East Sussex
Health Overview and Scrutiny Committee (HOSC)

Scrutiny review of long term conditions in East Sussex

Report to HOSC 17 March 2006

1. Recommendations

1.1 Health Overview and Scrutiny Committee is recommended to:

(a) Undertake monitoring of key issues at six monthly intervals using the scrutiny review board already established.; the key issues to be **information sharing** and **patient pathways relating to people with long term conditions** initially, and issues of **health inequality** at a later stage.

(b) suggest to the Transforming Chronic Care Programme (TCCP) Focus Group managers that the venue for meetings of the users' forum move around the region to facilitate wider attendance and geographical coverage so as to establish the extent to which there are any significant variations in the issues and views being expressed.

2. Background and scope

2,1 A strategic presentation to the Health Overview and Scrutiny Committee identified that about 5% of NHS patients have long term conditions and utilise some 42% of NHS resources. It is recognised that there is greater scope to apply care management principles and support for self care to this group of patients. This is likely to result in improved care and reduced dependence on NHS resources.

2.2 The recent health White Paper, *Our health, our care, our say: a new direction for community services* [1], says "It has been estimated that the number of people over 65 years old with a long-term condition doubles each decade." and "The number of people with severe disability will also increase as prevalence rises among children, partly due to the increased survival of pre-term babies."

2.3 At its meeting on 28 June 2005, HOSC established the scrutiny review board for long term conditions with a broad brief "to review the treatment and services for people who live with five [2] of the most common long term conditions".

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[1] Department of Health, January 2006, Cm 6737
[2] Diabetes, heart failure, respiratory disease (including asthma), dementia and stroke.

2.4 Initial research for the review highlighted the Transforming Chronic Care Programme (TCCP) in Surrey and Sussex. This programme has a well-defined set of objectives and a three-year programme of work running to 2008. The Board considered that the TCCP was very comprehensive in its approach and therefore found it difficult to devise a scope for a full scale scrutiny review of this topic without significantly overlapping the work of the TCCP.

2.5 The Board therefore has sought an alternative approach to a full scrutiny review which it considered would be equally beneficial. The proposed approach is to maintain a watching brief over progress in implementing the TCCP whilst addressing key questions of concern along the way. This would be undertaken by holding six monthly Board meetings at which members would identify questions or issues to be pursued for consideration at the following Board meeting. [3]

2.6 Because the TCCP is a collaborative programme of all 15 PCTs across Surrey and Sussex, the impending reconfiguration of PCTs may impact adversely on the priority and visibility currently afforded to it. The number and arrangement of PCTs will be known within the next six months and the Board will be able to engage with the new PCT(s) for East Sussex as part of its' monitoring.

3. Key findings

3.1 In conducting this review, three broad themes of particular importance have emerged:

- information sharing,
- patient pathways, and
- health inequalities.

3.2 The first two are quite closely connected and seen by the Board as warranting higher priority. Whilst health inequalities are an important part of the whole HOSC agenda and an important consideration for people with long term conditions, they are less easy to evaluate for this group of people. The Board has therefore not addressed them at this stage but would wish to do so in due course. The three themes are discussed in more detail below.

3.3 The Project Board proposes that it should undertake structured monitoring of progress on key areas at roughly six-monthly intervals. A suggested checklist of areas to be monitored is set out in the table below. The Board proposes to develop appropriate milestones for interim monitoring of progress rather than rely solely on end date targets.

Target	***Date***	***Source***
Everyone with a long-term condition and/or long-term need for support – and their carers – should routinely receive information about their condition	By 2008	White Paper

[3] Alternatively, the Project Board could be disbanded and monitoring undertaken by HOSC; however, the Board felt that time constraints would prevent such matters being explored in sufficient detail at full HOSC meetings.

