Clinical data standards and nursing

Alison Wallis describes the importance of nurses becoming involved in the development of data standards for e-health systems

Alison Wallis RGN, DNCert, BSc, MSc, is a nurse adviser at the National Clinical Dataset Development Programme, NHSScotland

FOR ALMOST all of us, computers have become commonplace. We not only use them when shopping, banking or making travel arrangements but, as all four UK countries have introduced national information and communications technology (ICT) programmes, they are now integral to our health care.

Although the names and methods of introducing ICT programmes used by UK healthcare services may differ, their aims are consistent: to deliver integrated clinical information to help ensure high quality patient centred care.

This article describes the benefits to nurses of ICT programmes, the challenges they offer, and the importance to them of data standards. It also studies the work of the National Clinical Dataset Development Programme (NCDDP) in Scotland.

The importance of e-health

The communicative and technological aspects of ICT as it relates to health care, including electronic patient records, healthcare decision support systems and the use of short message service (SMS) text messages in health care, is often referred to as ‘e-health’ (RCN 2006a).

Nurses are becoming more aware of e-health and, according to the RCN (2006b), are generally supportive of its contribution to patient care, particularly its ability to offer ways of sharing patient information, and the access it provides clinical data for benchmarking and audit.

If these benefits are to be achieved however, they must be underpinned by a standardised infrastructure. Clinical data standards are part of this infrastructure in that they ensure that the data in electronic systems are standardised in order to ensure interoperability of systems (Ozbolt 2004).

Data standards are sets of rules that impose structure on information so that its meaning and format are the same regardless of who views it or what kind of information technology (IT) system they use to access it.

To understand this, we can compare data standards to rules, such as those in grammar or traffic regulations, that are found in everyday life (California Healthcare Foundation 2004).

To use another example, in a dictionary, many words are shown to have more than one meaning. In clinical workplaces however, such an array of meanings would be confusing and could have potentially dangerous consequences. It is important therefore that, in such situations, each clinical term or phrase used has a single definition.

Data standards in Scotland

The NCDDP was established in 2003 to develop clinical data standards that would support clinicians in Scotland. These standards are an essential element for example of electronic health records, which have a central role in NHS Scotland’s e-health and other healthcare strategies.

Although the approach taken by the NCDDP is unique in the UK, the programme’s clinical director works closely with colleagues from the other three UK countries to ensure that there is general agreement on the form that e-health developments take and that the development of data standards moves in the same direction.

With the exception of GP systems however, use of electronic records in Scotland is patchy, and the support that different e-health systems offer to nursing care varies.

The programme’s principles are that clinical data standards support direct patient care, that development of clinical datasets is led and informed by clinicians, that this development is based on best practice guidelines and research, and that patient care information can have ‘secondary use’.

To achieve this, short-life working groups comprising relevant clinicians and agencies are established to develop sets of data standards for different areas of development.

Once a set of standards has been devised, there is a consultation period of up to six weeks during which a wide range of clinicians and organisations ensure that it is fit for purpose and can benefit patient care.
Areas of development for which data standards have been devised so far include cancer, coronary heart disease, stroke, diabetes, child health and mental health. Of these, standards pertaining to diabetes and cancer are already being implemented in national and local e-health systems throughout Scotland.

In the past year, nursing data standards for core assessment, continence and palliative care have been completed, and work is continuing on other data standards for nurses and allied health professionals.

Data standards developed by different working groups can be interoperable so that palliative care and cancer data standards for example share some data items.

Published data standards are available for viewing online in the Health and Social Care Data Dictionary, at www.datadictionary.scot.nhs.uk, and further information about the programme is available on the NCDDP website, at www.clinicaldatasets.scot.nhs.uk

Some nurses may regard the concept of data standards as detached from patient care, but there are good reasons why nurses should at least be aware of them and, at best, involved in their development. After all, the benefits of data standards accrue to nurses at all levels, whether they work in direct patient care, in unit management or at health board level.

Supporting care

At present, patients’ health records are often held in many different locations, in paper or electronic form, so that sharing their content between healthcare professionals in different locations is almost impossible.

The goal of NHS Scotland is for all aspects of patient care, including assessments, care plans, interventions and communications documented by the relevant clinicians, are recorded electronically. Such records can be stored, not on a single clinical information system, but on several interacting systems.

To ensure that this information can be accessed by professionals of different clinical disciplines in different geographic locations therefore, the same data standards must be used.

