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Primary care oncology: addressing the challenges

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ABSTRACT

The last decade has seen an emerging clinical discipline known as ‘primary care oncology’ that describes the involvement of general practitioners (GPs) in preventing, diagnosing, treating and following up patients with cancer. This paper reports the experience of our team in investigating the information required to develop a shared electronic care record system to link GPs and cancer specialists in Wales in order to facilitate information sharing between them in a timely and effective manner. It identifies a potential minimum dataset that can provide the basis for the development of a Welsh primary care cancer dataset. It also addresses the associated challenges to be overcome at implementation, namely information, technical, cultural/organisational and management challenges.

This work is a collaboration between the Department of Computer Science at Cardiff University and Velindre NHS Trust, the South East Wales Cancer Centre.

Keywords: cancer dataset, electronic patient record system (EPRS), primary care oncology

Introduction

Improving the quality of the information transferred between general practitioners (GPs) and hospital specialists has been an ongoing challenge with an impact on the value and safety of patient care. Since 1998, the Information for Health strategy highlighted many problems affecting the efficiency of this transfer, including:

- the absence of comprehensive nationally agreed standards and protocols for the capture and communication of clinical information
- the lack of a common record structure and terminology.

Yet, there is considerable diversity in the design and implementation of primary care electronic patient record systems (EPRSs) and secondary and tertiary care EPRSs (due to the different needs and roles of clinicians in each sector as shown in Table 1).

Even with the current technology, computerised hospital letters and discharge summaries cannot normally be sent to GPs electronically; instead they have to be printed and sent in a paper format. Primary care staff then have to scan them into their patients’ electronic records. The waste of time and the possibility of mistakes in scanning hospital correspondence into GP computer systems are considerable issues.
Furthermore, a recent study of discharge and out-patients letters from the Wellington Hospital to 12 local GPs in the period between June and August 2003 revealed a significant delay in information flow from the hospital to general practice. In a collaborative research project between the Department of Computer Science at Cardiff University and Velindre NHS Trust, the South East Wales Cancer Centre, we are investigating the information required to develop a shared EPRS between GPs and cancer specialists in Wales which will improve communication between the two groups.

This paper discusses the need for the shared record in Wales. It also addresses the main challenges faced during the project, namely information, technical, cultural/organisational and management challenges, and finally it highlights the benefits from this project.

**Background**

In prior decades healthcare packages were delivered in isolation; consequently EPRSs were designed and implemented to run separately. Nowadays, the healthcare delivery model has switched to a collaborative team approach and patients are often treated by a team of healthcare professionals from the three different sectors of care: primary, secondary and tertiary (known as a multidisciplinary approach); as a result, EPRSs have evolved to collect, hold and maintain required information across the three sectors.

Cancer care is no exception. Since the publication of the Calman-Hine report in 1995 care has changed from a cancer specialist-dominated approach towards an integrated multidisciplinary care approach involving healthcare professionals across the healthcare spectrum. For instance, a cancer patient could receive a package of care including surgery (delivered by secondary care) and chemotherapy (delivered by tertiary care), with a follow-up by his/her GP (primary care). This change in the care process has coincided with the growing acceptance of a policy to treat the patient in their local environment wherever possible. Treating locally rather than in a remote central institution reduces a patient’s stress levels. The role of GPs in cancer care has evolved to meet these factors. Lewis identified key stages for GPs during the cancer patient’s journey as follows:

- in the early detection and referral of suspected patients
- at the time of the diagnosis providing support for a patient and family
- after diagnosis, when a cancer specialist requires information about patient and families (such as medical or drug history and family dynamics)
- during the treatment, it is necessary that the GP is informed of the treatment plan, the key side effects and expected complications of the treatment
- additionally the GP is heavily involved with the patient and family if palliative care is needed.

