RCN e-Health programme

Policy Briefing 09/2008

e-Health and nursing practice:

Consent to access, share, and create e-Health records

Background

The electronic patient record is a UK wide initiative although each country has adopted a different approach to its construction and they are at different stages of development. You can find out what is happening in your country by visiting their websites:

Scotland: www.ehealth.scot.nhs.uk/ or
                www.nmahp.scot.nhs.uk/home/about-the-nmahp-ehealth-mkn.aspx
Wales: www.wales.nhs.uk/IHC/home.cfm
England: www.connectingforhealth.nhs.uk/
N Ireland: www.dhsspsni.gov.uk/ict-strategy.pdf

The first phase of the work is the record which will enable clinicians who treat patients in situations such as "out of hours" services or Accident and Emergency departments to have available the information that they need to make decisions at the point of care. This record is variously called (in England) the "Summary Care Recordt of 325 T0t7EuEmergenry Caho

What is consent?

Consent is the means by which an individual authorises interventions in their own care. Nurses are used to this concept in relation to consent to treatment: the same principles apply in relation to consent about electronic records. For consent to be effective it must be 'informed'; the consenting individual must have received sufficient information appropriate to their particular circumstances. They must be competent and understand the nature, risks, benefits and alternatives associated with the proposed intervention. It is also important that their decision is made independently, free from interference or coercion.

Although the creation of an electronic patient record does not in itself create unique ethical concerns - information management in whatever form demands rigorous ethical standards - a particular cause for ethical concern is the need to ensure informed consent to the creation of an electronic record and to the sharing and storage of personal information in this form.

In general, patients and clients should be informed of:

- what kinds of information are being recorded and retained;

- the purposes for which the information is being recorded and retained;

- what protections are in place to ensure non-disclosure of their information;

- what kinds of information sharing will usually occur;

- the choices available to them about how their information may be used and disclosed;

- their rights to access and where necessary to correct the information held about them on paper based and paper-less records.

They should be given an opportunity to discuss the implications of withholding consent or objecting to specific uses of information and their objection must then be recorded and respected. At the same time patients must be reminded that it is the responsibility of the professional to hold and record their action in whatever system is being provided for that purpose, including and electronic patient record.

The RCN's view is that it is therefore essential that relevant information is available that enables patients to make a considered decision. Nurses have an important part to play in ensuring that this happens.

Key issues_C

The key issues for nurses are:

- Patient consent to inclusion of their data in an electronic record

- Who can have access to a patient's electronic record

- Sharing a patient's record with others

- Using aggregated data for management and planning (secondary usage)

Consent to create a record
The NHS has the legal authority to create systems for recording patient information in either written or computerised format at a local or national level. This does not require an individual's express or implied consent. Therefore whilst patients may choose to opt out of their details being uploaded to the SCR, they cannot prev

- "Opt-out": where consent is presumed, unless the patient explicitly refuses

- "Hybrid": a mixture of the two.

The four countries of the UK have agreed to include different data elements in the SCR/ECR, and have adopted different ways of dealing with this issue.

In Scotland all patients have an Emergency Care Summary which has a two-tier or hybrid consent model. There is implied consent to the creation of an Emergency Care Summary record, with the ability to opt-out, and express consent to access except where extreme circumstances (e.g. an unconscious patient) mean that NHS staff may look at an Emergency Care Summary without consent to enable the best possible care. Other electronic records are being developed that will be linked, including a National Primary and Community Care System, a Patient Management System for acute care and a Generic Clinical System that is being developed by NHS Dumfries and Galloway to enable community nurses and AHPs record patients' care plans into an electronic health record. The new Scottish Government e-Health strategy to be published in summer 2008 is expected to demonstrate how existing information and systems will be brought together, whilst ensuring a focus on protecting confidentiality and security of patient information.

In Northern Ireland it is anticipated that the electronic health record will become operational regionally in 2011 in the context of a combined health and social care service. Some general practices are already using electronic patient records and these are also being rapidly developed as part of the Integrated Care and Treatment Services (ICATS) initiatives. The Northern Ireland government has recently announced that its Emergency Care Record will follow the Scottish model, including the Scottish procedures for consent.

