



Consent to create, amend, access and share eHealth records



Introduction



Record keeping is an essential element of nursing practice; it is an important method of communication, is used to monitor the quality of patient/client care, and serves as a legal record of a practitioner's care.

The principles of good record keeping in nursing are well established and apply equally to computerised or paper records¹. The RCN supports the introduction of electronic records, but is concerned to ensure the protection of both patients and nursing staff (nurses and other health care workers) in their use².

As electronic records become increasingly commonplace nursing staff need to familiarise themselves with the key concerns associated with their use. Many of these relate to issues of consent – what information is going to be included, who will see it, who it will be shared with, and what rights apply.

The governments of all four UK countries have produced and publicised information for patients/clients about their rights and the answers to these questions. This booklet has been prepared to clarify the RCN position on these issues, and to help nursing staff to understand the issues and their responsibilities so that they can help patients to make choices in relation to their personal records.

It sets out basic principles, and offers guidance to front line practitioners involved in making decisions about their own use of electronic patient records, and who have responsibility for explaining the position to patients and helping them to make their decisions.

The booklet is framed around several principal questions that practitioners might have about using electronic patient records, but it does not provide an exhaustive review of all the issues. For ease of reference, key RCN position statements are highlighted.

While the examples shown in this document may refer to the National Health Service (NHS) in the UK, the principles illustrated are also relevant to other sectors (such as the independent sector), as well as health care organisations operating in other countries.



Background

The electronic patient record is a UK-wide initiative that applies to both the NHS and the independent sector.

Within the NHS, each UK country has adopted its own approach to the electronic patient record and all are at different stages of development. You can find out what is happening in your country by visiting the relevant website:

Scotland

www.ehealth.scot.nhs.uk

Wales

www.wales.nhs.uk/ihc

England

www.connectingforhealth.nhs.uk

Northern Ireland

www.dhsspsni.gov.uk

Although there are differences in how electronic health records are being developed at a national level, all four UK countries have identified two main types of electronic patient record:

- one type includes detailed information about an individual's health – the linking together of different records (such as hospital records and community records) will allow clinicians who work together to access relevant detailed information about the care of individual patients
- a second type draws on summary information from more detailed records – this allows clinicians treating patients in out-of-hours services or A&E departments for example, to have the essential information they need to make decisions at the point of care. This record is known as the 'Summary Care Record' in England, the 'Emergency Care Summary' in Scotland, the 'Individual Health Record' in Wales, and the 'Emergency Care Record' in Northern Ireland.





What is consent?

Consent is the means by which an individual authorises interventions in their own care. Nursing staff are used to this concept in relation to consent to treatment, and the same principles apply in relation to consent regarding electronic records.

For consent to be effective it must be 'informed'. This means the consenting individual must have received sufficient information appropriate to their particular circumstances. In addition, 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:

- the kinds of information that are being recorded and retained
- the purposes for which the information is being recorded and retained
- the protections that are in place to ensure non-disclosure of their information
- the kinds of information sharing that 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.

Patients 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 record their action in whatever system is being provided for that purpose, including an electronic patient record.

The RCN's view is that it is essential that relevant information is available to enable patients to make a considered decision. Nursing has an important part to play in ensuring that this happens.



What are the key issues around creating, amending, accessing and sharing records?

What are the key issues around creating, amending, accessing and sharing records? Consent issues – all of which have direct or indirect implications for nursing – are associated with the following activities:

- creating an electronic record
- deleting a record
- amending a record
- including data in summary/emergency records
- determining who can access a record
- sharing records
- the use of aggregated data for management and planning (secondary use).

Creating an electronic record

The NHS has 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, and a patient cannot prevent the creation of a paper or electronic health record.

Deleting a record

Patient records have to be kept for a certain time. The minimum retention periods for paper and electronic health records in the NHS vary according to a number of factors – which include which country you are in, and what type of record it is.

Regardless of your local country directive, a clinician should never destroy a patient record. At the close of the minimum retention period a local records manager will decide whether to retain a record further or to destroy it.

Amending a record

Information should never be completely erased from an electronic health record. Electronic health record systems should automatically keep an audit trail of any changes: what was changed, when and by whom.

In rare cases where information is removed from a record, it is expected that an explanation should be provided in the record (what, why, when, and by whom).

In cases where a patient disagrees with the content of their record, a note should be added to indicate the concerns of the patient or to indicate that a correction has been made as appropriate (what, why, when, and by whom).