### Table 1 Diverse EPRS requirements in the different sectors of care

<table>
<thead>
<tr>
<th>Role</th>
<th>Focus of treatment</th>
<th>Clinicians’ need</th>
<th>Presentation style</th>
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| Primary care              | • Treating a known patient with any combination of problems  
                           | • Providing first contact, continuous, comprehensive and co-ordinated care       | • Chronological and less detailed information about the patient                 |
|                           | Any combination of problems that have to be dealt with simultaneously              |                                                                                 | Free text style                  |
| Secondary and tertiary    | • Treating a selected patient with a specific problem  
                           | • Providing special care with a defined beginning and end                        | • Specific disease episode related to his/her specialty                        |
| care                      | Specific disease episode related to his/her specialty                              | In-depth and specialty limited information about the patient                     | Structured record, e.g. filling in a form                                      |

Cancercareisnoexception. Since the publication of the Calman-Hine report in 1995 care has changed from a cancer specialist-dominated approach towards an integrated multidisciplinary care approach involving healthcare professionals across the healthcare spectrum. For instance, a cancer patient could receive a package of care including surgery (delivered by secondary care) and chemotherapy (delivered by tertiary care), with a follow-up by his/her GP (primary care). This change in the care process has coincided with the growing acceptance of a policy to treat the patient in their local environment wherever possible. Treating locally rather than in a remote central institution reduces a patient’s stress levels. The role of GPs in cancer care has evolved to meet these factors. As a consequence their participation in preventing, diagnosing and treating cancer is positively encouraged.

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- additionally the GP is heavily involved with the patient and family if palliative care is needed.
However, despite this expanding role for GPs in cancer care, both GPs and cancer specialists in Wales are not satisfied with the shared information and current methods of sharing it [personal communications 1:5, 9:18]. Moreover, targets set in national standards (for example, the GP must be informed of the diagnosis within 24 hours of the patient being informed)\(^{14}\) are not achieved despite it being a decade since the publication of the Calman-Hine report.

### The project aims

The overall aim of this project is to establish an information infrastructure to support the growing discipline of primary care oncology in Wales. This involves:
- identifying the key information that must be shared between GPs and cancer specialists
- determining the problems hindering information sharing
- implementing a prototype solution system which tackles these information problems.

### Methodology and results

This project is underpinned by the reflective practitioner role\(^ {15} \) of the main investigator, as her medical background provided a deeper understanding of the healthcare domain. As the project progressed, semi-structured interviews were conducted with 33 stakeholders, including GPs, cancer specialists, practising and research nurses, managers and IT professionals [personal communications 1:33]. Three software development methodologies were employed, namely ethnographic study,\(^ {16} \) Soft Systems Methodology (SSM)\(^ {17,18} \) and Unified Modelling Language (UML).\(^ {19} \) This has resulted in identification of 23 information categories that must be shared to support the key clinical activities (see Box 1).

It also identified seven information quality problems in the information currently shared (see Figure 1).

### Addressing the challenges

#### Information challenges

In 2000, the Department of Health published *The NHS Cancer Plan*.\(^ {20} \) As a result of this plan, national cancer datasets were developed to ensure consistent recording of the same standardised information by different team members. The English and Welsh approaches to the cancer datasets are different:
- In England, more, larger datasets have been developed, with trusts having to collect cancer data by any method available, usually individual databases created locally for this purpose.
- In Wales, fewer, smaller datasets (though in line with English datasets for data comparison) have been established. These datasets are collected as they are developed in the Information System for Clinical Organisations (ISCO),\(^ {9} \) an all-Wales electronic patient

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**Box 1 A potential outline primary care cancer dataset**

- Patient’s medical complaint
- Cancer referral guidelines
- Cancer diagnosis staging
- Contacts of the available MDTs
- Family history
- Genetic risk factors
- Cancer genetic contact
- Referral criteria for malignancy suspicion
- Referral to cancer genetic
- Confirmation or rejection of cancer
- Investigations results
- Available treatment options
- Past medical history and case mix
- Medical assessments notes
- Treatment plan
- Follow-up notes
- Treatment evaluation notes
- Assessed treatment details
- Planned care pathway
- Professionals involved in the care process
- Identification of the information relevant to patient’s care
- Relevant information destination
- Shared care formula

**Figure 1 The identified information problems**

- Inappropriate speed
- Incompleteness
- Inconsistency
- Accessibility problems
- Redundancy
- Unclear destination
- Irrelevancy
record system primarily for cancer patients. The National Programme, *Informing Healthcare*,\textsuperscript{21} is supporting this development under the implementation project Cancer Network Information System Cymru (CaNISC).