Everyone with both long-term health and social care needs should have an integrated care plan if they want one	By 2008	White Paper
Everyone with a long-term condition should be offered a care plan	By 2010	White Paper
East Sussex trusts will have an electronic care records service; this will include a basic support to the single assessment process	In second half of 2007	Connecting for Health
Fuller integration of records with social care	From 2008 to 2011	Connecting for Health
Adult Social Care access to NHSnet	During 2006	Local
Single assessment process – interim system	TBA	
PCTs and local authorities to have established joint health and social care managed networks and/or teams to support those people with long-term conditions who have the most complex needs	By 2008	White Paper
Review health inequalities	2007	Project Board

3.3 The Project Board would also maintain contact with the TCCP Focus Group as a means of assessing progress through the views of users and carers.

4. Information and information sharing

4.1 Services used by people with long term conditions and their carers may be provided by the public sector (principally the NHS and Adult Social Care), voluntary organisations and private sector providers. This complexity and range emphasises the need for good information, and in particular, for that information where necessary for continuity of care, to be shared between agencies and professionals. This has led the Project Board to ask:

- Does information sharing take place satisfactorily at a patient level? If not, why?
- Are there barriers to information sharing within and between agencies that inhibit satisfactory service planning and provision? Are they being addressed?
- Are there legal / legislative barriers that could be overcome?
- Do adequate information sharing protocols exist?

4.2 Service users and carers via the TCCP Focus Group have identified a number of similar themes related to improving communications and availability of information:

- How do we get health and social care to communicate and co-ordinate? Services and information should be continuously linked.
- Health and care professionals need e-access to the relevant information about me.
- Service users to carry their own notes.

4.3 All the above are reinforced in the National Service Framework (NSF) for Long-Term Conditions [4] which says that:

- The most effective support for people with long-term neurological conditions is provided when local health and social services teams communicate; have access to

[4] Department of Health, March 2005.

up to date case notes and patient held records and work together to provide co-ordinated service; and

- An integrated system of assessment and care planning can prevent unnecessary reassessment and repetition of basic information. It also helps to ensure that case notes are complete and people are receiving appropriate services.

4.4 The health White Paper, *Our health, our care, our say: a new direction for community services*, raises similar points to the Project Board and TCCP Focus Group:

> "By 2008, we would expect everyone with a long-term condition and/or long-term need for support – and their carers – to routinely receive information about their condition…." (This is interpreted by the Board as both information about the generic condition as well as information about their condition. Patients should have sight of their care plan as they are supposed to be involved in its compilation.)
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> "An integrated health and social care information system for shared care is planned as part of the NHS Connecting for Health strategy. It is an essential requirement for effective care co-ordination."
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> "An integrated health and social care information system will enable a shared health and social care plan to follow a person as they move through the care system. We will ensure that, ultimately, everyone who requires and wants one has a personal health and social care plan as part of an integrated health and social care record. Initially we will focus on offering integrated care plans to those individuals who have complex health and social care needs. By 2008 we would expect everyone with both long-term health and social care needs to have an integrated care plan if they want one. By 2010 we would expect everyone with a long-term condition to be offered a care plan."
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> "The NHS Connecting for Health strategy is already developing a system of electronic care records that will be accessible across the NHS by 2008. There are plans for these records to be accessible to social services from 2010. This key underpinning reform will avoid the need for people to repeat information about their condition, a major complaint in the listening exercise."

4.5 NHS health records generally lack adequate integration; thus, each hospital trust maintains its own records and primary care practices have their records. Whilst primary care records follow patients when they change GP practice, there is no automatic process for hospital records to follow patients. In reality, hospital records are requested if clinicians consider that the history from another trust is needed. Further barriers to integration are caused by clinical documentation tending to be a mixture of paper-based and electronic records, and some professional groups keeping uni-disciplinary records.

4.6 A major national information programme known as Connecting for Health, is commissioning and implementing an IT infrastructure to link the many different computer systems across the NHS [5]. The programme will solve current problems including

[5] The national programme is committed to spending £6.2 billion over the 10-year lifetime of its projects.

significant ones around inadequate record integration, and technical issues around record exchange and e-communication. Protocols and controls to ensure patient confidentiality whilst allowing essential information sharing form a further part of the programme.

4.7 This national programme should see East Sussex trusts having an electronic care records service in the latter half of 2007; this will include a basic support to the single assessment process. Fuller integration with social care is not envisaged until the period 2008 to 2011.