In Wales, following consultation with patients and professionals, the "Opt-out", position is used, with additional safeguards for the inclusion/exclusion of particular data, and for the patient to give or refuse consent to a professional to access the record at the point of care (consent is assumed only in emergency e.g. where a patient is unconscious or otherwise unable to indicate consent)

In England the position is still being discussed. However, in the places where the SCR is currently being piloted (the "Early Adopter Sites) the "Opt-out" position is being used and the data to be included is limited to the following information:

1. Allergies, adverse drug reactions and recent prescriptions, described as "life-saving" information, derived from the patient's GP record. This information will be placed on the SCR when it is created;

2. More detailed information about basic medical history, key operations and procedures, physiological and lifestyle details, which can subsequently be added to the SCR, again derived from the GP record; and

3. Basic details of hospital visits including discharge summaries, outpatient clinic letters and A&E summaries, which can be placed on the SCR from 2008

These decisions apply at this stage only to the SCR/ECR. As these records are expanded by the inclusion of more patient data, further discussion and decision will be required, especially about managing "sensitive" information such as mental health or sexual health issues. It is for this reason that nurses need to understand the issues involved and to be able to participate in the debate.

The RCN position is currently that it supports the "opt-out" model, provided that there are sufficient safeguards for the inclusion/exclusion of "sensitive data" and for access to the record at the point of care

Consent to Access: Who can see a patient's record?
Access by health professionals to electronic patient records should be very strictly controlled on a "need to know" basis. This means that some people can have access to the full record, others to the part that is relevant to them.

In all cases the RCN recommends that access should require use of a password, and the system should maintain an audit trail of who has accessed the record and when. You must have your own unique password which you must NEVER reveal to, or share with, anyone else.

The systems for managing access vary slightly from country to country. For example, in Wales, even where the patient has previously given full consent, the system prompts the user to ask the patient's consent before opening the record. There are special procedures when a patient is unable to consent e.g. if s/he is unconscious.

In most cases, patients have the right to see their records (computerised or paper-based) and there are national guidelines which your employer will

have implemented locally. However, this right does not normally extend to the patient's relatives, unless the patient consents.

The RCN believes that it is very important that you are familiar with your local procedures and are able to explain them to patients. Supporting patients who wish to see their record, and explaining and interpreting the information they contain, is an important part of the nurse's role.

Consent to share a record: with patients

It has long been considered good nursing practice for nurses to share their records with patients: in some fields of practice (e.g. child health, district nursing, midwifery) patients already hold their own records. The RCN supports this practice and wishes to see it extended.

The systems now being developed in the NHS in all four UK countries include provision to enable patients to access and in some cases to add to (but not change), their records on-line at any time.

Consent to share: with other people

Sharing information about patients generally is a highly sensitive and complex issue which is beyond the scope of this document. Information may be shared among the people directly caring for a patient at a particular point in time, across health sectors (e.g. when a patient is discharged from hospital), or across agencies (e.g. social services).

Maintaining confidentiality and protecting a patient's privacy is governed by legislation, by professional codes of conduct (e.g. the NMC Code of Conduct) and by explicit procedures which were established following the 1997 Caldicott Report. You can find details about these arrangements on the Department of Health website[3].

The most up-to-date guidance on patient confidentiality is provided by the NHS Confidentiality Code of Practice (England), and the RCN has published separate guidance on competencies for sharing information which can be downloaded from the RCN website[4].

The RCN believes that sharing information about patients is an integral part of nursing and multi-disciplinary care: no one person can provide all the care required all of the time, and communication of relevant information to other carers is essential for patient safety and continuity of care.

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[3]www.dh.gov.uk/en/Managingyourorganisation/Informationpolicy/Patientconfidentiality andcaldicottguardians/index.htm
[4] www.rcn.org.uk/development/publications

Using aggregated data for management and planning (otherwise known as 'secondary usage')

Data relating to many patients (sometimes thousands of patients or episodes of care) which has been anonymised and aggregated, is used for management and planning purposes such as clinical audit, quality monitoring, identifying outcomes and best practice, service planning and resource management. This is called "secondary usage".

The RCN believes that this data should be obtained as a by-product of the data obtained for the primary purpose of the patient's care. It supports the goal of "Record once, use many times for multiple purposes". However the RCN is concerned to ensure that the data obtained and stored includes relevant nursing data as well as medical and administrative data, and has published standards for the nursing content of electronic patient records[5].

When patient data is to be used for a specific research project, special conditions apply – for more information on research consent in research, please refer to RCN guidance 'Informed consent in health and social care research'[6]

Acknowledgements
This briefing was produced with contributions from the following:

- Information in Nursing Forum
- RCN Information and Knowledge Management Department
- RCN Professional Nursing Dept
- RCN Policy Unit (inc. RCN Scotland, Wales and Northern Ireland)

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[5] For position statement on nursing content of EPRs, see www.rcn.org.uk under e-Health
[6] www.rcn.org.uk/__data/assets/pdf_file/0010/78607/002267.pdf