

Information Management in Oncology

a report by

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The delivery of modern oncology has become very complex, with a heavy reliance on technology, not only for the accurate diagnosis of the patient, but also for the delivery of the agreed treatment. It is essential that physicians understand what they are doing in their practice and how they are doing it; for this to be effective they need information.

Background

The use of information in the UK National Health Service (NHS) has evolved from 'counting beans' to target monitoring, clinical audit, clinical governance and risk management and is aiming to reach decision support.

Early information management was based upon simple databases, usually designed to collate the activity statistics or replace similar paper-based systems. Often, these databases were designed and built by enthusiastic members of staff who understood the needs of the service and the requirements of the information. These databases offered a glimpse of the possibilities, with the simple monthly statistics being produced quickly and efficiently, taking the paper-based system to a new level. These early database requirements are purely activity-based and offer no real value to patient management.

The next level of database is to record the patient's activity, what was done and how was it done. This level of database offers much more usable information. These databases are limited only by their design. If the data requirements are built into the system and the information is recorded, it can be used to good effect. The failure of these systems is that the paybacks to the users may not be sufficient to overcome the effort required to record the information. The system often runs in parallel to the paper system and represents a duplication of effort.

The next level of database is a clinical management system. These systems should support the clinical workflow of the oncology centre. Where possible,

data should be collected as it happens with minimum input from clinical staff. This is comparatively easy in radiation oncology, where verification systems record the delivery of treatment. Where the verification data is accessible, the routine reports on activity are easily managed as are clinical summaries of delivered treatment. In the medical oncology environment a similar model may be adopted, where the administration of chemotherapy is recorded as it is delivered.

Whilst many of the drivers for this change have been value for money and activity-reporting, an increasing pressure has been coming from the clinician. The clinician asks questions – questions that the early databases could not provide the answers. The Calman-Hine report proposed a method of management for cancer patients that would involve a major restructure of cancer service in the UK. This report would also provide a major driver for information management.

Currently, in the NHS and in oncology practice in the UK, it is common for a paper-based system to be used to manage the patient. Paper-based systems tend to require high maintenance by clerical staff, and are very difficult to use for the retrieval of information.

Information Management

Information is a valuable resource, one that, with careful use, can offer tremendous advantages to the oncology service. Answering information requests can be a time-consuming task. When considering the questions physicians should also consider the information source and the accessibility of that source. Primary information sources are:

- hospital systems;
- laboratory/pathology systems;
- diagnostic imaging;
- hospital notes;
- clinical letters; and
- the patient.

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Hospital Systems

In the NHS, the primary source of information is the Hospital Information System. This system will hold the master patient index (MPI) with the unique identifiers for the patient. A further feature of this system is that it should conform to the National Minimum Dataset (NMD). Any patient will have a number of identifiers.

The hospital system will be accessible across the hospital site, but is largely an administrative tool, with few clinical details and therefore of little interest to the clinician. As the Connecting for Health (CfH) programme develops, the hospital systems will provide access to the Spine, which will effectively connect the NHS and primary care services for the exchange of information.

A consequence of the Calman-Hine report and the restructuring of cancer services is that a cancer centre can be associated with many hospitals over a wide geographical area. This results in a patient having many aliases and identifiers from other hospitals. Each hospital will have its own set of hospital notes. This creates a major clerical problem when trying to keep all these separate paper systems up to date and accurate.

Laboratory and Pathology Systems

These systems provide essential information related to the management of the patient. These systems will often have a wide distribution around the hospital or a method of displaying the result via the hospital intranet system. Despite this, it is usual for these reports to be printed and distributed to the clinical management team. When management of the patient is handled across many hospitals, the reports from the laboratory systems have to be sent to many locations.

Diagnostic Imaging

Many hospitals in the UK are now producing digital images and many are starting to use Picture Archiving and Communication Systems (PACS). Where available, this technology vastly improves patient management, but there is still the requirement to print the images where they are required across many sites.

The Solution

A solution to the problem of clinical data that is to be used effectively for the management of the service and the delivery of appropriate clinical care is to use a clinical database.

There are two approaches that can be taken to achieve a clinical database: build a database or purchase a database system from a manufacturer.

Building a Database

Many hours can be put into building a dedicated database for the collection of clinical data. These can be very accurate and follow the exact logic of the working practice. The research needed to ensure that the correct information is in the correct format can be daunting. If a practice proceeds with the project, it will be committing its service to a continual development cycle that will take several years to achieve. It will also be responsible for maintaining the specification of the datasets. The system will be unique, and will become at risk if key members of the development team leave the organisation.

Purchasing a System

There are two methods of buying the system. Method one would be to approach a software company and ask them to develop a system to the practice's specification. This is a huge task, but it would be bespoke.

A better proposition is to find a dedicated manufacturer who has already done the development work. The system should record the information that is required to manage the practice's service and provide the reports that are needed. Interfaces to the MPI and other hospital systems to provide key test results are essential.

In this case, the choice may be limited in the 'off the shelf' suppliers and it is likely that some degree of compromise may be required in direct support for working methods, but it is possible to find a close fit and work with the manufacturer to improve the fit for the practice's particular service. Change may be required on both sides.

In either case, a culture change may be required, which may cause some upheaval to the service. In this respect the modern oncology service has the advantage as there is already a high use of computer technology to deliver the service particularly radiation oncology.

