 4.3 FRT is multi disciplinary and has links to other teams of professionals who are based at the hospital including the Rapid Response Team, the Intermediate Care Team, Community Matrons and Haringey Adult Services. There are fortnightly meetings to discuss follow-up on recent FRT hospital discharges to community services and frequent attendees with long term conditions. There are also reviews of patients with significant social issues.
- 4.4 The team does not just operate in Accident and Emergency but is a constant presence across the hospital and particularly in assessment and care of the elderly wards. The service is not available 24 hours per day – its hours were 8:00 a.m. till 6:00 p.m. They have a particularly important remit in respect of care of the elderly and a key part of this is falls assessment.
- 4.5 The Trust is currently in the process of expanding the FRT as it has proven to be successful. It has been particularly effective in screening episodes where long term conditions may be a significant factor leading to a presentation at A&E. For example, a patient presents with a fall whose root cause was COPD/heart failure but is only treated in relation to fall.
- 4.6 NMUH does not currently have psychiatric cover for older people, which was a significant factor in the admission of a number of people to hospital. The lack of service meant that the issue was currently not being picked up. There had previously been an informal arrangement between the Mental Health Trust (MHT) and the hospital which the MHT had now decided to withdraw from. There are formal arrangements in place for mental health trusts to provide such cover in other hospitals.

- 4.7 NMUH felt that CMs had made a significant impact on success in admission avoidance. Links between the FRT and the CMs work well and they have been particularly effective in addressing asthma and COPD. However, they noted that some CMs post are still vacant. NUMUH feels that the most effective means of keeping people with long term conditions out of hospital is through multi disciplinary, multi agency action, rather than just through primary care.
- 4.8 The Panel noted a NMUH scheme that has been very effective in keeping people with sickle cell disease out of hospital. There are growing numbers of patients at the North Middlesex who suffer from sickle cell - there had been 470 admissions from Haringey residents last year due to it and 80% of those had been treated at NMUH. The dominant symptom is severe pain and there is a very high rate of hospitalisation amongst patients. A small number of patients had actually spent more time in hospital than at home. A four year study in the US had shown a similar picture. There is a particularly high rate of readmission.
- 4.9 Previous attempts to address frequent presenters had included counselling and case management. Whilst these had both been successful to some extent, the initiative that had worked best had proven to be the Home Care Outreach Nursing Team. The team works with patients to help manage uncomplicated pain out of hospital. It takes a multi agency, multi disciplinary approach with the emphasis on providing continuity of care. There has been a steady increase in patient numbers and the service now had 1.5 staff and was currently dealing with 87 patients. There has been a 19% drop in admissions and a 32% drop in duration of admissions and satisfaction levels with the service were high.
- 4.10 It is not clear whether the service saves money but it is felt to be a better quality service for patients that improves their quality of life. More patients are managing more or less independently now and many patients just use the home care service and are rarely admitted to hospital. However, there are nevertheless patients who continue to be admitted, as well as using the home care service. A CM is working with the small number of patients who are still being regularly admitted.
- 4.11 The service had been particularly helpful for children as they were much more comfortable being treated at home. In 2000, the first Roald Dahl paediatric home care nurse for children with sickle cell disease had been appointed at the North Middlesex Hospital in London. These posts had been highly successful. Care was now more home based from the start. The nurse provided general education and insights for families and was their first contact. They had changed the whole expectation of care needs. The 'then' 10 year olds were now all self caring 17 year olds. There were patients as young as 10 who were now able to self manage their condition. It was now unusual for child to be hospitalised 'just' for pain management.
- 4.12 The hospital was now getting more patients from other Boroughs and this had enabled "critical mass" to be achieved. This model could also be considered for other long term conditions such as COPD and asthma.

