

**PATIENT INFORMATION ADVISORY GROUP**

**Meeting on 28 April 2004 to Discuss the NHS Care Records Service**

**REPORT**

**Introduction**

The Patient Information Advisory Group met on 28 April 2004 to discuss the NHS Care Records Service (NCRS). Advisory Group members present at the meeting were: Professor Joan Higgins (in the Chair), Professor Michael Catchpole, Professor Sir Cyril Chantler, Ms Barbara Meredith, Professor Sir Denis Pereira Gray, Ms Karen Thomson, and Dr Michael Wilks. In attendance at the meeting were: Professor Martin Severs (Chair of the Information Standards Board); Mr Phil Walker, Mr Sean Kirwan and Ms Viki Lowther (all from the Department of Health), Ms Marlene Winfield and Mr Andy Truscott (from the National Programme for Information Technology); and Mr Peter Singleton.

**Purpose of the Meeting**

It was intended that the meeting would:

- Update the PIAG on progress made by the National Programme for Information Technology (NPfIT)
- Reassure the PIAG that patient information held on the NCRS would be processed according to the requirements of the law
- Consider how the PIAG and National Programme would work together more effectively

**The National Programme for Information Technology**

Ms Winfield reported that extensive research had been undertaken by the NPfIT into the views of patients and clinicians about the use of electronic systems to process patient information and the implications this might have for confidentiality. This work had involved:

- Explaining how systems might work in the future
- Consultation
- Finding out how to take account of concerns about patient confidentiality
- The publication of a NHS Code of Practice on Confidentiality
- The development of an Information Sharing Guarantee

Mr Truscott reported the “spine” of the NCRS would be a conduit to allow clinicians to drill down into particular episodes of care. Access controls would be based on the

doctor/patient trust model. Professor Severs added that the infrastructure of the NCRS would mean that the following controls would be technically possible:

- Information would be placed on the spine. Clinicians would be able to access data held on the spine through use of a smart card obtained through a robust registration process.
- Patients and their clinicians could opt to place information about some health care episodes in a sealed envelope so that it could only be accessed by other clinicians with the informed consent of the patient.
- Some information could be recorded locally and not be available through the spine – so that in effect it could be accessed only by the clinician with whom the patient had direct contact (eg the GP).

### **Implementation Schedule**

Mr Truscott said that it was intended that systems would be established but would not be utilised until a public information campaign had taken place. It was intended that as part of the communications strategy trigger points would be identified, and that patient information would be placed on the spine when these had been reached.

The first releases from the NPfIT would begin in June 2004, these would include: ability to record patients' consent preferences; piloting of the Secondary Uses Service, including NWCS message flows; ability to create and send birth and death notifications and eBS referrals. By the end of 2004 it was intended that the spine could be accessed and that the infrastructure would be available to begin creating national care records; there would be the ability to create and send a range of messages including - allergies and adverse reactions, out of hours service, generic clinic letter, discharge letter/summary, pathology results, diagnostic imaging and GP to GP transfer. By mid 2005 full Secondary Uses Service messages would be created and sent, enabling the provision of pseudonymised/anonymised information.

The Electronic Booking Service (eBS) would go live in 2 local service provider (LSP) clusters in June 2004, and would involve 100,000 patients by the end of the year. The Electronic Transmission of Prescriptions (eTP) service would go live in December 2005.

### **Key Issues**

Mr Walker advised the PIAG that the NCRS had been developed to ensure that it was fully compliant with the requirements of the Data Protection Act and the common law on confidentiality. Patients would have the right to review their records locally and to seek corrections when they believed errors had been made.

The Advisory Group accepted these assurances but agreed that further work would be required to ensure that clinicians processed patient information in an ethical way. It would be important to reassure patients that the NCRS would be designed in order to maintain patients' trust. This would require the development of a 'confidentiality culture' where clinicians routinely discussed with patients the key information that needs to be recorded for their own safety. Clinicians would then enter into a process of negotiation with patients to agree what additional information, if any, should be recorded on the spine.

Since there would be shared control of the NCRS it would be important to establish who would be responsible for breaches of confidentiality of the DPA – how could a patient identify an appropriate organisation against which to complain and seek redress?

The Advisory Group agreed that it would be necessary to have an integrated information campaign for NHS staff and patients. It was essential to ensure that clinicians were made aware of how the new systems would work and what their responsibilities would be. This would require:

- the provision of adequate resources to enable existing staff to be properly trained to use the new systems
- changes to the undergraduate curriculum for doctors and other clinical professions
- acknowledgement by NHS managers that consultations will take longer as clinicians negotiate with patients about information to be recorded in or made available via the NCRS

This would have fundamental consequences for clinical practice and the Advisory Group recommended that the NPfIT establish a partnership with the medical Royal Colleges.

It was also essential that the Department of Health should develop an Information Governance policy for the NPfIT in order to identify and promote good practice. In addition further thought would need to be given to the role of PIAG in providing oversight.