Tameside & Glossop

NHS

Primary Care Trust

Local Care Record Development Board

Update Report

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1. Purpose of this Report

1.1   The purpose of this report is to brief the members of the PCT Board on the role of the Local Care Record Development Board, and its activities to date.

1.2   Under the auspices of the NHS National Programme for IT the NHS has stated its aim to develop an NHS Care Record. The intention, over time, is to enable patients, the public and health and social care staff to access an electronic record containing details of care delivered in all care settings, subject to appropriate access controls.

1.3   In the summer of 2006, Tameside & Glossop PCT decided that it wished to establish suitable governance arrangements that would enable local patients, members of the public and health and social care staff to steer the development and implementation of the NHS Care Record.

1.4   The Local Care Record of Development Board was therefore set up by the PCT under the Chair of Graham Curtis. The role of chair passed to Mike Leigh in April 2007.

2. Objectives

When it was set up in 2006 the objectives agreed by the Local Care Records Development Board were to:

- Identify and promote the values and principles which should govern the development and implementation of the NHS Care Record.
- Promote the development of integrated health and social care records.
- Advise the PCT Board and PEC on the development of the NHS Care Record.
- Ensure that ethical and policy issues, including those concerning security and confidentiality are adequately addressed.
- Represent users of the NHS Care Record, including patients, the public and staff in health and social care, and reflect their views and interests.
- Enable users of the NHS Care Record to be included and engaged in its development and implementation.
- Support an inclusive communications strategy that keeps all stakeholder groups engaged in the development of the NHS Care Record.
- Identify the risks and issues arising from the development and implementation of the NHS Care Record, and to propose solutions to those risks and issues.

3. Membership

3.1   The Local Care Records Development Board includes the following
      stakeholder groups:

- Patients
- Public
- Primary Care Trust
- General Medical Practitioners
- Out of Hours GP Services
- Tameside Hospital NHS Foundation Trust
- Pennine Care Trust
- Tameside MBC
- Derbyshire County Council

3.2   It was agreed that other stakeholders, such as the voluntary and independent
      sector, would be brought into the Care Record Development Board as and
      when required.

4. Achievements to Date

4.1   Rules for Record Access.

4.1.1   In advance of the national NHS plans to provide patients with access
        to their own electronic health record. Some general practices have
        already begun to allow patients to access the electronic health record
        that is held on the GP clinical system.

4.1.2   In order to provide a suitable framework to support this process a
        document entitled The *Rules of Record Access* was drawn up to put
        forward a set of principles to work by. These are based on the *NHS
        Care Record Guarantee*, and on the regulations set down by
        professional bodies such as the General Medical Council.

4.1.3   The *Rules for Record Access* start from the position that the full patient
        record can be shared in its entirety, and that the person recording the
        information should consider how they share the information with other
        health and social care professionals based on the premise that the
        patient will see what is recorded about them. The rules make specific
        reference to the need for health professionals to make clear any
        information that should not be shared with the patient, and also make
        reference to the circumstances where patients might choose to give
        permission for a carer to be able to access their records on their
        behalf.

4.1.4   The *Rules for Record Access* have been discussed extensively by clinicians involved with the Local Care Record Development Board working in primary and secondary care settings and in mental health services, and also with patients and carers. The *Rules for Record Access* have also been discussed with the PCT Clinical Governance Committee.

4.2   Promotion of Patient Access to their Care Records.

4.2.1   At present patient access to the electronic records is limited to two local practices, Haughton Thornley Medical Centres and Manor House. The aim has therefore been primarily to continue to support the patients and clinicians at these practices to support records access whilst identifying issues and clarifying them.

4.2.2   A carer and a mother have come to the Local Care Record Board to present their views on their difficulties with access to the records and to identify ways to enable them to access their records.

4.2.3   A video plays in the waiting room for patients to view whilst they are waiting, informing them about the benefits of patients accessing their electronic records and how to become empowered.

4.2.4   There are magazines available for patients to read that explain the advantages as well as the disadvantages for patient accessing their electronic record.