The Whittington Hospital

- 4.13 The Whittington Hospital addresses the issue of high intensity users at both a strategic and specialist level. It works together with key local partners to jointly address the issue. It has a Rapid Response team, whose role is to identify such vulnerable people and work with partners to avoid hospitalisation and, if this was not possible, to reduce the length of stay. This work involves social workers, occupational therapists and a nurse. This service was currently funded by Islington. There is also a close working relationship with CMs and the matrons working within the hospital. In addition, there is also close liaison between discharge teams at the hospital and local authority social services departments.
- 4.14 The hospital had been asked by Islington PCT to take part in a pilot project called “Right Care, Right Place” that involved appropriate patients being redirected to primary care. The pilot is supported by clinical protocols to ensure safety and involves the triage nurse at A&E identifying appropriate patients. The pilot is being fully evaluated by Islington PCT.
- 4.15 The Respiratory Team provides treatment, education and support to COPD patients to help them manage their condition more effectively. The Respiratory Early Discharge Service (REDS) helps patients admitted as an emergency to get home earlier and avoid readmission. This service is provided by a multi-disciplinary team of nurses, physiotherapists and doctors and works in conjunction with primary care services in Islington and, to a limited extent, Haringey. The aim of the REDS team is for patients to be discharged from hospital as early as possible and to continue their treatment and recovery in their own home under the care of their GP. The respiratory team also has an active pulmonary rehabilitation programme that works with colleagues from leisure in both Islington and Haringey and involves Breathe Easy, a self help group for patients.
- 4.16 The Whittington is leading a new self-management programme in diabetes care with colleagues from both Haringey and Islington PCTs. It had been successful in being awarded the Health Foundation Co-creating Health programme; a 3 year programme aimed at empowering people with diabetes and improving self-management of long-term conditions. This will involve partners working with nurses, clinicians and GPs to develop support programmes and linking in with the work already undertaken as part of the Expert Patients Programme and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed). There will be 3 elements to the programme; an advanced development programme for clinicians; a self-management programme for people with Diabetes and a service redesign programme, across the health economy. The programmes developed could eventually be applied to other conditions in due course.
- 4.17 It was noted that there was an issue with people with low level dementia being admitted to hospital. The Whittington was now actively screening new admissions for evidence of alcohol abuse and liaising with community services in Islington if appropriate.

Camidoc

- 4.18 High intensity users may also use Haringey’s out of hours GP service, Camidoc. It was noted that Camidoc holds a large amount of information of patients and can, for instance, provide lists of all patients that have called them more than a certain number of times. The IT software that they use has various embedded reports that can be run if required.

Information from Camidoc is not directly taken into consideration by CMs in identifying patients for them to work with.

- 4.19 Clinicians working for Camidoc also do not have access to GP patient notes. However, they have what were referred to as “special patient notes”. These are patients whose notes have been shared with them by GP practices or other health professionals. They are generally cases where there are particular issues of concern. Camidoc is not yet systematically informed of complex clinical cases and CMs in Haringey do not habitually refer cases of people they were working with to them. In Camden and Islington, Community Matrons have visited Camidoc to share information on patients that they are working with.
- 4.20 Camidoc doctors are legally liable for the care of all patients that they deal with. Access to more relevant background information would help their doctors better able to make informed clinical decisions. 6-7% of callers are referred to hospital via A&E or ambulance. Doctors are more likely not to refer patients to A&E when there are concerns if they have access to relevant information and can be more confident that any level of risk involved is acceptably low.

Adult Services and Social Care

- 4.21 Keeping more people out of hospital has cost implications for Adult Services as additional social care services will be required to support a large proportion of them. This will be especially true of high intensity users. In addition, social care can play an important role in liaising with health professionals and alerting them to any concerns in respect of clients.
- 4.22 Discussions have been undertaken with the TPCT on the issue of resources and it is not unsympathetic to assisting with the additional cost to services. The advent of practice based commissioning and payments by result is making this more feasible. A significant difference between the NHS and social services that needs to be addressed is that the NHS is free at the point of delivery whilst services provided by social services were chargeable. Another key issue is that social work staff cannot currently administer medicines.
- 4.23 The Panel noted that until recently, the focus of attention had been on getting people out of hospital. Some progress with this has now been achieved. The government has allocated money that was previously put aside for fines for delayed discharges to local authority social services departments. Haringey has used this money creatively and are investing in appropriate projects such as therapy, home care, advocacy and a rapid response scheme with the TPCT. However, these are still at the embryonic stage. A five year strategy for integrated care services has now been drafted. The intention is to have a single point of access to services that people can be referred to but which provides a multi disciplinary response and access to hospital beds if required. The position would be helped if it was possible for patients to have intravenous antibiotics at home, as happened in some other areas.
- 4.24 The Council currently provides services for 2500 older people, including 600 people in care homes. These cover a wide spectrum of need. The Integrated Care Team has the

necessary skills to keep many people at home. The team includes a range of professionals, including social workers and nurses. However, it is felt that there are considerable additional savings that could still be made through reducing hospital admissions.