The Benefits of an Electronic Information System

A service or hospital-wide clinical system is able to provide many benefits to the service. To the clinician the biggest benefit is that the information required to manage the patient is available at any time. All updates to the system provide realtime information across the service.

It is essential that the system is capable of recording the essential clinical information: referral; history; diagnosis and morphology; treatment plan; clinical documentation; treatment details; follow-up records; and clinical status.

This data must be collected in a form that is easy to complete and is in a natural manner for the professional. If the data is to be useful for reporting, it must be coded.

Most clinical data items will have an agreed standard such as the tumour-node-metastasis (TNM) definitions. These data are well suited to being recorded in a database and will provide a valuable filtering method to identify patients.

As has been shown earlier, manual records require a large clerical input to keep them up to date, and much of the information may be missing. Reducing the clerical overheads can save time and money.

The collection and analysis of data can be undertaken as part of the routine work; instead of completing paper forms with a pen, a keyboard and mouse can be used to complete an electronic form.

Where the data is updated as part of the clinical work, it is integrated into the clinical record at the time of treatment delivery. This information is available instantly across the service. This can reduce much of the interdepartmental communication as the information is only a few clicks of the mouse away.

It is possible for the electronic record to replace the paper records. There are legal considerations related to the signature for authorisation of treatments and retention of records. Where these considerations can be managed, the bulk of the paper record becomes redundant. This can save not only on paper costs, but also in storage and retrieval of the notes.

In these cases a very good networking infrastructure is required. This will entail considerable early investment in communications hardware and computer technology. In oncology, it is common for a network to be in place that may be usable, but that may need to be extended. A further consideration will be using these networking in conjunction with other systems, particularly imaging, where large amounts of data are moved around the network.

As more data becomes centralised in the database, all reporting becomes simple. Every standard report should be part of the system and available to users with suitable security rights. The system should also support *ad hoc* queries, where simple questions, as defined above, are accessible.

Clinical decisions can drive the scheduling of treatments, resulting in a more efficient service delivery. This will result in savings for the operation

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of the service and reduce waiting times for patients.

The core oncology service operates within a defined range of time, but care is available and may be required outside the normal operating times. Access to information at this time can be near impossible. This is further compounded where the patient has had previous treatment. It is essential to know what treatment has been delivered and what area was treated. Failure to get the required information may delay emergency treatment. An electronic record overcomes this problem as it is available at any time.

The savings that can be made in clerical time, duplication costs, lost appointments and the increased activity resulting from greater efficiency will in part offset the maintenance of these systems. The further savings that will come about are further down the line. When the system has several years worth of clinical data, it becomes possible to interrogate the information and find answers to the clinical audit and clinical governance questions.

In oncology there are a few manufacturers available that create such systems. In the UK the major systems are: Clinisys; Impac; Nucletron; Varian; and IMS.

How Can This Information Be Used?

Access to the electronic record has many advantages. Physicians are able to take the clinical data that has been collected as part of the clinical management process and use this to manage their service. The common uses for the information are: activity monitoring; clinical audit; resource management; and business planning.

Activity Monitoring

A prime example of activity monitoring is the question of how many new courses of radiotherapy are started each month. This information is simple to collect. In most cases, radiotherapy is delivered using a verification system. Each time a treatment beam is delivered it is recorded. This data can be used to manage the workflow within the centre and track treatment trends. Waiting times can be extracted from such systems, and any delays or bottlenecks in the service can be sought.

It is possible to ensure that similar cases receive similar levels of resource. This is particularly important for the most commonly treated conditions. Optimising the treatment delivery process will give returns to the department in terms of efficiency and quality of treatment.

Clinical Audit

An increasing part of clinical practice is the peer

review of that practice. An electronic information system supports the usual audit questions. It becomes far simpler to find the patients that meet the audit criteria than any paper system.

The ability to create an audit dataset that can be filtered according to clinical criteria, such as the stage of the disease or the age of the patient or the exact tissue type of the tumour, would be near impossible in a paper-based system.

Resource Management

It is important for any service to get the best from the resources that are available. Using clinical data effectively and using scheduling systems will ensure that expensive equipment and staff are deployed efficiently and that the service performs well.

Business Planning

Ensuring that the service is able to respond to change and planning for the future is essential in healthcare. Using accurate historical data, it is possible to project what the future requirements are going to be. Using clinical data, physicians are able to explore other issues such as 'capacity versus demand' and 'what if' scenarios. In these cases, they are able to explore in detail how their service responds in different circumstances. An example might be what would be the impact upon the service of changing the fractionation of a treatment. With accurate clinical data it would be possible to examine what level of resource are taken up by that treatment type, and then examine the effect of the change and ultimately consider the consequences of the change either in financial terms or in waiting times for patients.

Conclusion

Having accurate and timely information is the key to effective clinical management of the patient and effective resource management of the service. Collecting that information centrally into a single data source provides an elegant solution to the information requirement.

Information systems are expensive to implement and require considerable effort to implement. The level of investment may not be repaid for a number of years, but they offer the service the ability to improve quality of care and efficient delivery of the service. ■

A version of this article containing references can be found in the Reference Section on the website supporting this briefing (www.touchoncologicaldisease.com).