4.2.5   A practice website (www.htmc.co.uk) has just been established which informs people on what patient access to GP records is and some of the issues surrounding records access. There are videos on You Tube that can be watched which includes a patient perspective as well as a clinician perspective. The website also provides details of the practice and links with other services including NHS Choices, Health Space, NHS Direct and Tameside & Glossop PCT's own website. It promotes an improved lifestyle as well as the Patient Participation Group and local services eg Off the Record or Tameside Citizens Advice Bureau and the Expert Patient Programme. Its aim is to help empower patients to look after themselves better and to use heath resources more efficiently.

4.2.6   It should be noted that in addition to patient access to records, the majority of local General Practices are live with GP to GP Record transfer. When a patient moves from one General Practice to another there used to be delay, often of several weeks, for the paper records to be transferred to the new practice. In most cases the records are now transferred electronically.

4.3   Training Course for Patients

4.3.1   One of the issues raised at the Local Care Record Development Board is the need to try and ensure that as many local residents as possible

are able to take advantage of the opportunities offered by developments in the Internet and in electronic access to information.

4.3.2   The Local Care Record Development Board has therefore worked with Tameside MBC to develop a training course for local people that would raise their awareness of how to use the internet, how to search for information online, and how to distinguish between the information that is available on accredited and non-accredited web sites.

4.3.3   The course is also aimed at helping patients to understand the confidentiality and security implications of accessing the internet, and training them to use the internet to book an appointment online, request repeat medication, and to access their live medical record.

4.4   Guidelines for Information Sharing

4.4.1   The Local Record Development Board has sponsored some work to provide guidelines on sharing and taking care of personal information.

4.4.2   These guidelines have been produced by Information Governance staff from the Primary Care Trust, Tameside Hospital Foundation Trust and Pennine Care Trust, with input from some patients. The leaflet provides guidelines for both patients and staff.

4.5   Secure Transfer of Patient Data

4.5.1   At present patient data is shared between NHS professionals in many different ways. In the long term, the development of the NHS Care Record should enable professional staff to share patient information in a secure environment without the need to send pieces of paper between organisations.

4.5.2   However at present there are many occasions where confidential information is printed out and sent by post from one organisation to another.

4.5.3   The Local Care Record Development Board decided that it wished to explore how technology could support new ways of working that support the delivery of better patient care, whilst taking account of the need to manage the risks that the introduction of new ways of working or different technologies can bring.

4.5.4   It was therefore decided to conduct a small case study to use the NHS Mail System to send and receive patient information that currently goes by post. The care pathway that is the subject of the study is the referral of patients from one General Practice based in Hyde, to the Medical Admissions Unit of Tameside Hosptial.

4.6   Raising the Profile of the Tameside & Glossop Local Health Community

4.6.1   In addition to the work streams referred to above, the Local Care Record Development Board has helped to raise the profile of the Local Health Community.

4.6.2   For example, two of the members of the group are on the national NHS Health Space Reference Panel. In addition to this members of the group have given presentations about the Local Care Record Development Board at national conferences such as the Healthcare Computing 2007 Conference and the British Computer Society's Primary Healthcare Specialist Group 2008 Conference.

4.6.3   One of the members of the group served for a year on the National Care Record Development Board, and has acted a scientific advisor to the conference board for the International Council of Medical Compunetics.

4.6.4   Members of the group are also on an editorial group working under the umbrella of the General Medical Council to write guidance about patients accessing their own records.

4.7   Future Direction

4.7.1   The challenge now is to understand how we can enable other practices to offer access to their records. The IM& T DES is encouraging practices to cleanse their data in preparation for summary care records to be uploaded to the national NHS Spine. We need to further understand what support patients and clinicians need to encourage better take up of access to records.

4.7.2   Since patients are the key people to benefit from access to their records, we need to continue to inform patients and the public along with other work going on inside the PCT and outside it to help reduce heath inequalities and improve health care.

4.7.3   Clinicians need to be supported further to understand why it is also in their interests to let patients see their records and how it ultimately benefits them and the local health and social community.

4.7.4   We need to link better with the needs of our partner organisations and their objectives so that there is a more coherent local health and social community plan, which the Local Care Record Development Board can link into, and support.

4.7.5   The Local Care Record Development Board has recently been allocated a budget of £20,000 by the PCT, and the group is currently looking into how that should be invested to support the aims set out section 2 of this report.

5. Conclusions

    5.1   The PCT Board is asked to note this report on the work of the Local Care Record Development Board