4.8 It is understood that a number of local initiatives are well developed for improving the sharing of information. In the Adult Social Care Department the main client system (Carefirst) holds the NHS number, and the social care identifier is shared with health for some of their equivalent systems. The Department is in the process of signing national protocols care to give access to NHSnet (the national NHS secure network) later this year. This should be a positive move to facilitating information sharing and it is planned to have Carefirst accessible as a web-based application over NHSnet to allow access to social care data by health professionals.

4.9 The electronic social care record was implemented in 2004 as an extension to Carefirst for recording all social care contacts and details, including some support to the single assessment process. It is not yet linked to any external health systems.

4.10 Underpinning any arrangement for sharing information is existence of an approved protocol. A Sussex-wide (East and West) information sharing protocol has been signed by the Caldicott Guardians [6] in social care, education, NHS trusts and PCTs. This should therefore be paving the way for satisfactory flows of information.

4.11 The Project Board propose to use some of the key markers in the White Paper and elsewhere in a checklist for systematic monitoring.

5. Patient pathways

5.1 A patient pathway may be thought of as the route that a patient will take from their first contact with an NHS member of staff (usually their GP), through referral, to the completion of their treatment. It can be viewed as a timeline, on which every event relating to treatment can be entered. Events such as consultations, diagnosis, treatment, medication, diet, assessment, teaching and preparing for discharge from the hospital can all be mapped on this timeline. The pathway gives an outline of what is likely to happen on the patient's journey and can be used both for patient information and for planning services.

5.2 For people with long term conditions this raises questions such as:

- Does the patient (service user) perspective and experience concur with that anticipated by the service provider?

[6] *Senior staff in the NHS and social services departments appointed to protect patient information – named following the Report on the Review of Patient-Identifiable Information* Department of Health, December 1997, chaired by Dame Fiona Caldicott.

- Can patients influence their pathways?
- Are they given choices or options?
- Are they involved in developing their pathway?
- Are there barriers to patients taking greater ownership of their care?
- Is cross-agency working (public, voluntary and private) sufficiently integrated? Are there barriers to improvement?
- What would better integration achieve for service users?

5.3 Service users and carers via the TCCP Focus Group have identified a number of themes they considered important in improving patient pathways and the experience of service users:

- GPs having a better understanding of my rare condition.
- Better linking up of services after hospital discharge.
- Joined up out of hours services.
- A recognition that the best care happens at home and with friends.
- Build in breaks / respite as part of care plans.
- Carers being better informed and involved.
- Better feedback to service users, for example, test results and explanations of what they mean.
- Explain the side effects of medication and what to expect.
- Staff understanding better the patient / carer experience.
- Doctors giving informed choices rather than telling patients what will happen and clinicians communicating better with service users.

5.4 These themes are reinforced in the NSFs for Long-Term Conditions[7] and Diabetes [8]. The former includes:

- Quality requirement 1: A person centred service - People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.
- The delivery of this 'core' requirement will improve the co-ordination of services and address many of the key issues service users and voluntary organisations have identified. These include information and the need for a holistic, integrated, interdisciplinary approach to care planning, review and service delivery involving a range of agencies.

[7] Department of Health, March 2005.
[8] Department of Health, December 2001.

5.5 The NSF for Diabetes includes:

- Standard 3: Empowering people with diabetes - All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process.
- Users of the NHS should have choice, voice and control over what happens to them at each step of their care.
- The health professional's role is to ensure that choices are informed by an understanding of, and information about, the risks and consequences of the choices being made.

5.6 The achievement of these NSF good practices would resolve many of the questions and concerns raised by the Project Board and TCCP Focus Group about the lack of service integration.

5.7 The health White Paper, *Our health, our care, our say: a new direction for community services*, also reinforces the points expressed above:

"… people remain concerned about poor co-ordination between health and social care services, and want more support for independent living. Overall, the current interface between health and social care appears confusing, lacking in co-ordination and can feel fragmented to the individual."