Currently, there is no primary care cancer dataset in Wales and it is envisaged that its development will take some time [personal communications 7,8]. Although the English primary care cancer dataset could be adapted for Wales [personal communications 26], it is felt that it is so comprehensive that the full set of data items are unlikely to be collected. Therefore, this project had to take a step forward and identify the minimal information required to support the key clinical activities. Although the information identified provided a base to inform the future development of a Welsh primary care cancer dataset, our analysis to some extent is still subjective because the interviewed stakeholders may not be representative of their groups.

Cultural and organisational challenges

In an ideal world, primary, secondary and tertiary care would work seamlessly to provide patient care. They all have important complementary roles to play in the early diagnosis and optimum treatment and long-term care of a cancer patient. However, in reality the organisational and cultural challenges are vast given the differences between them. For example:

- primary care is in overall charge of the patient but often remains poorly informed about the care cancer patients are receiving. Secondary and tertiary care, on the other hand, are potentially very well informed via the CaNISC–ISCO system
- primary care currently has little or no involvement in cancer trials whereas secondary care has a whole network support mechanism with the Wales Cancer Trials Network (WCTN)
- GPs see a small number of cancer patients at any time whereas secondary care specialists are encouraged to specialise and see larger numbers of patients with site-specific cancers
- GPs are isolated and expected to detect and deal with cancer among a sea of general problems and conditions. Secondary/tertiary cancer specialists are organised to supporting multidisciplinary teams
- considering the short GP consultation time,\textsuperscript{22} the time he/she needs to spend to enter cancer patient information twice (in the practice system and the CaNISC system) is a considerable issue.

There is a vital need to address these challenges; our way of doing that is to establish an information infrastructure that provides consistent information across the three care sectors. Implementing the system incrementally and providing the key information only at this stage will improve the availability of information without causing information overload and unnecessary extra work. To illustrate this, Figure 2 shows a discharge summary that contains key information required by a GP when a patient is discharged from a hospital.

![Figure 2 Discharge summary screen for a fictional patient Jo Bloggs](image-url)
Management challenges

Developing a fully working system across Wales brings about many managerial issues, including:

- resources: it is not just rolling out a computer system; it is the processes of finding, collecting and entering good quality information. Additionally, when the system is implemented the users will require continuous support
- many legal and ethical constraints have to be addressed (for instance, data protection, data sharing, data retrieval methods and policies)
- system ownership (that is, who is responsible for what).

Technical challenges

To implement the system, all GPs need to be connected to the NHS network in Wales. Also, to keep dual data entry to a minimum, interfaces are required between all the GP systems and ISCO. When the project started GPs were not connected to the network and there were many different GP systems in use. This would have prevented the implementation of this prototype. However, GPs are now connected to the network and there are only three major suppliers of GP systems in Wales. Ideally we would interface the GP system with ISCO to prevent dual data entry. However, more work needs to be done to overcome the obstacle of interoperability between the different systems.

Why this project is making a difference

- The Cancer Information Framework (CIF)\(^{23}\) and its implementation project (CaNISC)\(^{9}\) focused on the information supporting secondary and tertiary care as an immediate priority. It also identified that the definition of the information required to support primary care is an important issue that needs more investigation. Section 42 of the framework states: 'More work is needed to define the information needs of primary care'. This project closes this loop by identifying the information required to bring primary care into the cancer network.
- The information requirements identified and inherited by this project and its associated challenges provide the basis for the development of a Welsh primary care cancer dataset and its incorporation into the electronic cancer record for Wales (CaNISC).
- Implementation will facilitate delivering information at the point of care. This will provide the required information in the right place at the right time for clinicians.
- The cultural, organisational and technical aspects of the system were addressed in a holistic development approach. If we ignore the holistic view and develop the required system from a traditional computing point of view we will develop a computerised interface which will not necessarily be of any use. 'It is not only software and hardware but “people-ware” too.'\(^{24}\)

More particularly this project specifically focuses on the cultural, organisational and people challenges implicit within the primary care cancer dataset, so that by addressing the challenges as part of the implementation in Wales we can make the difference between success and failure of the integrated care approach.

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CONFLICTS OF INTEREST
None.

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