- 4.25 There are a range of networks available to identify vulnerable people and staff make contact with GPs if there are sufficient concerns. There are particular issues with low level dementia and COPD. Agreement has been reached so that people with dementia can be referred to day hospital via their GP. Not all GPs are helpful and the response in some cases is to assume that conditions are just the inevitable consequence of getting old.
- 4.26 Whilst services are coordinated, the service feels that they are not yet sufficiently integrated. Current arrangements have evolved in an ad hoc way rather than through a strategic approach. However, it appears that the right people are being targeted and there is good dialogue between services. In particular, CMs are working closely with Adult Services.

Telecare

- 4.27 The Panel received evidence from the Council's Community Alarm Service on the use of IT to support vulnerable people. This is mainly done by monitoring emergency calls via a warden's call out system for people living in Supported Housing and dispersed units for people living in their own homes. It has expanded over the years and currently supports up to 4500 people within Haringey.
- 4.28 Following improvements in information technology, the government set up the Preventative Technology Grant scheme to expand services that were provided. This was done in order to encourage the greater use of such technology and create greater links between local authority social service departments and other organisations and individuals that support individuals, such as occupational therapists, integrated care teams, home care agencies, Housing Association supported housing officers, district nurses, community matrons and GP's.
- 4.29 In Haringey, people are now considered for telecare as part of assessments that have been undertaken in response to referrals. The scheme aims to;
- Reduce hospital admissions and readmissions
 - Reduce dependence on care services and families
 - Provide security in the home and enable greater independence.
 - Reduce anxiety
 - Improve the quality of life for patients and informal carers
 - Delay the move into long-term residential care.
- 4.30 The basic systems just involve a button that is carried around the neck and can be pushed by clients in the event of an emergency. This is connected to a telephone line and will alert relevant staff. There were also a range of other sensors such as ones that detected movement, flood, carbon monoxide, falls, property exit and epilepsy. The

equipment is battery operated and does not require hard wiring. It provides a warning to the control room when batteries were low.

- 4.31 Door exit sensors can be particularly effective for individuals with increasing dementia, which can be exacerbated when people are removed from home into residential care. The sensor monitors when the client leaves the home. If and when they do, a call is generated and received in the Control Room, where appropriate action is taken.
- 4.32 The funding that is allocated to local authorities from the Preventative Technology Grant is intended for the purchase of equipment. However, it is important for the applications to be supported by appropriate staff. Haringey's system is backed up by a call centre that is covered around the clock and based at Woodside House on Wood Green High Road. There is also a response service which ensures that calls are acted upon. Some local authorities have installed systems but do not have the support systems to respond effectively to calls.
- 4.33 The basic cost to the client is £5.95 per week for the alarm on its own. Additional items are charged at 50p. per two items. Each local authority has its own way of charging. The service tries to keep the cost low and has taken advice on fair charging. In addition to direct benefits to the individual, the sensors can help give carers and relatives peace of mind.
- 4.34 The service has also set up a pilot scheme in partnership with Primary Care Trust involving the use of Vivatech Wrist Care. This entails the individual wearing a wrist alarm, which sends wellness data via the internet to Vivatech. This is passed onto community matrons. Community matrons are able to assess a range a data including sleep patterns and well being, which are measured by the patient's circadian rhythm. As the patient's level of health improves, the patient is moved off wrist care and assessed by the Community Alarm service for Telecare products such as a pendant alarm, fall detector, medication dispenser etc.
- 4.35 The Panel noted that considerable savings can be made as a result of the use of the equipment. For example:

Case History 1

Mrs R had been taken to hospital 4 of times at a cost of £400 for ambulance calls. She also had a high level of dependency on her sister, who had to travel from Brighton to take her out. When Mrs R was given a wrist alarm and Community Matron input, she began to go out every day, after notifying the control room of her movements. The knowledge that help was never far away increased her confidence and independence. There was a reduction of hospital admissions to zero over a 6 month period. The Community Matron was able to utilise the data and spot the start of urinary tract infection early enough to prescribe antibiotics and avoid hospital admission. It reduced the number of journeys that her sister made. In fact, the roles were reversed and her sister was admitted into hospital with Mrs R visiting her in Brighton.