"Over a third of those receiving social care had not had a review in the last year. Half of all people with long term conditions were not aware of treatment options and did not have a clear plan that lays out what they can do for themselves to manage their condition better. As a consequence a significant proportion of all medicines are not taken as intended."

"Our aim for people with longer term needs is the same as our aim for all people who use services…… They should be seamless, proactive and tailored to individual needs."

"People need to be treated sooner, nearer to home and before their condition causes more serious problems. Individuals need information, signposting and support, so that they can take control and make informed choices about their care and treatment."

"Where needs are complex, it is essential to identify a skilled individual who can act as a case manager and organise and co-ordinate services from a wide source of providers, following the guidance set out in the National Service Frameworks and the NHS and social care long-term conditions model."

"By 2008 we expect all PCTs and local authorities to have established joint health and social care managed networks and/or teams to support those people with long-term conditions who have the most complex needs. Models for this can already be seen in mental health and intermediate care teams."

5.8 The Project Board propose to use some of the key markers in the White Paper and elsewhere in a checklist for systematic monitoring.

6. Health inequalities

6.1 Health inequality is normally considered in terms of the differences in health status between different groups of the population. Although a multi-factorial issue, access to, and take of services are two important facets and are an overarching part of the whole HOSC agenda. The Project Board believes health inequalities need to be examined as part of this review; however, they are not easy to evaluate for this group of people due to the limited availability of data, something which also affects planning services.

6.2 Questions that the Board wish to pursue include:

- Setting aside their long-term conditions, does this group of people have other attributes that adversely impact on their health status? Are they being addressed?
- Are there geographic or social inequalities in this group of the population that affect their overall health?

6.3 Health inequalities have not been addressed at this stage but should be pursued later in the review.

7. Membership and evidence

7.1 The Project Board comprises Councillor David Rogers (Chairman), Councillor Eve Martin, Councillor Ruth O'Keeffe and Councillor John Wilson and has met twice (November 8th 2005 and February 14th 2006).

7.2 The Board has formed its' views by considering research material and receiving presentations from NHS officers and through feedback from interviews conducted on behalf of the Board.

7.3 Interviewed by the Project Board:-

- Julia Ross, Programme Director, Surrey and Sussex Transforming Chronic Care Programme.
- Fiona Henniker, Chief Executive, Sussex Downs & Weald Primary Care Trust and lead chief executive for TCCP.
- Helen Davies, Programme Manager (Sussex) Connecting for Health, Surrey & Sussex Strategic Health Authority.

7.4 Interviewed by the Project Manager:-

- Judi Dettmar, Quality Officer, East Sussex Adult Social Care.
- Jen MacDonald, Caldicott Guardian, East Sussex Adult Social Care.
- Jessie McArthur, Policy Officer, East Sussex Adult Social Care.
- Peter Manning, Head of E-business, East Sussex Adult Social Care.
- Angie Wadsworth, E-business Team, East Sussex Adult Social Care.
- Isobel Warren, Single Assessment Process Lead, East Sussex Adult Social Care and East Sussex Health.

7.5 The TCCP has established a Focus Group as a means of involving service users and carers in service design. There have been two structured meetings of this Group, both facilitated by the TCCP; the Project Manager participated in both. Some 30 people attended the first meeting and about 50 the second, comprising a mixture of service users, carers, members of Patient and Public Involvement (PPI) fora and service users from the expert patient programme. Whilst it is inevitable that those attending may be atypical of the community generally, the Focus Group seems to be an effective mechanism for generating constructive discussion. Both meetings of the Focus Group have been in Crawley and therefore attracted a Central Sussex population, principally very local [9].

7.6 The Board both welcomes and supports the approach and outcomes of the Forum's work to date. It appears comprehensive in coverage of the issues raised to the point where the Board does not see the need to set up its own panel of service users and carers to identify issues of concern. The Board would however, welcome seeing the venue move around the region to facilitate wider attendance to encourage a wider geographical coverage and check whether there are any significant variations in the issues and views being expressed.

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[9] About half of the people attending the first meeting were from Crawley.