Further guidance is available from the NHS (England) Information and Governance Board for Health and Social Care³.

Including data in summary/emergency records

The four countries of the UK include slightly different data elements in their NHS summary/emergency records. However, all four countries have adopted similar ways of dealing with consent, which will take one of two forms:

- explicit consent or 'opt-in' – where the record can be created and data included only with the expressed consent of the individual patient
- implied consent or 'opt-out' – where consent is presumed, unless the patient explicitly refuses.

In all four countries there is implied consent to the creation of the summary/emergency record (Summary Care Record, Individual Health Record, Emergency Care Summary, or Emergency Care Record) with the ability to opt-out and explicit consent

to access except in extreme circumstances (for example, an unconscious patient). In Scotland, there is the possibility to opt-out of the uploading of information to the Emergency Care Summary.

In England, if patients give explicit consent to the creation of a Summary Care Record then this currently assumes consent also for enrichment of the record beyond medications, allergies and adverse reactions.

In Wales, patients have the option of both opting-out and rejoining the programme.

The RCN position is that it supports an implied consent or 'opt-out' model, provided that the consent is informed, and that there are sufficient safeguards for the inclusion/exclusion of sensitive data and for access to the record at the point of care.



In cases where information included in a patient's summary/emergency record is subsequently found to be inaccurate and has been corrected in the originating system, then systems should be in place to correct the information in the summary/emergency record.

Determining who can access a patient's record

Electronic patient record systems should allow only authorised people involved in care to have access to a patient's record; and to have access only to those parts of the record that are needed for care.

This means that some people can access the full record, while others will only be able to access the part that is relevant to them. To achieve this, a number of safeguards need to be put in place.

For example, NHS Care Records Service systems can only be accessed using a smartcard and a password (and only by people who have a good reason to access a patient's record). The smartcard includes information about the owner's role, and this information is used to determine the level of access. The electronic health record system audit trail will maintain a record of who accesses each record and when, and any entries that were made. Other services in other countries may vary in their approach but will have a similar degree of rigour.

In all cases the RCN recommends that access should require use of internationally agreed security measures, and the system should maintain an audit trail of who has accessed a record and when and any entries that were made. As technologies such as smartcards and passwords are associated with practitioners as individuals, they must never be shared with others.

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 consents⁴.

The RCN believes that it is very important that practitioners are familiar with local procedures associated with patient's rights to viewing their own records 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 nursing.



Sharing a record

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

The systems now being developed within 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.

Sharing information about patients with others 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 (for example, when a patient is discharged from hospital) or across agencies (for example, social services).

Maintaining confidentiality and protecting a patient's privacy is governed by legislation, by professional codes of conduct (for example, the Nursing and Midwifery Council's Code of Conduct), and by local and national policy and procedures⁵.

The RCN believes that sharing information about patients, subject to appropriate safeguards, 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.

Using aggregated data for management and planning (secondary use)

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 use'.

The RCN believes that data for secondary use should generally 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 records⁶.

Note that when patient data is to be used for a specific research project, special conditions apply⁷.



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- 1 Nursing and Midwifery Council (2009) *Record keeping: guidance for nurses and midwives*, London: NMC. Available from www.nmc-uk.org
- 2 RCN members can access resources relating to information disclosure from the Learning Zone section of the RCN website at www.rcn.org.uk
- 3 National Information Governance Board for Health and Social Care (2010) *Requesting amendments to health and social care records: guidance for patients, service users and professionals*, London: NIGB. Available from www.nigb.nhs.uk
- 4 Comprehensive information relating to the access of health records is available from the UK Department of Health website at www.dh.gov.uk
- 5 Detailed information and resources relating to patient confidentiality are available from the UK Department of Health website at www.dh.gov.uk
- 6 Royal College of Nursing (2008) *Nursing content of electronic patient / client records*, London: RCN. Available from www.rcn.org.uk
- 7 Royal College of Nursing (2007) *Informed consent in health and social care research*, London: RCN. Available from www.rcn.org.uk





Find out more and get involved

The Royal College of Nursing supports the direction of travel of eHealth in each of the four UK countries. And we recognise that the people who use IT are key to realising its potential.

For more information on eHealth, and to discover how you can get involved, visit the RCN's eHealth and Information in Nursing (IN) Forum web pages at the RCN website www.rcn.org.uk/ehealth

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

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