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Information System for Clinical Organisations: from Hospital Information System to a Sustainable National Service for Treatment and Long Term Research in Wales

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Abstract

Information System for Clinical Organisations (ISCO), originally developed as a clinical information system at the Velindre Cancer Centre in South East Wales, is now an All-Wales Electronic Health Record, primarily for cancer, serving 1000 users in 43 sites across Wales. Clinical information in ISCO is shared across organisations in Wales, improving communications between healthcare professionals and smoothing the patient pathway from referral to secondary care through to diagnosis, treatment and death. Data collected in the system is used to inform audit and research which in turn require the system to adapt. ISCO has proved to be a sustainable system in the medium term and its longer term sustainability should be assured by developments for Informing Healthcare.

Keywords:

Medical Records System, Computerised,
Hospital Information Systems,
Management Information Systems

Introduction

The Information System for Clinical Organisations (ISCO) is an Electronic Health Record (EHR) for cancer and other diseases across Wales, a principality within the United Kingdom. Designed to meet the audit needs of clinicians at Velindre Hospital in 1991, development of ISCO has always taken place with the full participation of clinicians and other users, as advocated by Protti [1]. Regular User Group meetings are held and ISCO has always had the support of the cancer centre management since its inception, ensuring financial stability.

A single casenote, multiple provider model was implemented in 1997 to meet users' and other organisations' needs, including palliative care [2]. ISCO as an EHR was born. Users may see a summary of patient care wherever it has taken place in Wales. For cancer patients the entire cancer history from screening to diagnosis, treatment and death is available. This is an individual health record event model as envisaged in the national information management and technology strategy[3].

The Cancer Information Framework has driven expansion of ISCO to include the All Wales Tumour Site Specific Cancer Datasets [3]. Cancer Services Units in hospitals across Wales collect cancer dataset information, for which purpose the system is known as Cancer Network Information System Cymru (CaNISC)[3]. Cancer data sets are used to monitor adherence to Cancer Standards and the statutory cancer waiting times.

ISCO now has 1000 users across 43 sites in Cancer Services, palliative care, Wales Cancer Trials Network, Wales Cancer Genetics, Wales Cancer Bank, Cervical Screening Wales for Colposcopy and Welsh Movement Disorder e-Network in South East Wales. There are over 338,000 individual patient records in the database.

Methods

System development and delivery

The prototyping approach is used for development where a working model of a new system module is given to users to evaluate, allowing early identification of any problems. The model is then improved incrementally according to the users' needs, as advocated by Heeks [4].

Requests for system developments, systems analysis, training, information and support needs are all met by the Clinical Information Unit (CIU) at Velindre Hospital where the critical nature of the application is well understood.

As "interoperability is the key... issue" [5], national and international standards are used where possible. There are plans to move to SNOMED CT coding in the near future.

As many organisational numbers as necessary can be stored for each patient as well as the NHS number. A unique internal system identifier and a rigorous registration process, using links to other patient databases, keep duplicate patients at a very low level.

The data structure is patient based, with logical separation of each care provider's information allowing a security model where system users can access the information they need but only edit information added by their own organisation.

Users outside of the hospital access ISCO via a web browser client. Access to the system is controlled by an authorised signatory system. Users receive training appropriate to their role before being issued a password to access the system.

Information use

The database structure allows reporting at the individual clinician level through to multi-disciplinary team, organisational and national level. Participation in United Kingdom national audits is possible by extracting the appropriate data. A set of data analysis tools allow users to validate data, perform their own analyses using a pivot table and run reports without understanding the underlying data structure. Ad hoc requirements are provided by CIU.

New innovations

Several innovative strands of work are underway in ISCO that should ensure the system's longer-term sustainability:

- a Multi-Disciplinary Team (MDT) module, supported by Informing Healthcare, enables attendance at meetings, patients listed for discussion, relevant patient information and the outcome of the discussions to be viewed and recorded
- pathology Integration and Electronic Sign Off of Results are automatically downloaded into ISCO using HL7, which is a healthcare messaging standard
- ISCO Today Sidebar, an alerter system, tailored to users, enabling them to be pro-active rather than reactive with patient pathway management and care
- an anonymised link between ISCO and The Wales Cancer Bank [6] database will allow future researchers to use clinical information matched to tissue samples from patients contributing to the development of more effective, targeted treatment for cancer.

Discussion and conclusions

The major challenges of a multi-purpose (clinical, administration and audit), local and national system are:

- organisational: robust administration processes need to be in place before new modules are implemented
- reconciling local versus national requirements
- data accuracy and consistency across all teams and organisations
- difficulties getting agreement for sharing data electronically between organisations.

Overcoming these problems has however encouraged closer working between all organisations involved.

ISCO has proved to be a sustainable system in a rapidly changing environment by:

- continually evolving to meet users' needs, with regular user group meetings
- being developed within a team that also provides users' information needs, training and support
- enjoying the support of local and national management
- providing good quality information
- investigating organisational issues before the release of new modules.

The linkage of present clinical information at a national level with future research as with the Wales Cancer Bank provides an important lesson for future sustainability. ISCO/CaNISC is to be mandated for collection of the cancer datasets and cancer waiting times within Wales and taken together with the support of IHC and the view that it is 'an EHR for Cancer' [3] should ensure its long term sustainability.

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