The cost savings were as follows:

4 Ambulance calls	£404.00
- cost of alarm for 6 months	£154.86
	= £250.86
- Cost of wrist data 25 x 6	£150.00
	<i>Saving of £100.86</i>

Case history 2

Mrs L had COPD and heart failure. She had had 6 hospital admissions over a year at a cost of 3518 x 6 = 21,102. In the 6 months prior to wrist care installation she had 3 admissions to hospital at a cost of £10,051. In the 6 months since having the wrist care alarm, there had been no admissions to hospital and a reduction in the number of community matron visits.

Cost savings:

9 Community Matron Visits at £50 per visit	= £450
Wrist care alarm and wellness data	= £304.86
Total cost over 6 months	= £754.86
Savings to the Primary Care Trust	= £9296.14

4.36 The service is currently in the process of launching another telehealth scheme called Doc@home. This is a portable device which is left in peoples homes for a minimum of 3 months. It can ask the patient specific questions about their health and take readings of blood oxygen levels, ECG, weight, pulse and blood pressure. The data can be monitored via the internet. If a patient's health is deteriorating, it can produce alerts that can be picked up and acted upon by CMs. Doc@home can be used alongside a telecare alarm so that urgent emergency alerts can be made when necessary. Using the doc@home helps to educate the patient to take responsibility for monitoring their health and carrying out healthy practices such as eating healthily and reducing smoking and consumption of alcohol. Studies have shown very good results and reduced hospital admissions. The scheme is being undertaken in partnership with the TPCT and is aimed particularly at high intensity users, such as people suffering with COPD. In addition to reducing the number of visits to the hospital, it also reduces anxiety. Doc@home has been tested in several EU countries as well as 15 PCTs. It is initially being used with 30 patients.

4.37 The Panel noted that the cost of emergency care is as follows;

- Accident and emergency attendance: £101
- Cost of ambulance: £100
- Hospital admission £3,518

4.38 Wellness data could be of considerable benefit to health professionals. For example, sensors can detect whether people had had a restless night. Community matrons can

access this data via the net and pick up the possibility of patients having a Urinary Tract Infection (UTI). It has therefore been of great benefit.

- 4.39 The service saves the NHS money by reducing the need for hospitalisation but the income that the team receives does not cover the cost of it providing the service. The service generates money from a range of sources, including Housing Associations and Supporting People but this does not cover all the costs and it is often a challenge making up the shortfall. The TPCT is currently in a relatively strong financial position and discussions are taking place on how financial resources from the TPCT can be used to support social care activities, such as this, undertaken by the Council that have the potential to make savings for the TPCT. The Panel noted that the cost could deter some people from having the equipment. People who were on certain benefits could get help with the cost. If people were referred, the service was free.
- 4.40 The Panel noted evidence from Professor Procter that there was very little UK evidence so far on the effectiveness of telemedicine. Its implementation was still beset by technical problems. It required a well maintained system of response and worked best when linked to telecare and call alarm systems. An evaluation undertaken in NE London indicated that telemedicine aided communication between patients and health care professionals and could lead to the resolution of seemingly intractable problems. However, it was not universally acceptable to all very high intensity users. In addition, patients and families already experiencing high levels of stress may not welcome additional stress when technical problems are experienced with telemedicine.

The “Virtual Ward”

- 4.41 One particular initiative that had been undertaken was the “virtual ward”. This involved a network of virtual wards caring for the top 0.3% of a PCT’s registered population ranked according to predicted risk of emergency hospital admission in the following year. Each ward had a capacity to care for 100 patients and was linked permanently with a group of GP practices. The clinical work of a virtual ward was led by a community matron. There was also a ward clerk and the telephone number for him/her the ward clerk was the sole point of contact for the entire virtual ward. Patients were cared for at different intensities according to need: of the 100 patients, 5 were reviewed daily, 35 weekly and 60 monthly. When a patient fell below the top 100 for the virtual ward’s catchment area, discharge was considered. In the first two years following discharge the GP practice conducted quarterly rather than annual reviews.

5. THE ROLE OF VOLUNTARY SECTOR ORGANISATIONS

Introduction

- 5.1 Voluntary sector organisations can play a number of different roles in respect of high intensity users. They can bring service users together, act as their advocates and also provide services. Efforts were made to obtain a user perspective on services and this was obtained through evidence from Breathe Easy and the Sickle Cell Support Group. Evidence was also received from Age Concern and the Alzheimers Society but this was in the context of them being service providers, such as advocacy. The Panel noted that there was a lack of local patient and self help groups and, in particular, the Haringey diabetes group was now defunct.