For example, a patient’s height may be measured in metres and centimetres in one record but in feet and inches in another. In order for this patient’s record to be shared between different systems therefore, a standardised measure of patient height is required.

In addition, the different but linked systems containing patient records must be accessible from different locations simultaneously so that, for example, a physiotherapist looking after a patient in ward A of a hospital can, subject to clinical need and confidentiality safeguards, add to this patient’s record from a different location via a physiotherapy system, at the same time that a nurse accesses the same record on the ward system to update it.

Interoperability of systems

The information that makes up patient records usually originates from different sources, such as GP or hospital records, laboratory or imaging results, or the patients themselves and their families.

To ensure that patient records are complete and accurate, such information must be gathered together and shared among clinicians, and the use of data standards allow this to be done.

Such sharing of patient information between systems allows for example ward nurses to view summaries of community nursing records for patients being admitted to hospital, or alert relevant staff to drug risks.

Meanwhile, the management of patients with long term conditions in their own homes can be supported by e-health records that are accessible to care providers, including social care providers, who contribute to the day-to-day management of patients and clients (Lunney et al 2005). Data standards can also support links to systems used for workforce planning, allowing the best use of nursing resources.

Secondary uses of patient information

Information recorded for patient care purposes can be re-used in various ways to benefit patients and increase nursing knowledge.

At the care provision level for example, nurses can obtain data on their patients’ wound healing rates, and compare these with data from other areas, or with national statistics.

Similarly, nurse managers can use clinical quality indicators recorded during the care process to flag up areas for further investigation, such as high infection rates in specific wards, or to monitor the effectiveness of interventions (Casey et al 2006).

Other secondary uses of patient information include the monitoring of clinical services by local and national NHS organisations to gather data on healthcare trends that can be used to predict future service requirements.
Data standards are needed in this however because, to understand and compare care outcomes, information must be clearly defined and consistently used and interpreted.

As Radford et al (2007) suggest: 'The development of quality performance measurement initiatives has further raised awareness among the professional community regarding the importance of data standards. For the first time, a wide audience, including non-medical professionals may draw conclusions about care and outcomes.'

Clinicians used to writing patient records on paper are often concerned that a move to electronic record keeping will constrain the use of descriptive language and therefore the amount of information that can be recorded (Walsh 2004).

The ability to use meaningful words is, according to Ballard (2006), 'the reason why many nurses are more comfortable using paper records and their own notes rather than the reduced and simplified structure of computer records'.

Of course, consistency of spelling, meaning and format cannot be guaranteed in written texts, so it is important to strike a balance between the benefits of descriptive narrative and those of using standardised text.

Data standards must meet the needs of their users, and the terms used in them must make sense within patient records. Gaining consensus in this from a wide range of users presents the NCDDP with a considerable challenge.

Nurses and data standard development

Nurses in Scotland can be engaged in data standards in several ways: through their involvement with working groups, by responding to consultations or by implementing standards in clinical information systems.

Nevertheless, there are only limited opportunities for front line nurses to be released from their clinical areas to take part in the development of data standards. This may have severe implications for their use by nurses, as the quality and appropriateness of data standards can be put at risk without sufficient involvement of clinical staff.

According to anecdotal evidence, nurses who have been involved in data standard development working groups benefit from their improved understanding of e-health and become better able both to communicate the importance of standardised information in electronic records to their work colleagues and managers and to influence the form taken by electronic records to meet their needs.

By allowing their nurses to become more involved in the development of data standards, healthcare organisations will not only benefit from there being better data for service planning, but will also acquire a more IT-aware workforce when e-health systems are implemented.

Patients will also benefit because, as their records become more accessible to clinicians, they will become safer, while the secondary uses of patient care information will improve care for all.

Conclusion

The benefits of data standards are: the improved availability of clinical information to follow patient journeys; an enhanced ability to share this information between relevant clinicians; the use of consistent clinical terminology to make complete, legible, accurate and up-to-date records with explicit clinical meaning; and the availability of better data for secondary use.

Data standards make up a small but important part of e-health and, at first sight, do not appear to have a great impact on nursing. But the ability to use and share the information contained within electronic patient records depends on data standards, and nurses must be involved in their development to ensure that data standards reflect their professional needs

References


RCN (2006a) Putting Information at the Heart of Nursing Care. RCN, London.