Islington and Haringey Breathe Easy

- 5.2 It was noted that there are approximately 12 people who are actively involved in the local group. The aim of the group is to make life as comfortable as possible for its members. Its members suffered from a range of lung conditions such as COPD, asthma and asbestosis. It meets on a monthly basis.
- 5.3 Most people with lung disease have their own way of managing their condition and the ability to self manage is very important. The group is integrated into the Whittington's hospital's rehabilitation programme. Referrals can be made by the hospital, who provide some support for the group. Exercise is of great benefit for people with lung problems. The group is currently trying to set up a regular exercise session for its members and is trying to obtain suitable funding for this. One particular aim for the group is to publicise lung conditions as they feel that there is a lack of appreciation of their range and what they entail.

Enfield and Haringey Sickle Cell Support Group

- 5.4 The support group was been set up in 1985 and was the first in the country. It is a voluntary group and currently receives no funding. They are currently trying to register as a charity. They have over 800 members and help to signpost services and increase awareness of sickle cell disease. In particular, they feel that there is a need to increase awareness amongst health and social care professionals and especially the fact that cold weather can trigger it off. They have good links with the NMUH medical team at the George Marsh Centre. They are trying to get into schools to increase awareness amongst young people.
- 5.5 The Group feel that there had been a great improvement in service when the NMUH had introduced its outreach service where nurses went out to visit patients who were experiencing problems. However, it was felt that the service could be improved further if there was a greater availability of nurses. At present, patients are only able to have two visits in 24 hours and had to wait till a nurse was available. The nurses are very busy and are not available overnight. The nurses are often required to administer opiates to help control pain and these could only be given by appropriately qualified professionals.

Age Concern

- 5.6 Age Concern provide a service that involves acting as an advocate in cases where elderly patients from Haringey are subject to delayed or failed discharge. This covers situations where patients do not want to go to where they had been allocated or where they have been unable to find accommodation. Sometimes people cannot afford care or found it hard to accept it. Local authorities are fined £120 per day unless for delayed discharges, unless they were the fault of the NHS. In addition, they can provide benefits advice. Advocacy is currently only available in hospital and was provided at both the North Middlesex and the Whittington.
- 5.7 It was noted that there are gaps in this particular area. This was especially true of the Whittington Hospital, which has experienced problems with patients refusing to move out of the hospital. The service had been established using pooled budget money with the North Middlesex and the Whittington and services were commissioned jointly with them. The objective of the service was to try and assist in resolving difficult issues, where an impasse had been reached. In addition to addressing delayed and failed discharges, advocates could also help to prevent readmission to hospital. For instance, preventative action could be taken to reduce the risk of falls.

Alzheimer's Society

- 5.8 The Alzheimer's Society is a small, national charity. They provide a number of services within Haringey including advocacy, a drop in facility and a café. There are approximately 1400 people in Haringey with dementia. Significant numbers are treated at St. Ann's. There is a high prevalence of vascular dementia within the Borough.
- 5.9 Dementia can present problems if people were admitted to hospital. They can, for instance, refuse to get into an ambulance. Dementia also affects those who care for people with the condition. Carers can, however, play a key role in helping to keep people out of hospital.
- 5.10 It was noted that older people generally see hospital as a safe place to go. Accident and emergency (A&E) was particularly often seen as a safe haven. However, A&E takes a long time to deal with people and, more often than not, did not have the full history of patients. T
- 5.11 They felt that there was a particular problem with out-of-hours care. People with dementia are particularly prone to wandering and other problems at night. Provision of a 24 helpline and training on dementia for relevant health staff would also assist. In addition, there is a need for improved respite care and better integrated day care and training for carers.
- 5.12 The Panel noted that the majority of respite care provided through the Council was for carers looking after people with dementia. £1/2 million was currently spent on such facilities. People with dementia are normally dealt with via mental health services at St. Ann's. However, there are a lack of medical facilities there. Most people need both medical and care services.

Suggested Key Issues for Discussion:

- Strategic approach
- Resourcing of services
- Information systems
- Co-ordination and joint working
- Community Matrons
- Self management and self help
- The role of the voluntary sector
- Telecare